



# Community Engagement:

Definitions and Organizing Concepts from the Literature

## Chapter 1

# Community Engagement: Definitions and Organizing Concepts from the Literature

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### INTRODUCTION

Over the last two decades, research and practice in health promotion have increasingly employed community engagement, defined as “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people” (Centers for Disease Control and Prevention [CDC], 1997, p. 9). In general, the goals of community engagement are to build trust, enlist new resources and allies, create better communication, and improve overall health outcomes as successful projects evolve into lasting collaborations (CDC, 1997; Shore, 2006; Wallerstein, 2002).

The rationale for community-engaged health promotion, policy making, and research is largely rooted in the recognition that lifestyles, behaviors, and the incidence of illness are all shaped by social and physical environments (Hanson, 1988; Institute of Medicine, 1988). This “ecological” view is consistent with the idea that health inequalities have their roots in larger

socioeconomic conditions (Iton, 2009). If health is socially determined, then health issues are best addressed by engaging community partners who can bring their own perspectives and understandings of community life and health issues to a project. And if health inequalities are rooted in larger socioeconomic inequalities, then approaches to health improvement must take into account the concerns of communities and be able to benefit diverse populations.

The growing commitment to community engagement is reflected in a number of major federal initiatives, including the Clinical and Translational Science Awards (CTSA) program and the Research Centers in Minority Institutions program of the National Institutes of Health (NIH), CDC's Prevention Research Centers, and the practice-based research networks of the Agency for Healthcare Research and Quality (AHRQ). In addition, new work by AHRQ highlights the potential benefits of engaging patients and families in the redesign of medical care (Scholle et al., 2010). Healthy People 2020, which lays out our national health objectives, emphasizes collaboration among diverse groups as a strategy to improve health.

This emphasis on community engagement has encouraged health professionals, community leaders, and policy makers to imagine new opportunities as they face new challenges (Doll et al., 2008). This initial chapter addresses concepts, models, and frameworks that can be used to guide and inspire efforts to meet those challenges. It does not pretend to cover all the available and relevant social science and public health literature, but it provides an overview of some of the critical organizing concepts that shed light on the idea of community and the practice of community engagement. Sociology, political science, cultural anthropology, organizational development, psychology, social work, and other disciplines have all contributed to the development and practice of community engagement (Minkler et al., 2009). Moreover, community engagement is grounded in the principles of community organization: fairness, justice, empowerment, participation, and self-determination (Alinsky, 1962; Chávez et al., 2007; Freire, 1970; Wallerstein et al., 2006). The interdisciplinary background offered in this chapter provides a rich array of concepts for stakeholders, such as public health agencies, practice-based researchers (in

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clinics, agencies, after-school programs, and nursing homes), policy makers, and community organizations, to draw from when developing partnerships in community engagement.

This chapter is more extensive than the corresponding chapter in the first edition, reflecting growth in the literature and the increased collective experience in community engagement.

## CONCEPTS OF COMMUNITY

There are many ways to think about community. We will explore four of the most relevant, each of which provides different insights into the process of community engagement.

### Systems Perspective

From a systems perspective, a community is similar to a living creature, comprising different parts that represent specialized functions, activities, or interests, each operating within specific boundaries to meet community needs. For example, schools focus on education, the transportation sector focuses on moving people and products, economic entities focus on enterprise and employment, faith organizations focus on the spiritual and physical well-being of people, and health care agencies focus on the prevention and treatment of diseases and injuries (Henry, 2011). For the community to function well, each part has to effectively carry out its role *in relation to the whole organism*. A healthy community has well-connected, interdependent sectors that share responsibility for recognizing and resolving problems and enhancing its well-being. Successfully addressing a community's complex problems requires integration, collaboration, and coordination of resources from all parts (Thompson et al., 1990). From a systems perspective, then, collaboration is a logical approach to health improvement.

### Social Perspective

A community can also be defined by describing the social and political networks that link individuals, community organizations, and leaders. Understanding these networks is critical to planning efforts in engagement. For example,

tracing social ties among individuals may help engagement leaders to identify a community's leadership, understand its behavior patterns, identify its high-risk groups, and strengthen its networks (Minkler et al., 1997). Chapter 6 explores this approach to understanding a community in greater depth.

### **Virtual Perspective**

Some communities map onto geographically defined areas, but today, individuals rely more and more on computer-mediated communications to access information, meet people, and make decisions that affect their lives (Kozinets, 2002). Examples of computer-mediated forms of communication include email, instant or text messaging, e-chat rooms, and social networking sites such as Facebook, YouTube, and Twitter (Flavian et al., 2005). Social groups or groups with a common interest that interact in an organized fashion on the Internet are considered “virtual communities” (Rheingold, 2000; Ridings et al., 2002). Without question, these virtual communities are potential partners for community-engaged health promotion and research. Chapter 6 focuses on social networking and expands on the virtual perspective.

### **Individual Perspective**

Individuals have their own sense of community membership that is beyond the definitions of community applied by researchers and engagement leaders. Moreover, they may have a sense of belonging to more than one community. In addition, their sense of membership can change over time and may affect their participation in community activities (Minkler et al., 2004).

