

# PART

# 1

## INTRODUCTION TO COMMUNITY-BASED PARTICIPATORY RESEARCH

*In the six years since the first edition of this book went to press, community-based participatory research (CBPR) has achieved growing attention as a collaborative approach to research that offers new hope for studying and addressing some of our most intractable health and social problems. In contrast to more traditional investigator-driven research, CBPR begins with an issue selected by, or of real importance to, the community, and*

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*involves community members and other stakeholders throughout the research process, including its culmination in education and action for social change. An overarching term for a wide variety of approaches such as action research, participatory action research, mutual inquiry, and feminist participatory research, CBPR is not a method but an orientation to research (Cornwall & Jewkes, 1995) that emphasizes mutual respect and co-learning between partners, individual and community capacity building, systems change, and balancing research and action (Israel, Schulz, Parker, & Becker, 1998). As Lawrence Green and Shawna Mercer (2001) suggest, CBPR thus effected a change in the balance of power by which “research subjects became more than research objects. They gave more than informed consent; they gave their knowledge and experience to the formulation of research questions” (pp. 1926–1927) and to many other aspects of the research process.*

*We begin in Chapter One with a broad overview of CBPR, including the reasons for its growing popularity among researchers, funders, and community and other partners. We briefly describe the notion of CBPR as a continuum of approaches and highlight its special relevance for addressing issues of health disparities and inequities. We also provide in this first chapter the goals and purposes of this book, which include in particular a desire to provide both newcomers to the field and more advanced scholars and practitioners a highly accessible text that will offer historical, conceptual, and practical grounding, as well as a variety of tools and techniques that can be used in applying this approach to action-oriented research with a wide range of community and other partners to address an equally wide range of health concerns and disparities. In Chapter One we also introduce several new issues and emphases that are a special focus of this second edition. These include greater attention to external validity, practice-based evidence, and implementation contexts (Fixsen, Naoom, Blasé, Friedman, & Wallace, 2005; Green, 2006) and to the evolution of the field of CBPR from a primary focus on process to an equally strong emphasis on the study of CBPR outcomes, particularly on the policy level. The book’s increased use of case studies is described as providing professionally trained researchers and their community partners with useful examples of the integration of theoretical and practice-based concepts, situating the latter in real-world CBPR settings.*

*Chapter One also introduces the book’s increased accent on diverse venues for CBPR, including nursing and academic and clinical medicine (Macaulay & Nutting, 2006; Wells &*

*Norris, 2006) and a closer look at CBPR in tribal communities. We highlight as well the book's increased attention to involving community partners in data analysis and interpretation and on moving into action, particularly policy-level action, through CBPR.*

*In Chapter Two, Nina Wallerstein and Bonnie Duran offer a deeper look at CBPR and other participatory research approaches, situating this tradition historically, conceptually, and in practice. The authors provide a more in-depth look at the notion of CBPR as a continuum of approaches ranging from the "Northern tradition" of action research rooted in the work of German social psychologist Kurt Lewin (1946) in the 1940s to the more revolutionary "Southern tradition" grounded in the popular education work of Brazilian educator Paulo Freire (1970, 1982), along with other critical theory, feminist, postmodern, and postcolonial contributors to the field.*

*In Chapter Three, Barbara A. Israel and her academic and community partners share the core set of principles they developed through their work at the University of Michigan Urban Research Center. These principles, including conceptualizations of CBPR as a participatory, empowering, and co-learning process that accents systems development and balances research with action, are widely used as touchstones in the field. Yet as the chapter authors also point out, every partnership is unique, and each CBPR initiative should therefore create its own set of guidelines for practice.*

*We conclude Part One with a case study that does just that, while also demonstrating the immense potential of CBPR in fields like clinical and community medicine. In Chapter Four, Loretta Jones and her colleagues discuss the new form of CBPR known as community-partnered participatory research (CPPR) and its principles and core beliefs. Jones and her colleagues also describe how a CPPR partnership involving the University of California, Los Angeles (UCLA), Medical School and the RAND Corporation has used this approach in the planning of a large experimental design study to test CPPR as an implementation strategy for evidence-based depression care interventions.*

*We hope the first part of this book will give readers a solid understanding of the conceptual and practical base of CBPR and its utility in diverse settings with a range of community-based partnerships. We also hope Part One will encourage readers to explore these challenges further and discover how versatile this orientation is for varied settings, using varied methodologies.*

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# CHAPTER

# 1

## INTRODUCTION TO COMMUNITY-BASED PARTICIPATORY RESEARCH

### NEW ISSUES AND EMPHASES

**MEREDITH MINKLER & NINA WALLERSTEIN**

GROWING INTEREST among health professionals and academics in finding new ways to study and address complex health and social problems has intersected in recent years with increasing community demands for research that is *community-based*, rather than merely *community placed*. The new focus on translational research to improve intervention outcomes within diverse cultures and contexts (Bammer, 2005; Fixsen, Naoom, Blasé, Friedman, & Wallace, 2005; Neuhauser, Richardson, MacKenzie, & Minkler, 2007) has also shone a spotlight on the potential of action-oriented and community-partnered approaches to health and health disparities research.

