CHAPTER

1

ON COMMUNITY-BASED PARTICIPATORY RESEARCH

NINA WALLERSTEIN, BONNIE DURAN, JOHN G. OETZEL, AND MEREDITH MINKLER

COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR) has established itself as a valued research approach for its contributions to increasing health equity through an orientation that is *community-based*, and often *community-directed*, rather than merely *community placed*. Increasing demand by communities, tribal nations, governmental and philanthropic funders, and committed academics have altered much of the landscape of research and its production of knowledge by integrating community leaders and members as key partners throughout a community-engaged research process. The W.K. Kellogg Foundation's Community Health Scholars Program (2001) defined *community-based participatory research* in the health field as "a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities" (p. 2).

Reflecting the growing application of CBPR principles and strategies in community development, program design and implementation, and evaluation, we propose a broader definition that still incorporates the use of research and data. "CBPR embraces collaborative efforts among community, academic, and other stakeholders who gather and use research and data to build on the strengths and priorities of the community for multilevel strategies to improve health and social equity."

Together with many related action, participatory, and community-engaged research traditions, CBPR turns upside down the more traditional applied research paradigm, in which the

outside researcher largely has determined the questions asked, the research tools employed, the interventions developed, and the kinds of outcomes documented and valued (Gaventa & Cornwall, 2015). In their new edited book, Budd Hall and Rajesh Tandon, two of the early founders of global participatory research, reiterate the call for knowledge democracy to reclaim the "expertise residing in the world of practice, beyond academia" (Hall, Tandon, & Tremblay, 2015, p. 26).

Although often and erroneously referred to as *research methods*, CBPR and other collaborative approaches are not methods at all but an *orientation or a fundamentally different approach to research*. As Cornwall and Jewkes (1995) classically pointed out, what is distinctive about this approach "is not the methods but the methodological contexts of their application; the attitudes of researchers, which in turn determine how, by and for whom research is conceptualized and conducted," and "the corresponding location of *power* at every stage of the research process" [italics added, p. 1667].

Central to CBPR and related approaches is a commitment to consciously change the power relationship between researcher and researched, seeking to eradicate the distinction between who does the studying and who gets studied (or decides what gets studied). CBPR, as an overall approach, has been used with every kind of research method (Israel, Eng, Schulz, & Parker, 2013): from qualitative focus groups or ethnographic inquiry, to neighborhood mapping or use of geographical information systems, to epidemiology, and to survey methods. What matters is "the experience and partnership of those we are normally content simply to measure" (Schwab & Syme, 1997, p. 2050) and the creation of a "mutually reinforcing partnership" (Cargo & Mercer, 2008, p. 327).

NEW AND CONTINUING CHALLENGES AND OPPORTUNITIES

In the decade since the publication of the second edition of this book (Minkler & Wallerstein, 2008), CBPR has grown as a field in its effectiveness in creating culture-centered research (Dutta, Anaele, & Jones, 2013), improving external validity and attention to implementation contexts (Yano et al., 2012), honoring practice-based and community evidence (Green, 2006), strengthening reflexive practice (Muhammad et al., 2015), and solidifying connections to communities of color and other marginalized communities to challenge health inequities (Wallerstein & Duran, 2010). However, CBPR faces continuing and new challenges.

Key among these is the stark contextual realities within which we work. Health and social inequities continue to rise to untenable levels, across the United States and globally (Bor, Cohen, Galea, 2017; Marmot & Bell, 2012). Within the United States, structural racism within institutions, such as the criminal justice system, and conscious and unconscious bias still pervade our national consciousness and contribute to the suffering of real people and communities. As this book goes to press, a new and troubling political context in the United States, with grave threats to vulnerable groups, including to undocumented immigrants, the devaluation of science and inquiry, and the threatened withdrawal of federal funding in a wide range of areas, portend real threats to CBPR partnerships and health and social equity. These conditions affect all of us and our capacities to recognize and redress power and privilege differences across academia and communities and agencies.

The research institution is not immune from this context, with historical and current abuse or misuse all too often having fostered mistrust of research within communities who have faced "helicopter" or "drive-by" research when data is solicited, taken, and not returned to the

community. "Evidence-based" approaches, those that have received sufficient funding to be systematically evaluated and published in the academic literature, still dominate the acceptable choices for research interventions and privilege internal validity over external validity, or relevance of findings to "real-world" contexts. Such approaches are sometimes unacceptable or non-translatable to other diverse communities. Further, the "evidence-based" approaches that "count" in traditional academic and other research settings often ignore, discount, or erase the "community evidence" and local knowledge necessary to create culturally effective and sustainable interventions. Growing calls for translational research, whose findings can more quickly and effectively be incorporated into practice, programs, and policies, have been critical in beginning to redress such imbalances (Cytron et al., 2014). Yet often, translation is thought to be unidirectional, that is, a one-way or top-down approach to move research results from the academy to the community, rather than as bidirectional, mutual-learning processes.

Despite these challenges, there has been increased visibility of and support for CBPR and community-engaged research (CEnR) in multiple sectors. The Centers for Disease Control and Prevention (CDC) launched its Prevention Research Centers in 1986 with community participation a central part of their mission. The first of the National Institutes of Health (NIH) to fund CBPR was the National Institute of Environmental Health Science (NIEHS), supporting environmental justice research in 1995. NIEHS was followed by multiple other institutes, most notably the National Institute of Minority Health and Health Disparities and the Native American Research Centers for Health, a partnership between the Indian Health Service and NIH.

Since the mid-2000s, there has been additional growth in federal and foundation funding opportunities for CBPR (see Appendix 5). These have included community engagement components within Clinical Translational Science Awards (CTSAs); the Patient Centered Outcomes Research Institute (PCORI), inviting patient, family, and patient advocate engagement; NIH transdisciplinary team science centers that include community partner involvement; as well as leading foundations sponsorship of CBPR training programs (see Chapter 19 and Appendix 5).

Support has become evident through new federal publications, with a recent Institute of Medicine (IOM) call to educate health professionals about social determinants through forming community partnerships for transformational learning (IOM, 2016). This builds on an Office of Behavioral and Social Science Research (OBSSR) report, calling for working with communities to understand the complexities of culture (Kagawa-Singer, Dressler, George, & Elwood, 2015) and a previous IOM call for leveraging community involvement and culture for improved health interventions (IOM, 2012). In 2015, the North American Primary Care Group updated their 1988 policy on responsible participatory research in primary care settings and called for even greater patient and community involvement in research (Allen et al., 2017).

CBPR and CEnR publications have grown across multiple health, clinical, education, and social science disciplines, with top-ranked academic journals offering special issues on CEnR, CBPR, and Action Research in addition to multiple new books (Abma et al., 2018, Blumenthal, DiClemente, Braithwaite, & Smith, 2013; Bradbury, 2015; Hacker, 2013; Hall et al., 2015; Israel et al., 2013; Rowell, Bruce, Shosh, & Riel, 2017; Stringer, 2014; Wright & Kongats, 2018). Finally, many new resources, training programs, and guides are proliferating, and can often be found through the Community Campus Partnerships for Health and CES4 Health websites, as well as on individual program sites (see, for example, Parry, Salsberg, & Macaulay, 2017; see Appendix 10 for resources specifically on measures of engagement).

Although these increased opportunities, especially in the acceptance of CEnR and CBPR, have been welcome, they also have brought new challenges. The first of these is definitional, with the question of whether we have fallen into the trap of believing that any community engagement is a good thing (Draper, Hewitt, & Rifkin, 2010). Trickett (2011) has raised concerns about utilitarian usage of CBPR by researchers, for example, seeking engagement to facilitate recruitment of minorities into "our" research trials, versus a broader worldview that seeks a range of community capacity, health, and social justice outcomes.

A second challenge is the need for more rigorous and mixed-method evaluation of whether and how participatory practices contribute to outcomes, with a complementary inquiry to identify metrics or measures to assess engagement practices and outcomes. A plethora of reviews within the last several years have begun to identify multilevel health outcomes from CBPR and related research, with several analyzing the ingredients of participatory practices that make a difference (Drahota et al., 2016; O'Mara-Eaves et al., 2015; Rifkin, 2014; Salimi et al., 2012). Although many of us are part of this effort to identify emerging "best" or promising practices, the most important questions may be (1) under what conditions and contexts do partnerships choose which practices are "best" or promising in their experience; and (2) how will our chosen practices affect research designs and interventions to produce our desired (and also possibly unintended) outcomes within communities and the academy, including, most importantly, improvement of health equity?

Further, some still question the scientific rigor of the field, for example, regarding the challenge of how to maintain community decision-making after starting a randomized control trial protocol (Buchanan, Miller, & Wallerstein, 2007; Coghlan, 2004; Northridge et al., 2000; Salimi et al., 2012). Greater interest in complexity science, adaptive designs, and social network analyses, however, have enabled a broader discussion of methodologies for evaluating community participation and interventions (Franco et al., 2015; Hawe, 2015; Trickett et al., 2011) and for incorporating strategies that promote a broader bandwidth of validity (Bradbury, 2015). Decolonizing research methodologies (Denzin, Lincoln, & Tuhiwai Smith, 2008; Tuhiwai Smith, 2012) have called for Indigenous and community knowledge and use of mixed methodologies for ascertaining partnership effectiveness to reach broad goals of knowledge democracy and justice.

AGENDA FOR THE NEW EDITION

With this backdrop of challenges and opportunities, this is an almost completely new edition of *Community-Based Participatory Research for Health*, offering a twofold agenda. First, we wish to celebrate the recognition of CBPR and CEnR as solid, community-driven, and shared leadership enterprises and their importance for making inroads toward health equity. Second, we wish to tackle head on the challenges frequently encountered in this work through interweaving theory, methods, and case studies with thoughtful exploration of core issues of trust, racism, cultural humility, power and privilege, self-reflective practice, and ethics, with emphasis on practices that contribute to outcomes.

We invite you, as students, academics, and community practitioners in fields such as public health, social welfare, nursing, medicine, communication, community and regional planning, public policy, education, social sciences, and other fields, to enter these explorations with us

and become more inspired by and proficient in applying CBPR approaches in your own work. The new edition has been reframed to follow the CBPR conceptual model first presented in the second edition (Wallerstein et al., 2008). Use of this revised model (see Chapter 6) enables us to more deeply present cases that address the contextual settings for research, the partnership relationships and practices, the ethics and choice of research and evaluation methods, and a commitment to individual and community health, equity, and social justice outcomes. All of our case studies are new, many of which tackle core issues of our time, such as institutional racism and its contributions to inequities and suffering. We look to CBPR as one strategy for promoting healing within communities and for advocating for desperately needed policy and societal change.