In the United States, *community-based participatory research* (CBPR) is increasingly being used as an overarching term for this alternative research paradigm. Building

on the work of Barbara Israel, Amy Schulz, Edith Parker, and Adam Becker (1998) in Michigan and of Lawrence W. Green and his Canadian colleagues (1995), 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).

Together with many related action research and participatory research traditions, CBPR turns upside down the more traditional applied research paradigm, in which the outside researcher largely determines the questions asked, the tools employed, the interventions developed, and the kinds of results and outcomes documented and valued (Gaventa, 1993). For, in the words of Budd Hall (1992), "participatory research fundamentally is about who has the right to speak, to analyze and to act" (p. 22). Although often and erroneously referred to as *research methods*, CBPR and other participatory approaches are not methods at all but *orientations to research*. As Andrea Cornwall and Rachel Jewkes (1995), have pointed out, what is distinctive about such approaches "is not the methods but the methodological contexts of their application"; what is new is "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" (p. 1667). Central to CBPR and related approaches is a commitment to consciously muting the distinction between who does the studying and who gets studied (or decides what gets studied). Similarly, enhancing community members' awareness of the assets they bring as researchers and agents of change is a hallmark of CBPR (Israel, Eng, Schulz, & Parker, 2005). As Cargo and Mercer (2008) suggest, "A key strength of [participatory research] is the integration of researchers' theoretical and methodological expertise with nonacademic participants' real-world knowledge and experiences into a mutually reinforcing partnership" (p. 327).

In epidemiology, often described as the *basic science* of public health, movement toward a more participatory and action-oriented approach has also been increasingly advocated and demonstrated (Krieger, 2000; Lantz, Israel, Schulz, & Reyes, 2005; Leung, Yen, & Minkler, 2004; Wing, 1998). Michael Schwab and S. Leonard Syme (1997) are among those pointing up the potential of such an approach, which embraces "the experience and partnership of those we are normally content simply to measure" (p. 2050).

Such perspectives, of course, are not without critics. Although participatory research is gaining legitimacy in academic circles (see Appendix B), much of the academy remains skeptical of participatory and action-oriented approaches to scholarship (Buchanan, Miller, & Wallerstein, 2007; Coghlan, 2004; Northridge et al., 2000). This book addresses these concerns regarding scientific rigor in later chapters and also includes numerous case studies that demonstrate that CBPR can be both community driven and scientifically sound. In the process we underscore the message of environmental epidemiologist Steve Wing (1998) when he notes that if this nation is to transform society to eliminate health disparities and promote social justice, "a more democratic and ecological approach to

scientific study is necessary,” one in which “education between scientists and the public must take place in both directions” (p. 250). It is with this *orientation to research*, with its heavy accent on issues of trust, power, dialogue, community capacity building, and collaborative inquiry toward the goal of social change to improve community health outcomes and eliminate health disparities, that this book is concerned.

## THE GROWING SUPPORT FOR CBPR

Community-based participatory research has received increasing recognition in public health, as evidenced in its being named by the Institute of Medicine (IOM) as one of eight new content areas in which all schools of public health should offer training (Gebbie, Rosenstock, & Hernandez, 2003). The IOM described CBPR-enhanced public health as “epidemiology enriched by contemporary social and behavioral science because it incorporates what we have learned about community processes and engagement, and the complex nature of interventions with epidemiology, in order to understand how the multiple determinants of health interact to influence health in a particular community” (p. 7).

Beyond public health, a solid tradition of participatory research exists in nursing (see, for example, Anderson & McFarlane, 2004; Falk-Rafael, 2004; Averill, 2005; see also Appendix F), and growing interest in the participatory research potential for medicine also is evident. In North America, practice-based research networks (PBRNs), which initially stressed collaborative research with physicians, are broadening their reach to include patients, family members, and communities (Green, 2007; Macaulay & Nutting, 2006; Westfall, VanVorst, Main, & Herbert, 2006). Special issues of such peer-reviewed publications as the *Journal of General Internal Medicine* (Felix-Aaron & O’Toole, 2003) and *Ethnicity & Disease* (Wells & Norris, 2006) have been published. In both the United States and the United Kingdom, new journals devoted to participatory research (that is, *Progress in Community Health Partnerships* and *Action Research*) have been successfully launched, and a book devoted to methods in CBPR for health (Israel et al., 2005) is widely used and cited. Nationally and internationally, a plethora of academic and community centers and also broad networks supporting participatory research may now be found (see Appendix L).

Federal and philanthropic support for CBPR in the health field has also grown substantially in recent years (Minkler, Blackwell, Thompson, & Tamir, 2003; see also Appendix B), albeit still lagging far behind that available for more traditional approaches to health research. As described in Appendix B, following the early lead of the National Institute of Environmental Health Sciences (NIEHS) and the Centers for Disease Control and Prevention (CDC), many divisions in the National Institutes of Health (NIH) have increasingly called for proposals mandating the use of CBPR to study and address health disparities. New, NIH-funded Clinical and Translational Science Centers (CTSCs) also represent a major opportunity to bring CBPR into health sciences research through required community engagement components, which seek community involvement in defining research priorities to transform the academic research enterprise.