In this chapter, we now situate CBPR principles within a brief history of other traditions and provide an overview of current reviews of CBPR and community engagement effectiveness. We end the chapter with an outline of the book and a hope that the conceptual frameworks, case studies, and practical tools presented through the chapters and appendices are useful as you reflect on and strengthen your own partnering practices.

CORE PRINCIPLES OF CBPR WITHIN A CONTINUUM OF COMMUNITY ENGAGEMENT

Over the last several decades, the term *community-based participatory research* has moved solidly into US and global health discourse and practice. Numerous variations of the term exist, however; key among them are action research (widely used in the education field and within the United Kingdom, Australia, and New Zealand); collaborative action research (used in Australia); community-based research (term in Canada); participatory action research and participatory research (widely used in Latin America, the Global South, and for youth); collaborative inquiry; reflexive practice, feminist participatory research; community-partnered participatory research; tribal participatory research; street and citizen science; and participatory health research, the term of the International Collaboration for Participatory Health Research (see Appendix 3).

These terms have largely come from two historical traditions: the Northern, more pragmatic tradition (with social psychologist Kurt Lewin originally proposing action research in the 1940s as a cycle of fact-finding, action, and reflection) and the Southern emancipatory tradition (with the terms participatory research and participatory action research emerging from the roots of Brazilian educator Paulo Freire's (1970, 1973) popular education and the liberatory movements in the 1970s in Asia, Africa, and Latin America). (See Chapter 2 for discussion of these traditions.)

Adherents to these different terms continue to engage in lively debate over which one best captures the principles and ideological commitments espoused. We argue, however, that although these different approaches often vary in goals and in change theories, they also share a set of core principles, summarized by Israel and her colleagues (see Chapter 3), who say the following of CBPR:

- It is participatory.
- It is cooperative, engaging community members and researchers in a joint process in which both contribute equally.

- It is a co-learning process.
- It involves systems development and local community capacity building.
- It is an empowering process through which participants can increase control over their lives.
- It achieves a balance between research and action.

Building on the work of scholars of color, Indigenous, and feminist participatory researchers, we add to these principles an additional one, recognizing the importance of intersectional power and privilege, i.e., how race-ethnicity, racism, immigrant status, gender, sexual orientation, social class, and culture affect the research process (Minkler, Garcia, Rubin, & Wallerstein, 2012). As discussed in Chapter 4, such realities underscore the need for academics to adopt cultural humility (see Appendix 4) and its task of lifelong learning, being open to reflecting on one's biases and positions of power and privilege.

Indigenous researchers have added other principles grounded in tribal sovereignty, recognizing the authority of tribal communities to control research processes, demand that data be shared and returned to tribes, and approve all publications, in addition to deepening the recognition of core values of respect and relevance (Noe et al., 2006; Walters et al., 2009). Tribal institutional review and research review boards have added the principle of returning benefit to the communities (Becenti-Pigman et al., 2008) as part of their authority (Chapter 14), and so have emerging numbers of community ethics boards and review processes (see Chapters 15 and 16).

The growth in the use of the term *community-engaged research* in the 2000s was spawned, in part, by the extensive investment in CTSA translational research infrastructures in academic health centers. A CTSA published continuum of engagement (in English and Spanish) ranges from community outreach at one end, through coordination and collaboration, to shared leadership at the other (McCloskey et al., 2011). Although recognizing that community engagement can shift over time, the inclusion of outreach, unfortunately, may reinforce a unidirectional, rather than bidirectional, perspective. The continuum, "onin-with," from the Community Engagement Core of the University of New Mexico NM-CARES Health Disparities Center clearly shows the difference of research that takes place on targeted communities, versus in community settings, versus research with community partners. It is the with perspective that reflects the CBPR definition of equity and strengths of all partners.

Community development advocates and public health professionals, however, have long warned against the cooptation or manipulation of communities through language and methods that purport to foster participation and engagement, while in fact using local communities to the advantage of the researchers (Arnstein, 1969; Cooke & Kothari, 2001; Draper et al., 2010). Although an extreme example, the four-decade-long Tuskegee study of untreated syphilis in Black males, which continued to withhold treatment long after penicillin was available, to study the long-term effects of the disease (Reverby, 2009), provides a deeply disturbing example. As Thomas and Quinn (2001) point out,

the study included culturally-appropriate and grassroots approaches to ensure the involvement and continued participation of [Black physicians and prisoners]... The Public Health Service was extremely successful in enlisting Black church leaders, elders in the community and plantation owners to encourage participation. (p. 1499)

The underlying racism inherent in this study remains an indelible reminder of the human costs of unethical scientific research and the ways in which "community participation," can, and sometimes has, been used to for horrific and unjust ends.

To ensure the inclusion of CBPR values and principles, in a recent review of the accelerating extent of community-engaged and partnered research awards within the US Environmental Protection Agency, Yuen, Park, Seifer, and Payne-Sturges (2015) added a "community-driven" column to the CTSA continuum, beyond shared leadership, which mirrors the CBPR definition that research should be based on community priorities, strengths, and actions. Balazs and Morello-Frosch (2013) have gone further in constructing an explanatory continuum that shows the evolution from community members being research subjects to becoming research partners, depending on their level of participation. Focus groups to elicit community opinions, for example, are not in themselves CBPR. CBPR requires structures for participation such as community advisory boards or equitable partnership teams that have decision-making authority. As Balazs and Morello-Frosch (2013) further assert, integrating community members as full research partners enables science to be rigorous and relevant, with greater reach, by working deeply with communities (see Chapter 15).