Large and small philanthropic organizations, prominently including the W. K. Kellogg Foundation in the United States ([wkkf.org](http://wkkf.org)) and the Wellesley Institute in Canada ([www.wellesleyinstitute.com](http://www.wellesleyinstitute.com)), are supporting both participatory research and its use to help effect health-promoting changes in programs, policies, and practices. Through the Community Track of its Kellogg Health Scholars Program, the W. K. Kellogg Foundation (2008) further supports postdoctoral training of a new cadre of researchers with experience in CBPR and a commitment to scholarly and pedagogical use of this approach in their future careers.

New tools and approaches have also been developed, making possible more rigorous and relevant assessment of CBPR, with special attention to its effectiveness in attending to both CBPR principles and the ethical and methodological challenges often inherent in this work (see Chapter Twelve and Appendixes C and G).

Finally, and most important, CBPR and related approaches increasingly have been identified as promising strategies for research aimed at studying and reducing health disparities (Israel et al., 2005; Wallerstein & Duran, 2006; Wells & Norris, 2006). As Paula Lantz and her colleagues (2005) point out, “even if research is purely descriptive (for example, it is attempting to identify patterns and differentials in some phenomenon by race, ethnicity or social class), a participatory approach can help to reframe or refocus the research questions in ways that improve the research” (p. 245).

Building on these developments, this book’s aim is to excite students, practitioners, and scholars in public health, medicine, nursing, social work, community psychology, and other disciplines about the potentials of CBPR as a potent alternative to outside expert-driven research approaches to studying health and social problems. We hope that both those with substantial experience in CBPR and newcomers to this paradigm will find themselves challenged by the theoretical frameworks offered, the ethical and methodological dilemmas explored, and the theory-driven case studies used throughout to illuminate this approach. The intent of this new edition is to continue to ground the field through relevant theoretical frameworks and case studies while also offering some new directions. As discussed later in this chapter, key among these new directions is more emphasis on outcomes of CBPR, including policy-related outcomes, indicators of sustainability, and factors that predict outcomes. Additionally, this book explores new applications of CBPR (for example, in the data analysis phase of research) and new settings for this endeavor, including clinical and other organizational settings. We begin here, however, by taking a step back to look more closely at the processes, goals, and principles that lie at the heart of this orientation to research.

## SEMANTICS AND CORE PRINCIPLES

Since the publication of the first edition of this volume in 2003, the term *community-based participatory research* has achieved growing popularity, particularly in the United States. Numerous variations of the term exist, however; key among them are *action research* (widely used in the U.K., Australia, and New Zealand); *community-based research*—often the preferred term in Canada (Flicker & Savan, 2006); *participatory action research* and *participatory research* (widely used in many developing countries);



*mutual inquiry*; *feminist participatory research*; and most recently perhaps, *community-partnered participatory research* (Jones & Wells, 2007; see also Chapters Two and Four). Adherents to these different terms continue to engage in lively debate over which one—and which corresponding approach—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 and characteristics (Wallerstein, 1999; Wallerstein & Duran, 2006), summarized by Israel and her colleagues (1998, 2005; see also Chapter Three), who say of CBPR that

- 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 and feminist participatory researchers, such as Patricia Hill Collins (2000), bell hooks (1989), Patricia Maguire (2006), M. Brinton Lykes (1997), and Ella Edmonson Bell (2006), we add to these principles that attention to issues of gender, race, class, and culture should also be central to CBPR, as these issues interlock and influence every aspect of the research enterprise. Especially in the health field, in the United States, where the four-decade Tuskegee study of untreated syphilis in black males remains an indelible reminder of the human costs of unethical scientific research (Thomas & Quinn, 2001), issues of race and ethnicity and of racism must not be overlooked. As discussed in Chapter Five, such realities underscore the need to acknowledge, through “cultural humility,” that although no one can ever be “competent” in another’s culture, individuals can demonstrate an openness to critical reflection and learning about each other’s cultures while also examining the biases they bring to the table and being open to genuine partnership (Tervalon & Murray-Garcia, 1998).

The contributors to this volume each bring their own values and assumptions to CBPR, and their different but complementary views provide alternative perspectives on the processes of and forces shaping respectful engagement with communities in combining research with education and action for change. CBPR is used in this book as an overarching name for this orientation to research and praxis, which stresses the principles and values just outlined and explored in greater detail in subsequent chapters.

Although there has been a growing convergence of principles and values, the majority of participatory and action-oriented approaches to research stem from two separate traditions that fall on opposite ends of a continuum (this topic is discussed in depth in Chapter Two). At one end of the continuum is action research in the tradition of Kurt Lewin (1946) and his followers (Coghlan, 2004; Greenwood & Levin, 1998), for whom the accent is on involving people affected by a problem in practical problem solving through a cyclical process of fact finding, action, and evaluation. As illustrated in Chapter Thirteen, the term *action research* has more recently been used, particularly in the U.K.

and Australia, to reflect an overarching family of “participatory inquiry and practice” approaches (Reason & Bradbury, 2008; Stringer & Genat, 2004; Stringer, 2007). In the United States, however, the term *action research* continues most commonly to reflect the narrower and often more conservative approaches used in industrial psychology and related fields. In this tradition there is some, but not necessarily extensive, involvement of affected individuals and typically little commitment to broader social change objectives (Brown & Tandon, 1983; Coghlan, 2004).