Ultimately, these continua remind us of the importance of reflecting on our own values and commitment to confront power dynamics within research processes to benefit communities. To live up to the espoused principles of CBPR for health—principles accenting true partnerships among researchers, communities, clinical providers, patients, and other stakeholders and achieving a balance between research and action toward health equity—is the emancipatory end of the continuum that should serve as a gold standard for CBPR practice. Particularly for professionals in fields such as public health, social welfare, and community planning, among others, with their roots in concerns for social justice, CBPR in this sense provides an important goal for which to strive in our collaborative work with communities.

EFFECTIVENESS OF CBPR AND COMMUNITY-ENGAGED RESEARCH

The first systematic review of CBPR, by the Agency of Health Care Research and Quality in 2004, spanned the years 1975-2003 and found sixty CBPR studies, with thirty identified as interventions and thirteen with a policy focus. Few of these studies had rigorous designs and only twelve documented outcomes (Viswanathan et al., 2004). Within Britain, corollary interest in assessing the impact of community engagement within research and population health initiatives spawned multiple reports (Popay et al., 2007; Staley, 2009).

Since that time, and especially since 2009, when CBPR became a medical subject heading (MESH) in the Library of Medicine, there has been a significant growth of systematic reviews and meta-analyses that have found compelling evidence of positive impacts on health outcomes (Anderson et al., 2015; Carter, Tregear, & Lachance, 2015; Cook, 2008; Cyril, Smith, Possamai-Inesedy, & Andre, 2015; de las Nueces, Hacker, DiGirolamo, & Hicks, 2012; Drahota et al., 2016; Milton et al., 2012; O'Mara-Eves et al., 2015; Yuen et al., 2015).

In a systematic review of impacts of community engagement among disadvantaged populations, Cyril and colleagues (2015) found that 88 percent of twenty-four studies had positive outcomes, with defined CBPR studies showing higher community involvement throughout research processes. A meta-analysis of 131 CEnR articles, including randomized and non-randomized

designs, found positive impacts on health behavior, health consequences, self-efficacy, and perceived social support (O'Mara-Eves et al., 2015). de Las Nueces et al. (2012), in a systematic review of CBPR clinical trials with racial-ethnic minorities, found 89 percent of their nineteen articles to have behavioral and clinical outcomes and high success in retaining minority participants.

Thompson et al. (2016) identified NIH-funded population health and disparities centers that focused on CBPR projects to empower communities toward health equity. Salimi and colleagues (2012) sought to review community empowerment by assessing community participation in all the stages of research. They found that more studies involved community members in selecting research questions (42 percent), with only 8 percent having community members involved in proposal writing or with financial responsibilities. Involving community members throughout research processes has been validated as a promising practice that is associated with outcomes of shared power relations in research and community transformation (see Chapters 6 and 17). Drahota and colleagues (2016), in their systematic review across multiple disciplines, identified fifty community-academic partnership studies, documenting 78 percent with proximal outcomes, such as synergy or knowledge exchange, with one-third reporting capacity and system outcomes, such as improved community care, sustainable partnerships, or changed community context.

Some studies have sought to identify the type of participatory engagement, such as communities identifying health needs and mobilizing, communities collaborating on design, communities consulting on intervention design, and community members collaborating or leading intervention delivery, such as using lay health workers (Brunton, O'Mara-Eves, & Thomas, 2014; O'Mara-Eves et al., 2015). Lay-delivered interventions had the largest effect sizes in a recent Cochrane Review of collaborations, which found limited other impacts on ethnic-racial minority health (Anderson et al., 2015).

The growing number and positive outcomes of these reviews help document the power of CBPR and CEnR in contributing to intermediate outcomes such as community capacities and longer-term health outcomes. Recent NIH-funded experimental trials, based in long-time culturally-grounded CBPR partnerships, are producing more evidence of outcomes (Dickerson et al., in press). For meta-studies, however, the Cochran criteria of comparison trials or healthspecific outcomes are too limited.

A growing literature exists, for example, in CBPR policy studies, which don't show up in comparison designs but that document substantial health impacts from policy changes (Minkler et al., 2012). Because they often affect the health and social environments of large numbers of people, such studies (see Chapters 20 to 23) also should be included in systemic reviews.

Increasing evidence of impacts from participatory processes document that they are highly complex and not controllable as defined intervention impacts (Abma et al., 2017; Rifkin, 2014; South & Phillips, 2014; Trickett et al., 2011). Empowerment strategies in CBPR, for example, based on Paulo Freire's (1970) dialogical methods, are not predictable interventions but rather dynamic processes within dynamic contexts. Evaluation of such efforts needs to include context as much as processes and outcomes. Jagosh and colleagues (2012) have found that broader goals of joint policy advocacy and capacity-building may be equally important to perceived partnership success, in addition to specific grant outcomes. Calls for CBPR as a liberatory social movement further challenge us to critically analyze how we can best achieve improved health equity for all (Devia et al., 2016; Tremblay, Martin, Macaulay, & Pluye, 2017).

In sum, CBPR should not be seen simply as an instrumental strategy but rather as grounded by its commitment to community priorities and decision making. Although we are pleased by the growing evidence of specific outcomes, we also seek broader intermediate and long-term outcomes, such as changed power dynamics, cultural revitalization, community empowerment, and improved health and social equity (see Chapters 17 and 18).

ORGANIZATION OF THIS BOOK

In this third edition, we build on our core values of health equity and social justice as we present new diverse case studies that represent ongoing frontiers of CBPR and CEnR. With the addition of two new editors, we have made major changes in our framing, following the domains of the CBPR conceptual model (see Chapter 6), first introduced in the second edition. Although much cuttingedge participatory research continues outside the United States, our purpose is to focus primarily on CBPR in the contemporary United States, in part so that we can carefully attend to the geopolitical and sociohistorical contexts so central to this work. However, we frequently draw on the wisdom of leading participatory research, action research, participatory action research, and participatory health research scholars and practitioners in the Global South from Latin America, Asia, and Africa, and from Canada, Europe, the United Kingdom, Australia, New Zealand, and elsewhere, and we believe that many of the skills and conceptual and ethical issues raised will have relevance beyond the United States. (See global issues in Chapters 7, 18, 23; Appendices 3, 6; and the Afterword.)

Part 1 begins with this chapter introducing the field, with Chapter 2 presenting its historical and theoretical antecedents and new concepts of cognitive justice and knowledge democracy from the Global South. Chapter 3 describes and illustrates the classic, as well as evolving principles of CBPR.

In Part 2, Chapter 4 examines race, racism, power and privilege; Chapter 5 discusses the dynamics of trust in partnerships.

Part 3 begins the new framing by introducing the CBPR conceptual model with its four domains, with case studies focusing on the first domain, "Context," and the second domain, "Partnering Processes." Chapter 6 first introduces the history and domains of the CBPR conceptual model. Chapter 7 discusses CBPR within a youth context. Chapter 8 provides a randomized control trial to transform structural racism and bias within the context of cancer health care. Chapter 9 discusses the challenges of alignment and misalignment among academic and community partners.

Part 4 continues to the third domain of the model, "Research and Interventions," with case studies on how partnering processes contribute to the promising practices of culturally and locally appropriate research design and implementation. Chapter 10 explores communityengaged methods within health care system research projects. Chapter 11 speaks to the creation of culture-centered interventions within the Deaf and hearing impaired community. Chapter 12 challenges us to integrate CBPR principles into interventions with highly diverse Asian populations. Chapter 13 presents a developmental process for engaging Latino communities in every step of research design and implementation.

In Part 5, we extend our research methods into core ethical promising practices. We learn the importance of culture and governance within tribal contexts (Chapter 14) and unpack ethical issues within (Chapter 15) and beyond (Chapter 16) institutional review boards (IRBs) and research review boards.

Part 6 then continues to the fourth "Outcomes" domain of the model, with Chapter 17 providing evidence, from testing the CBPR model, of promising partnering practices associated with a range of intermediate and long-term outcomes. Chapter 18 showcases US and Nicaraguan case studies of participatory evaluation outcomes with lay health advisors. Chapter 19 shares personal stories and outcomes for faculty members of color who have benefited from CBPR pipeline programs.

In Part 7, we deepen the focus on policy outcomes, with Chapter 20 providing an overview and an adapted CBPR policy model. We incorporate powerful examples of policy environmental changes within food security and healthy retail (Chapter 21), criminal justice reform (Chapter 22), and youth mapping of their living conditions within Kenyan and Brazilian slums (Chapter 23).

We conclude with appendices designed to provide tools and applications so partnerships can put some of the messages central to this book into practice in their own CBPR efforts. The afterword by long-time participatory research international scholars brings us back to knowledge democracy in the global context.

CONCLUSION

Although the United States continues to have profound health and social inequities based on race, ethnicity, class, gender, age, ability-disability, sexual orientation, and gender identity, the fight for equity can be won only if vulnerable and oppressed communities can be fully engaged as partners in taking action to address the health and social problems about which they—not "outsider experts"—know most deeply. With communities now more directly under siege, the need for CBPR visibility and sustainability is even more pronounced.

Our primary goal in this book is to provide a highly accessible text that will stimulate practitioners, students, and academics in health and related fields, as well as community partners and researchers, as they engage—intellectually and in practice—in collaborative inquiry for action. We hope that those with substantial experience and newcomers will find themselves challenged by the theory, methods, and case studies.

We end this chapter with a quote from Pia Moriarty (1993), who in her work with the Commission on Social Justice for the San Francisco Archdiocese wrote about the visceral nature of deep learning and its importance for us, as we seek to create equitable partnerships and knowledge for personal and societal transformation:

Deep learning involves the whole body, blood and bone, not just the theoretical or cataloguing of insightful facts and analyses. Deep learning moves the feet to walk in a new way, moves the eyes to see from the new perspective won by that walking, and moves the hands to fashion the tangible world into a new image envisioned by the new seeing. (p. 1)

QUESTIONS FOR DISCUSSION

1. Cornwall and Jewkes (1995) argue that CBPR is not a research method but an "orientation to research" that reflects a different stance from traditional research. How would you describe this alternative paradigm to a friend or colleague who's never heard of CBPR?

- 2. CBPR is described as a promising approach for health equity research. What CBPR characteristics do you think are most important for the study of health inequities *with* marginalized communities?
- 3. Community engagement is described as a continuum from outreach to shared leadership and community-driven approaches. The more emancipatory forms of CBPR are presented as a "gold standard" for which professionals might strive. Do you agree with this? Why or why not?