At the other end of this continuum is the more emancipatory focus of the *participatory research* (PR), *collaborative action research*, and *participatory action research* (PAR) traditions, which have their roots in popular education and related work in the 1970s with and by oppressed peoples in Africa, Asia, and Latin America (Hall, Gillette, & Tandon, 1982). Such approaches often developed as a direct counter to the often “colonizing” nature of the research to which these peoples were subjected (Fals-Borda & Rahman, 1991; Freire, 1982; Swantz, Ndedy, & Masaiganah, 2006). As Budd Hall (1999) has suggested, “participatory research was very largely theorized and disseminated from a social movement or civil society base: (p. 35). Among the original premises were the importance of ‘breaking’ what Hall referred to as the ‘monopoly over knowledge production’ by universities . . . [with] recognition that the academic mode of production was, and remains, in some fundamental way, linked to different sets of interests and power relations than [those held by] women and men in various social movement settings or located in more autonomous community-based, nongovernmental structures” (p. 35).

As discussed in Chapter Two, feminist participatory research approaches, postmodern research, and postcolonial research are among the important contributors to PR and PAR in this tradition. The accent placed by feminist scholars on the importance of *voice*—of having women speak of their own experience and reality, in part as a means of understanding power relations—has thus heavily shaped the work of many participatory researchers (including Cornwall & Jewkes, 1995; Lykes, 1997; Maguire, 2006). Feminists and postcolonial research traditions have similarly reinforced structural transformation as the ultimate goal of an integrated activity combining “social investigation, educational work, and action” (Hall, 1981, p. 7; Maguire, 2006). Finally, and in an interesting alternative to discussions that most often take place from the perspective of academically trained research partners, the new term *street science* is used by Jay Corburn (2005) to describe an approach to environmental health justice that “joins local insights with professional techniques.” As Corburn suggests, street science “does not devalue science, but rather revalues forms of knowledge that professional science has excluded and democratizes the inquiry and decision-making processes” (p. 3; see also Ansley & Gaventa, 1997).

As the contributors to this volume well demonstrate, CBPR can and does occur at many places along the continuum from Lewinian action research through participatory (action) research. Yet for all involved to really live up to the definition and espoused principles of CBPR for health—principles accenting having true partnerships between outside researchers and communities and achieving a balance between research and action toward the goal of ending health disparities—it is the emancipatory end of the continuum

that ideally should serve as a gold standard for CBPR practice. Particularly for professionals in fields like public health and social welfare, with their roots in concerns for social justice, CBPR in this latter sense provides an important goal for which to strive in their collaborative work with communities.

## **CBPR AND THE FIGHT TO ELIMINATE HEALTH DISPARITIES**

In August 2005, the tragedy of Hurricane Katrina and its bitter aftermath starkly revealed the depth of the race and class disparities in health and life chances in the United States generally and epitomized in New Orleans's Ninth Ward. Through the images seen around the world on television screens and the Internet, many people came to grips with the extent to which there is a "Third World" within the "First World" that is the United States (Omi, 2000) and that in this Third World, mini-Katrinās happen on a daily basis (see Chapter Five). As PolicyLink founder and chief executive officer Angela Glover Blackwell is fond of pointing out, perhaps the only silver lining to Katrina was that it forced Americans to confront head on the dramatic race and class-based inequities that continue to exist in this country and in the process brought about the most sustained dialogue on race and poverty in America since the civil rights movement. It is a goal of this book to contribute to that dialogue, in part as the contributors explore through multiple case studies the continued profound health and social inequities based on race, ethnicity, class, gender, age, disability, sexual orientation, and gender identity and well documented in the literature (Krieger, Rowley, Herman, Avery, & Phillips, 1993; Marmot & Wilkinson, 2006; Schulz & Mullings, 2006; Williams, Neighbors, & Jackson, 2003). But readers also will see how involving communities of color and other stigmatized groups as equal partners in a strengths-based and action-oriented research process, beginning with community definition of the problem to be explored, can improve the quality and outcomes of the research.

The need for new approaches in the efforts to study and address health disparities and inequities cannot be overstressed. Despite some recent progress, racial and ethnic disparities in health and health care access and quality remain profound and have been associated with sociostructural factors such as poverty, racism, minimal public infrastructure, lack of employment opportunities, and neighborhood characteristics (Berkman & Kawachi, 2003; Gee, Spencer, Chen, & Takeuchi, 2007; Krieger et al., 1993; Smedley, Stith, & Nelson, 2003; Williams et al., 2003). Environmental factors, such as outdoor air quality and the prevalence of mite allergens or mold in low-income homes, often exacerbate asthma and other conditions in communities of color, which are disproportionately located in poor neighborhoods (Krieger, Allen, Roberts, Ross, & Takaro, 2005; LaVeist, 2005). Finally, when social capital, which is measured in terms of social networks and feelings of reciprocity and trust (Szreter & Woolcock, 2004; Kawachi, Kennedy, Lochner, & Prothrow-Stith, 1997), is low, it has been shown to bear a relationship to poverty and health disparities (James, Schulz, & van Olphen, 2001). New research showing low social capital in neighborhoods characterized by racial or ethnic heterogeneity (Putnam, 2007) is particularly disturbing, underscoring as it does how far this nation has to go in developing cross-cultural understanding and trust (see Chapter Five).