NOTE

1. http://hsc.unm.edu/programs/nmcareshd/cec.shtml

REFERENCES

- Abma, T., Cook, T., Ramgard, M., Kleba, E., Harris, J., & Wallerstein, N. (2017). Social impact of participatory health research: Collaborative non-linear processes of knowledge mobilization. *Journal of Action Research*. www.tandfonline. com/doi/full/10.1080/09650792.2017.1329092
- Abma, T., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J., & Wright, M. (2018). Participatory research for health and social well-being. New York: Springer Basic.
- Allen, M. L., Salsberg, J., Knot, M., LeMaster, J. W., Felzien, M., Westfall, J. M., Herbert, C. P., Vickery, K., Culhane-Pera, K. A., Ramsden, V. R., Zittleman, L., Martin, R. E., & Macaulay, A. C. (2017). Engaging with communities, engaging with patients: Amendment to the NAPCRG 1998 policy statement on responsible research with communities. Family Practice, 34(3), 313–321.
- Anderson, L. M., Adeney, K. L., Shinn, C., Safranek, S., Buckner-Brown, J., & Krause, L. K. (2015). Community coalition-driven interventions to reduce health disparities among racial and ethnic minority populations. *Cochrane Database of Systematic Reviews*, 6(CD009905). doi:10.1002/14651858.CD009905.pub2
- Arnstein, S. R. (1969). A ladder of citizen participation. Journal of American Instructional Planners, 35, 216-224.
- Balazs, C. L., & Morello-Frosch, R. (2013). The three Rs: How community-based participatory research strengthens the rigor, relevance, and reach of science. *Environmental Justice*, 6(1), 9–16.
- Becenti-Pigman, B., White, K., Bowman, B., Palmenteer-Holder, N. L., & Duran, B. (2008). Research policies, processes and protocol: The Navajo Nation Human Research Review Board. In M. Minkler & N. Wallerstein, *Community-based participatory research for health: Processes and outcomes* (2nd ed., pp. 441–446). San Francisco, CA: Jossey-Bass.
- Blumenthal, D., DiClemente, R., Braithwaite, R., & Smith, S. (2013). Community-based participatory health research: Issues, methods and translation to practice (2nd ed.). New York: Springer.
- Bradbury, H. (Ed.). (2015). The Sage handbook of action research (3rd ed.). Thousand Oaks, CA: Sage.
- Bor, J., Cohen, G. H., & Galea, S. (2017). Population health in an era of rising income inequality: USA, 1980–2015, *Lancet*, 389(10077), 1475–1490.
- Brunton, G., O'Mara-Eves, A., & Thomas, J. (2014). The "active ingredients" for successful community engagement with disadvantaged expectant and new mothers: A qualitative comparative analysis. *Journal of Advanced Nursing*, 70, 2847–2860.
- Buchanan, D. R., Miller, F. G., & Wallerstein, N. (2007). Ethical issues in community-based participatory research: Balancing rigorous research with community participation in community intervention studies. *Progress in Community Health Part*nerships: Research, Education, and Action, 1, 153–160.
- Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: Strengthening its practice. Annual Review of Public Health, 29, 325–350.
- Carter, M. W., Tregear, M. L., & Lachance, C. R. (2015). Community engagement in family planning in the U.S.: A systematic review. *American Journal of Preventive Medicine*, 49(2 Suppl 1), S116.
- Coghlan, D. (2004). Action research in the academy: Why and whither? Reflections on the changing nature of research. *Irish Journal of Management*, 25(2), 1–10.

- Cook, W. K. (2008). Integrating research and action: A systematic review of community-based participatory research to address health disparities in environmental and occupational health in the USA. *Journal of Epidemiology and Community Health*, 62(8), 668–676.
- Cooke, B., & Kothari, U. (2001). Participation: The new tyranny? New York, NY: Zed Books.
- Cornwall, A., & Jewkes, R. (1995). What is participatory research? Social Science & Medicine, 41, 1667–1676.
- Cyril, S., Smith, B. J., Possamai-Inesedy, A., & Andre, M.N.R. (2015). Exploring the role of community engagement in improving the health of disadvantaged populations: A systematic review. *Global Health Action*, 8, 1–12.
- Cytron, N., Pettit, K. L., Kingsley, G. T., Erickson, D. J., & Seidman, E. S. (Eds.). (2014). What counts: Harnessing data for America's communities. San Francisco, CA: Federal Reserve Bank of San Francisco and Washington, DC: Urban Institute. Retrieved from www.whatcountsforamerica.org
- de las Nueces, D., Hacker, K., DiGirolamo, A., & Hicks, L. S. (2012). A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups. *Health Services Research*, 47, 1363–1386.
- Denzin, N. K., Lincoln, Y. S., & Tuhiwai Smith, L. (2008). *Handbook of critical and indigenous methodologies*. Thousand Oaks, CA: Sage.
- Devia, C., Baker, E., Sanchez-Youngman, S., Barnidge, E., Golub, M., Motton, F., Muhammad, M., Ruddock, C., Vicuña, B., & Wallerstein, N. (2017). CBPR to advance social and racial equity: Urban and rural partnerships in Black and Latino communities. BMC International Journal of Health Equity, 16, 17. doi:10.1186/s12939-016-0509-3
- Dickerson, D. L., Baldwin, J., Belcourt, A., Belone, L., Gittelsohn, J., Kaholokula, J. K., Lowe, J., Patten, C., & Wallersteinl, N. (in press). Encompassing cultural contexts within scientific research methodologies in the development of health promotion interventions. *Prevention Science. Special Issue: Innovations in intervention research with indigenous populations in the U.S.*
- Drahota, A., Meza, R., Brikho, B., Naaf, M., Estabillo, J. A., Gomez, E., Vejnoska, S., Sufek, S., Stahmer, A., & Aarons, G. (2016). Community-academic partnerships: A systematic review of the state of the literature and recommendations for future research. *Milbank Quarterly*, 94(1), 163–214.
- Draper, A. K., Hewitt, G., & Rifkin, S. (2010). Chasing the dragon: Developing indicators for the assessment of community participation in health programmes. *Social Science & Medicine*, 71, 1102–1109.
- Dutta, M. J., Anaele, A., & Jones, C. (2013). Voices of hunger: Addressing health disparities through the culture-centered approach. *Journal of Communication*, 63, 159–180.
- Franco, Z. E., Ahmed, S. M., Maurana, C. A., DeFino, M. C., & Brewer, D. D. (2015). A social network analysis of 140 community-academic partnerships for health: Examining the Healthier Wisconsin Partnership Program. *Clinical and Translational Science*, 8, 311–319.
- Freire, P. (1970). Pedagogy of the oppressed. New York, NY: Seabury Press.
- Freire, P. (1973). Education for critical consciousness. New York, NY: Seabury Press.
- Gaventa, J., & Cornwall, A. (2015). Power and knowledge. In H. Bradbury (Ed.), *The Sage handbook of action research: Participative inquiry and practice*. (3rd ed.). Thousand Oaks, CA: Sage.
- Green, L. W. (2006). Public health asks of systems science: To advance our evidence-based practice, can you help us get more practice-based evidence? *American Journal of Public Health*, 96, 406–409.
- Hacker, K. (2013). Community-based participatory research. Thousand Oaks, CA: Sage.
- Hall, B., Tandon, R., & Tremblay, C. (Eds.). (2015). Strengthening community-university research partnerships: Global perspectives. Victoria, BC, Canada: University of Victoria.
- Hawe, P. (2015). Lessons from complex interventions to improve health. Annual Review of Public Health, 36, 307–323.
- Institute of Medicine (IOM). (2012). An integrated framework for assessing the value of community-based prevention. Washington, DC: National Academies Press.
- IOM. (2016). A framework for educating health professionals to address the social determinants of health. Washington, DC: National Academy of Sciences.
- Israel, B. A., Eng, E., Schulz, A. J., & Parker, E. A. (Eds.). (2013). Methods in community-based participatory research for health (2nd ed.). San Francisco, CA: Jossey-Bass.
- Jagosh, J., Macaulay, A. C., Pluye, P., Salsberg, J., Bush, P. L., Henderson, J., Sirett, E., Wong, G., Cargo, M., Herbert, C. P., Seifer, S. D., Green, L. W., & Greenhalgh, T. (2012). Uncovering the benefits of participatory research: Implications of a realist review for health research and practice. *Milbank Quarterly*, 90(2), 311–346.

- Kagawa-Singer, M., Dressler, W. W., George, S. M., & Elwood, W. N. (2015). The cultural framework for health: An integrative approach for research and program design and evaluation. Bethesda, MD: Office of Behavioral and Social Sciences Research.
- Lewin, K. (1946). Action research and minority problems. Journal of Social Issues, 2, 34-46.
- Marmot, M., & Bell, R. (2012). Fair society, healthy lives. Public Health, 126, S4-S10.
- McCloskey, D. J., et al. (2011), Principles of community engagement (2nd ed.). NIH Publication No. 11-7782, Clinical and Translational Science Awards Community Engagement Key Function Committee Task Force on the Principles of Community Engagement. Bethesda, MD: National Institutes of Health. Retrieved May 15, 2017, from www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf; see: https://ncats.nih.gov/ctsa/community.
- Milton, B., Attree, P., French, B., Povall, S., Whitehead, M., & Popay, J. (2012). The impact of community engagement on health and social outcomes: A systematic review. *Community Development Journal*, 47, 316–334.
- Minkler, M., Garcia, A., Rubin, V., & Wallerstein, N. (2012). Community-based participatory research: A strategy for building healthy communities and promoting health through policy change. Retrieved from www.policylink.org/sites/ default/files/CBPR.pdf
- Minkler, M., & Wallerstein, N. (2008). Community-based participatory research for health: Processes and outcomes (2nd ed.). San Francisco, CA: Jossey-Bass.
- Moriarty, P. (1993). Deep learning for earthquake country. Future of prophetic Christianity: Essays in honor of Robert McAfee Brown. New York, NY: Orbis Books.
- Muhammad, M., Wallerstein, N., Sussman, A. L., Avila, M., Belone, L., & Duran. B. (2015). Reflections on researcher identity and power: The impact of positionality on community-based participatory research (CBPR) processes and outcomes. *Critical Sociology*, 41(7–8), 1045–1063.
- Noe, T. D., Manson, S. M., Croy, C., McGough, H., Henderson, J. A., & Buchwald, D. S. (2006). The influence of community-based participatory research principles on the likelihood of participation in health research in American Indian communities. *Ethnicity & Disease*, 17(1 Suppl 1), S6–S14.
- Northridge, M. E., Vallone, D., Merzel, C., Greene, D., Shepherd, P., Cohall, A. T., et al. (2000). The adolescent years: An academic-community partnership in Harlem comes of age. *Journal of Public Health Management and Practice*, 6(1), 53–60.
- O'Mara-Eves, A., Brunton, G., Oliver, S., Kavanagh, J., Jamal, F., & Thomas, J. (2015). The effectiveness of community engagement in public health interventions for disadvantaged groups: A meta-analysis. *BMC Public Health*, 15(1), 1352.
- Parry, D., Salsberg, J., & Macaulay, A. C. (2017). Guide to researcher and knowledge-user collaboration in health research.