The fight against disparities can be won only if the most oppressed communities can be fully engaged as partners in exploring and in taking action to address the health and social problems about which they—not experts as outsiders—care most deeply (Minkler, 2005; Wells & Norris, 2006).

## GOALS OF THIS BOOK: CONTINUING CONCERNS AND NEW EMPHASES

Our primary goal in this book is to provide a highly accessible text that will stimulate practitioners, students, academics in health and related fields, and their community partners as they engage—intellectually and in practice—in community-based participatory research as an alternative approach to collaborative inquiry for action to eliminate health disparities. Further, and although much cutting-edge participatory research continues outside the United States (see, for example, Mosavel, Simon, van Stade, & Buchbinder, 2005; Reason & Bradbury, 2006; Rice, 2007; Stringer, 2007), our purpose is to focus primarily on CBPR in the contemporary United States, in part so that we can more carefully attend to the geopolitical and sociohistorical contexts that are so central to this work. We frequently draw on the wisdom of leading PR, AR, and PAR scholars and practitioners in developing nations, the U.K., Canada, Australia, and elsewhere (De Koning & Martin, 1996), and believe that many of the skills and conceptual and ethical issues raised will have relevance beyond the United States. We also acknowledge our deep indebtedness to earlier landmark participatory research in North America, to which we cannot do justice here (see Park, Brydon-Miller, Hall, & Jackson, 1993). These classic studies address, for example, popular epidemiology in occupational and environmental health in Appalachia conducted over two decades ago by and with the Highlander Research and Education Center in Tennessee (Couto, 1987; Lewis, 2006; Merrifield, 1993).

As we build on this rich history, our central concern is with helping students, scholars, community members, and practitioners in fields such as health, social welfare, and city and regional planning become more inspired by, comfortable with, and proficient in applying CBPR approaches in their community-based work. Within this context the contributors to this volume explore such issues as cross-cultural and power dynamics in the CBPR process, with particular attention to race and racism; methods and techniques for helping communities identify their strengths and concerns; issues of rigor and validity in CBPR; and special considerations in conducting CBPR with hidden populations, youths, and other diverse groups.

Alongside these continuing concerns, however, this new volume introduces—and considers in more depth—several new emphases. The first of these grows out of an increased call across public health, medicine, and related disciplines for evidence-based practice and outcomes-based research (Green, 2006; Green & Glasgow, 2006). A recognition that evidence in one setting is no longer sufficient for translating interventions to diverse settings has led to calls for greater attention to external validity, *practice-based evidence*, and implementation contexts (Hall, 2001; Fixsen et al., 2005; Miller & Shinn, 2005; Green, 2006). Examining the added value of CBPR and the pathways through which CBPR may improve health has become increasingly important with the growing attention

to translational research (Bammer, 2005; Best, Hiatt, & Norman, 2005; Neuhauser et al., 2007; see also Chapter Twenty-One). Consistent with these concerns, the focus of the field of CBPR is evolving from an initial and continued interest in *process* (that is, in how to form authentic partnerships or involve community members in the research) to an interest in the study of *outcomes*, whether these are systems change CBPR outcomes (that is, health-promoting policies or practices) or outcomes related to health and the reduction of health disparities. In this second edition we study CBPR processes leading to outcomes within a translational context, as a potential key to better understanding implementation and sustainability within interventions research. In addition to new chapters presenting case studies selected in part because they feature demonstrated effectiveness in getting to outcomes, we have included updated chapters from the first edition that now discuss documented, longer-term outcomes. Our strengthened emphasis on case studies provides professionals with valuable examples of integrating theoretical and practice-based concepts, as these case studies situate and apply these concepts in real-world CBPR settings.

We also provide in this new edition a final chapter that explores the contributions of CBPR to outcomes and the potential pathways to both intermediate system change outcomes and more distal health changes. Reporting on the first-year results of a two-year pilot study to identify these core processes and pathways, the chapter offers a unifying conceptual model to guide researchers' and practitioners' thinking in this area and inform future intervention research. The chapter also offers a series of hypotheses that could profitably be tested for their ability to move the field forward. Although we present this work as an integrative chapter at the end of the book, readers who are familiar with CBPR may wish to read it early on, using its discussion of the state of the science of CBPR and the challenges in the field to provide context as they explore the various case studies and theoretical, ethical, and methodological issues discussed in other chapters.

A second new focus of this book involves the growing interest in academic and clinical medicine in incorporating CBPR in work with patients, providers, and health and other social service agencies (Felix-Aaron & O'Toole, 2003; Macaulay & Nutting, 2006; Wells & Norris, 2006). As Loretta Jones and Ken Wells point out (2007), "community-based participatory research has been used more as a paradigm for public health than for clinical or health services research," and "many features of CBPR, such as spending time in the community, power sharing, and action research methods, might challenge physicians given their clinical training" and the demands and expectations of their work (p. 407). Yet as Jones and Wells go on to note, in medicine too, new collaborations and NIH funding opportunities (see Appendix B) are encouraging physicians and other clinicians to employ CBPR in innovative ways (Macaulay & Nutting, 2006; Wells & Norris, 2006). Although this book remains focused primarily on the use of CBPR in community settings and within the context of public health, we have broadened our gaze in this second volume to increase its utility to physicians, nurses, social workers, and other clinicians who are exploring the use of CBPR within health care and provider contexts (see Chapter Four and Appendix F).

As discussed in Chapters Three and Sixteen, although CBPR frequently involves community partners in issue selection, study design, and data collection and dissemination, data analysis is typically left up to the academic or other outside research partners. The third new area of emphasis in this volume concerns actively involving community

partners in data analysis and understanding both the advantages and the challenges of doing so (see Chapter Sixteen). We further have devoted more attention to participatory evaluation with community partners, both in the expanded and updated chapter on that theme (see Chapter Twelve) and in case studies, such as the study of the Healthy Native Community Fellowship (see Chapter Ten).

A final expanded area of emphasis involves the use of CBPR to help bring about policy changes. Several seminal works in this area have been produced, key among them the user-friendly monograph *Speaking Truth, Creating Power*, by Cassandra Ritas (2003), available through Community-Campus Partnerships for Health. Yet efforts to document the impacts of CBPR on policy have been slower in coming. Of the sixty CBPR case studies identified through the comprehensive literature review commissioned by the Agency for Healthcare Research and Quality (Viswanathan et al., 2004), just thirteen were seen as having a strong policy focus. With support from funders including the W. K. Kellogg Foundation and The California Endowment, several efforts to chronicle the impacts of CBPR on policy have since gotten under way and are building the evidence base in this area (see, for example, Morello-Frosch, Pastor, Sadd, Porras, & Prichard, 2005; Petersen, Minkler, Breckwich Vásquez, & Baden, 2006; Minkler et al., 2008; Minkler, Breckwich Vásquez, Tajik, and Petersen, 2008). In this second edition we contribute an expanded overview chapter on CBPR and policy and three case studies designed to show the breadth and diversity of work in this area (see Chapters Seventeen through Twenty).

In sum this second edition offers the reader several new and expanded areas of emphasis that reflect some of the exciting developments in the theory and practice of community-based participatory research. The chapter authors have in common a belief in the power of CBPR, tempered with an awareness of the very real ethical and practical dilemmas that arise in the course of CBPR application. Speaking from both personal experience in the field and a broad understanding of underlying theoretical, methodological, and ethical and value issues, they help the reader to grapple with some of the steps and considerations that underlie ethical and effective community engagement. The contributors share as well the formal and informal theories guiding their work, because, in the words of social epidemiologist Nancy Krieger (2000), “by clarifying our theories we are likely to enhance our understanding of what kinds of questions we need to ask, and with whom it is we need to think and work, to generate knowledge and action useful in rectifying social inequalities in health” (p. 27).

Finally, the book’s contributors provide, through both case studies and an appendix of concrete tools, a host of techniques and methods that may be useful in working collaboratively with communities in different phases of the CBPR process.

## ORGANIZATION OF THIS BOOK

In Chapter Two, Nina Wallerstein and Bonnie Duran situate CBPR and other participatory research approaches historically, conceptually, and in practice, identifying a far-reaching sweep of historical and theoretical underpinnings, including the popular education work of Brazilian educator Paulo Freire (1970, 1973, 1982) and other critical theory, feminist, postmodern, and postcolonial contributions to the field.



In Chapter Three, Barbara Israel and her academic and community partners share the core set of principles they developed through their work at the University of Michigan Urban Research Center, and discuss ethical considerations for the field, including a recommendation that each CBPR initiative come up with its own set of guidelines. Loretta Jones and her colleagues conclude Part One with an introduction, in Chapter Four, to the new form of CBPR known as *community-partnered participatory research* (CPPR) and its principles and core beliefs. Jones and her colleagues also describe how a CPPR partnership involving the University of California, Los Angeles (UCLA) Medical School and the RAND Corporation used this approach in the planning of a major experimental design study to test CPPR as an implementation strategy for evidence-based depression care interventions.

In Part Two we grapple further with issues of trust, power, dialogue, and race or ethnicity and racism as we focus on the challenges of building relationships with community members, clinical providers, and policymakers in multiple settings. In Chapter Five, Vivian Chávez and colleagues examine the multiple dimensions of race and privilege, historical trauma and internalized oppression, and conversely, the existence of strong social movements in communities. The context these factors create for understanding cross-cultural CBPR is also examined.