 Retrieved May 2017 from www.cihr-irsc.gc.ca/e/documents/Guide_to_Researcher_and_KU_Collaboration.pdf
- Popay, J., Attree, P., Hornby, D., Milton, B., et al. (2007), Community engagement in initiatives addressing the wider social determinants of health: A rapid review of evidence on impact, experience and process. London, UK: National Collaborating Center of Community Engagement, National Institute for Health and Health Care Excellence.
- Reverby, S. M. (2009). Tuskegee's truths: Rethinking the Tuskegee syphilis study. Ann Arbor, NC: UNC Press Books.
- Rifkin, S. (2014). Examining the links between community participation and health outcomes: A review of the literature. Health Policy and Planning, 29, ii98–ii106.
- Rowell, L., Bruce, C., Shosh, J., & Riel, M. (Eds.). (2017). *Palgrave international handbook of action research*. New York, NY: Springer Nature.
- Salimi, Y., Shahandeh, K., Malekafzali, H., Loori, N., Kheiltash, A., Jamshidi, E., Frouzan, A. S., & Majdzadeh, R. (2012).
 Is community-based participatory research (CBPR) useful? A systematic review on papers in a decade. *International Journal of Preventive Medicine*, 3(6), 386–393.
- Schwab, M., & Syme, S. L. (1997). On paradigms, community participation, and the future of public health. American Journal of Public Health, 87, 2049–2052.
- South, J., & Phillips, G. (2014). Evaluating community engagement as part of the public health system. *Journal of Epidemiology and Community Health*, 68, 692–696.
- Staley, K. (2009). Exploring impact: Public involvement in NHS, public health and social care research. Eastleigh, UK: INVOLVE.
- Stringer, E. (2014). Action research (4th ed.). Thousand Oaks, CA: Sage.
- Thomas, S. B., & Quinn, S. C. (2001). Light on the shadow of the syphilis study at Tuskegee. *Health Promotion Practice*, 1, 234–237.

- Thompson, B., Molina, Y., Viswanath, K., Warnecke, R., & Prelip, M. (2016). Strategies to empower communities to reduce health disparities. *Health Affairs*, 35, 1424–1428.
- Tremblay, M. C., Martin, D. H., Macaulay, A. C., & Pluye, P. (2017). Can we build on social movement theories to develop and improve community-based participatory research? A framework synthesis review. American Journal of Community Psychology. doi:10.1002/ajcp.12142
- Trickett, E. J. (2011). Community-based participatory research as worldview or instrumental strategy: Is it lost in translation(al) research? *American Journal of Public Health*, 101(8), 1353–1355.
- Trickett, E. J., Beehler, S., Deutsch, C., Green, L. W., Hawe, P., McLeroy, K., Miller, R., Rapkin, B., Schensul, J., Schulz, A., & Trimble, J. (2011). Advancing the science of community-level interventions. *American Journal of Public Health*, 101, 1410–1419.
- Tuhiwai Smith, L. (2012). Decolonizing methodologies: Research and Indigenous peoples (2nd ed.). New York, NY: Zed Books.
- Viswanathan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K. N., Griffith, D., et al. (2004). Community-based participatory research: Assessing the evidence (Evidence Report/Technology Assessment No. 99; Prepared by RTI International–University of North Carolina). Rockville, MD: Agency for Healthcare Research and Quality.
- Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. American Journal of Public Health, 100(Suppl 1), S40.
- Wallerstein, N., Oetzel, J., Duran, B., Tafoya, G., Belone, L., & Rae, R. (2008). What predicts outcomes in CBPR? In M. Minkler & N. Wallerstein (Eds.). Community-based participatory research for health: Processes and outcomes (2nd ed., pp. 371–392). San Francisco, CA: Jossey-Bass.
- Walters, K., Stately, A., Evans-Campbell, T., Simoni, J., Duran, B., Schultz, K., Stanley, E., Charles, C., & Guerrero, D. (2009). "Indigenist" collaborative research efforts in Native American communities. In A. R. Stiffman (Ed.), *The field research survival guide* (pp. 146–173). New York, NY: Oxford University Press.
- W.K. Kellogg Foundation Community Health Scholars Program. (2001). Stories of impact [brochure]. Ann Arbor: University of Michigan, School of Public Health, Community Health Scholars Program, National Program Office.
- Wright, M., & Kongats, K. (Eds.). (2018). Participatory health research: International perspectives. New York: Springer.
- Yano, E. M., Green, L. W., Glanz, K., Ayanian, J. Z., Mittman, B. S., Chollette, V., & Rubenstein, L. V. (2012). Implementation and spread of interventions into the multilevel context of routine practice and policy: Implications for the cancer care continuum. *Monographs: Journal of the National Cancer Institute*, 2012(44), 86.
- Yuen, T., Park, A. N., Seifer, S. D., & Payne-Sturges, D. (2015). A systematic review of community engagement in the US Environmental Protection Agency's extramural research solicitations: Implications for research funders. *American Journal of Public Health*, 105(12), e44–e52.