Although this book is premised on the assumption that concerned outside researchers can make useful contributions to community-driven research, Randy Stoecker, in Chapter Six, takes a step back to examine that assumption, asking whether outside academics do have a legitimate role to play in participatory research and then offering “guideposts” for effective and ethical engagement. Further exploring many of these issues, Ann Cheatham-Rojas and Eveline Chen then analyze in Chapter Seven a CBPR project involving Cambodian girls studying sexual harassment in their school. They illustrate in the process the powerful contributions youths can make as genuine partners in CBPR efforts. Issues of trust, dialogue, and problem solving when working with youths and also outcomes, such as new school and district policies to prevent sexual harassment and the birth of a new nonprofit organization of and by young Cambodian women, are among the topics discussed.

Conducting research with “hidden populations” presents special challenges to trust building and effective cross-cultural partnerships. In Chapter Eight, the final chapter in Part Two, Kristen Clements-Nolle and Ari Bachrach describe and analyze the CBPR approach employed in the first major epidemiological study of and with transgender people, including the multiple roles of community partners in gaining access to this hidden and stigmatized population. A ten-year retrospective look at this project and its many subsequent program, policy, and practice outcomes is provided, along with lessons learned.

Part Three focuses on one of the most important but often neglected processes in CBPR—creating a setting in which community members, rather than outsiders, truly drive the decisions around issue selection and actively participate in project and partnership evaluation.

In Chapter Nine, Meredith Minkler and Trevor Hancock discuss three core principles that lie at the heart of ensuring community-driven issue selection: starting where the people are, building on community strengths, and fostering authentic dialogue. They then present a variety of collaborative strategies for identifying strengths and issues, such as

windshield tours, town hall meetings, community asset and risk mapping, a modified Delphi technique, and neighborhood indicator development.

Next, in Chapter Ten, Marita Jones, Shelley Frazier, and their colleagues explore the successes and challenges encountered in using Internet-based tools in a CBPR partnership to build local capacity, cross-community sharing, leadership, and knowledge creation in geographically dispersed urban and rural communities. The national Healthy Native Community Fellowship and the Just Move It physical activity program, which serve tribes and tribal agencies across the nation, are used to illustrate the utility of the Internet in such capacity-focused collaborations.

In Chapter Eleven, Caroline Wang and Cheri Pies explore the potency and challenges of the *photovoice* method, which integrates “community participation, health concerns, and the visual image” for collective action for change (Wang & Burris, 1994, p. 177). Using as a case study the experiences of a local health department working on maternal child health issues with low-income residents, they illustrate the strengths of photovoice in broadening and deepening academics’ and practitioners’ understandings of local concerns and strengths, and how these understandings may in turn help a community to effect change.

In Chapter Twelve, the final chapter in Part Three, Jane Springett and Nina Wallerstein critically examine participatory evaluation, consider its relationship to participatory research, explore the multiple and sometimes conflicting roles of the evaluator, and contrast participatory and traditional evaluation. They end with a brief case study of a statewide youth policy project in New Mexico, which shows how collaborative development of youth and policy change indicators facilitated program effectiveness.

Part Four turns a spotlight on some of the knottiest issues in CBPR: the validity and quality of the research and the many difficult ethical and practical issues involved in the implementation of research findings. We begin, in Chapter Thirteen, with Hilary Bradbury and Peter Reason’s thoughtful examination of these issues, such as how to identify “choice points” for improving the quality of action research, and how to “broaden the bandwidth of validity” to include how well a program is grounded experientially and whether it builds infrastructure so that the work may endure over time.

In the following chapter, Chapter Fourteen, Meredith Minkler and Andrea Corage Baden draw on both reviews of the literature and in-depth interviews from a cross-site case study analysis (Minkler et al., 2008a, 2008b) to explore the impacts of CBPR on the outside researchers, the research quality and methodology, and the way in which CBPR addresses power differentials between community and academic partners.

To further illustrate a number of the methodological and ethical issues faced in CBPR, Part Four also presents several in-depth case studies. In Chapter Fifteen, Stephanie Farquhar and Steve Wing discuss two unique community-academic partnerships designed to document and expose health problems and potential social and environmental racism in rural North Carolina. They pay particular attention to how academic and community partners handled the controversies generated when findings had political fallout, such as charges of bias and “unscientific” research, and demands to disclose confidential data sources. In Chapter Sixteen, the last chapter of this section, Suzanne Cashman and her colleagues use brief case studies (involving surveys, geographic information system [GIS] mapping, focus groups, and mixed methods) to highlight the



involvement of community partners in data analysis and interpretation. Illustrated is the value of authentic partnerships in producing far richer understandings of a problem area than outsiders could achieve working on their own, and in leaving behind a community of people better able to systematically study and act on their issues in the future.

One of the defining features of CBPR that sets it apart from more traditional research approaches is its commitment to action (Israel et al., 1998; Minkler, 2005). Part Five takes an in-depth look at the action component of CBPR, giving particular attention to how CBPR can foster health-promoting policy changes in the public and private sectors. Makani Themba-Nixon, Meredith Minkler, and Nicholas Freudenberg begin this examination, in Chapter Seventeen, by summarizing two conceptual frameworks for understanding the public policymaking process in the United States and also a third framework more directly tailored to policy advocacy through CBPR. Drawing on case examples they then illustrate the roles and entry points for CBPR partners interested in influencing policy. In Chapter Eighteen, Peggy Shepard and her colleagues describe one of the most frequently cited examples of a successful effort to study and address the disproportionate exposure to environmental insults in low-income communities of color. Although the original CBPR collaboration between West Harlem Environmental Action (WE ACT) and its academic partners took place well over a decade ago, its successes in helping to bring about policy change and the continuing collaborative work it has helped to spawn are useful reminders of the need to look at CBPR efforts over the long haul.

Although policy is most often thought of in broad public policy terms, the potential for improving health through changes in private sector arenas should not be forgotten. In Chapter Nineteen, Pam Tau Lee and her colleagues examine two union-supported CBPR projects, undertaken by university partners and hotel room cleaners in San Francisco and Las Vegas. These authors document the key role of the room cleaners in the research—including their high-level participation at the bargaining table—and in bringing about contract changes to improve workload and other working conditions.

In Chapter Twenty, Victoria Breckwich Vásquez and her colleagues explore the efforts of a partnership between a youth-focused environmental justice organization and a local health department to promote policy changes to address lack of access to fresh fruits and vegetables in a low-income neighborhood in San Francisco. The chapter chronicles the partnership's innovative data collection, its work with city policymakers to mount a major new program incentivizing local stores to become "Good Neighbors," and the impacts of this work on fresh food access locally as well as on broader state policy efforts.

In this book's final chapter Nina Wallerstein and Bonnie Duran and their research team return to a central theme of this volume while also offering a bridge to future efforts to understand the pathways through which CBPR processes lead both to intermediate capacity and systems level outcomes and to more distal health changes. These authors present a logic model that captures the core participatory characteristics and mediating or moderating processes that may matter most in getting to outcomes in CBPR. Enhanced partnerships, culturally based interventions, institutional practice changes, and policy changes are among the core factors identified.

The book concludes with twelve appendixes designed to provide a variety of tools and applications to outsider researchers and their community partners so that they can put

some of the messages central to this volume into practice in their own CBPR efforts. Among the instruments included are sample protocols for community–outside researcher collaboration in CBPR; tools for communities to use in conducting their own asset and risk mapping; a brief historical look at federal support for participatory research in the United States; and new, reliability-tested guidelines for assessing participatory research in health promotion. The appendixes include as well a glimpse of CBPR in the field of nursing; recommendations for modified institutional review board (IRB) questions when reviewing CBPR proposals; insights into the use of “undoing racism” training in the context of CBPR; recommendations and resources that academic CBPR partners can use for strengthening their case for promotion and tenure; and contact information for many key CBPR centers and networks based in North America.

## SUMMARY

Growing disillusionment with the limitations of traditional, “outside expert” approaches to understanding and addressing some of our most complex health and social problems have helped shine a spotlight on the potential of the alternative paradigm, which in the United States increasingly goes under the heading of community-based participatory research. An orientation to action-oriented inquiry, rather than a particular methodological approach, CBPR is time consuming and filled with challenges as local communities and their outside research collaborators navigate difficult ethical and methodological terrain, addressing issues of power and trust; race, ethnicity, and racism; research rigor; and, often, conflicting agendas (Maguire, 2006; Minkler, 2005; Stringer, 2007). Leveraging sufficient funding for CBPR also is a challenge, and although increasing substantially over the past decade, such financial support lags far behind the level of funding available for more traditional research approaches. Yet as the contributors to this volume demonstrate, CBPR also holds immense promise for insuring that research focuses on topics of deep concern to communities and is conducted in ways that can enhance validity, build community capacity, promote systems change, and work to reduce health disparities. At the same time, CBPR can foster the conditions in which professionally trained researchers adopt the role of co-learner, rather than outside expert, and communities better recognize and build on their strengths and become full partners in gaining and creating knowledge and mobilizing for change. As CBPR continues to evolve as a field of practice and an orientation to research, a new emphasis is being placed on the pathways linking processes to outcomes and on applications across a wide range of disciplines, settings, and populations. By introducing the reader to such issues using a broad brush, this first chapter has attempted to set the stage for the more in-depth coverage of each issue in the pages that follow.

## QUESTIONS FOR DISCUSSION

1. Cornwall and Jewkes are cited in this chapter as arguing that community-based participatory research is not a research method per se but rather an “orientation to research” that reflects a very different stance from that taken by traditional research approaches in relation to communities and community members. How would you

describe this alternative research paradigm to a friend or colleague who's never heard of CBPR? Also, what other elements, if any, would you add to the definition, cited earlier, of CBPR used by the Kellogg Community Health Scholars Program (2001, p. 2): "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"?

2. CBPR is described in this chapter as a particularly promising approach for health disparities research. What characteristics of this orientation to research might especially lend themselves to the study of health and social problems that adversely affect people from underserved communities?
3. The authors describe CBPR as existing on a continuum running from action research (in the tradition of Kurt Lewin) on one end to the more "emancipatory" approaches (such as participatory research or participatory action research [PAR]) on the other. They go on to suggest that the more emancipatory forms of CBPR represent a "gold standard" for which professionals might strive. Do you agree with this characterization? Why or why not?

## KEY TERMS

Action research

Participatory action research

Health disparities

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