The philosopher and psychologist William James shed light on this issue in his writings. James thought it important to consider two perspectives on identity: the “I,” or how a person thinks about himself or herself, and the “me,” or how others see and think about that person. Sometimes these two views agree and result in a shared sense of an identity, but other times they do not. People should not make assumptions about identity based on appearance, language, or cultural origin; nor should they make assumptions about an individual's perspective based on his or her identity (James, 1890). Today, the multiple communities that might be relevant for any individual — including families, workplace, and social, religious, and political associations — suggest that individuals are thinking about themselves in more complex ways than was the norm in years past.

The eligibility criteria that scientists, policy makers, and others develop for social programs and research projects reflect one way that people perceive a group of proposed participants, but how much those criteria reflect the participants' actual view of themselves is uncertain. Practitioners of community engagement need to learn how individuals understand their identity and connections, enter into relationships, and form communities.

## WHAT IS COMMUNITY ENGAGEMENT?

In the first edition of *Principles*, the authors developed a working definition of community engagement that captures its key features:

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

Community engagement can take many forms, and partners can include organized groups, agencies, institutions, or individuals. Collaborators may be engaged in health promotion, research, or policy making.

Community engagement can also be seen as a continuum of community involvement. Figure 1.1 below, modified from a diagram originally drawn by the International Association for Public Participation, illustrates one way of thinking about such a continuum. Over time, a specific collaboration is likely to move along this continuum toward greater community involvement, and any given collaboration is likely to evolve in other ways, too. Most notably, while community engagement may be achieved during a time-limited project, it frequently involves — and often evolves into — long-term partnerships that move from the traditional focus on a single health issue to address a range of social, economic, political, and environmental factors that affect health.

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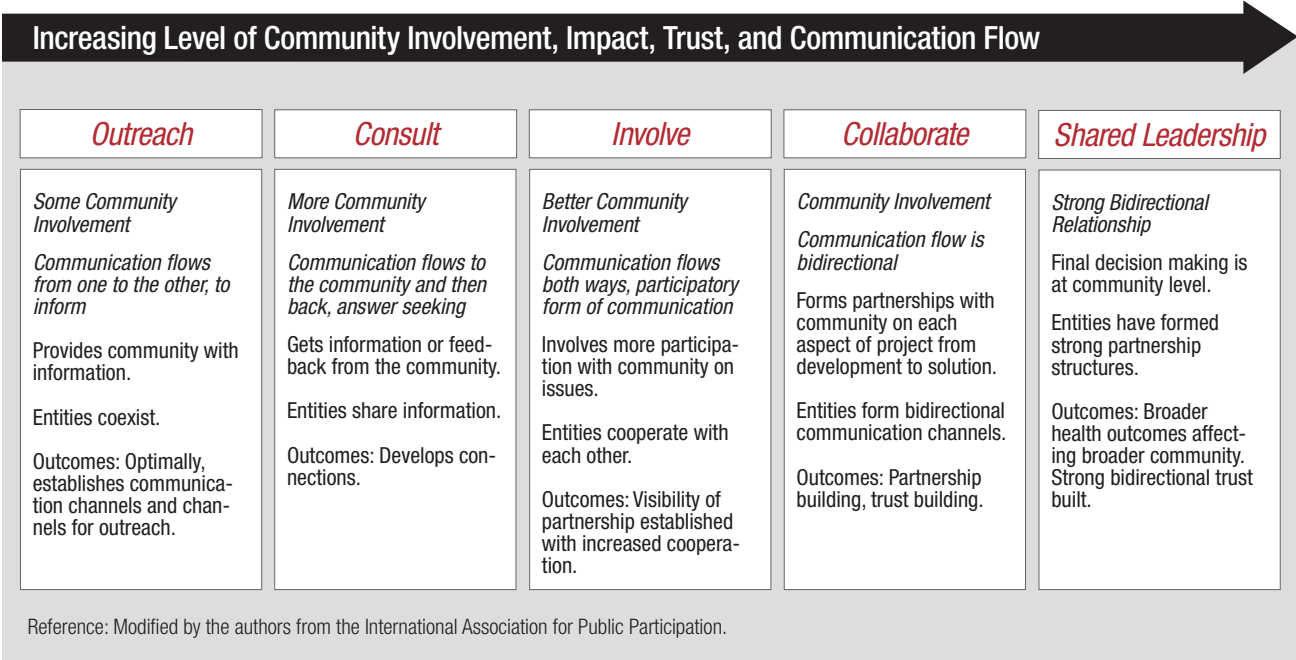


Figure 1.1. Community Engagement Continuum

**Why Practice Community Engagement?**

Advocates of community engagement assert that it improves health promotion and health research. However, the processes, costs, and benefits of community engagement are still a relatively new field of study. In 2004, AHRQ brought attention to the importance of empirical work in this area and greatly advanced our knowledge through a synthesis of the research, much of which indicated that community engagement strengthened the conduct of research (Viswanathan et al., 2004).

A recent review of the literature on community engagement identified nine areas in which community engagement made a positive impact (Staley, 2009). Although this study focused on research partnerships, many of its findings are relevant to community engagement in general. The nine areas and the corresponding benefits were as follows:

1. **Agenda**—Engagement changes the choice and focus of projects, how they are initiated, and their potential to obtain funding. New areas for collaboration are identified, and funding that requires community engagement becomes accessible.

2. **Design and delivery**—Improvements to study design, tools, interventions, representation/participation, data collection and analysis, communication, and dissemination can be implemented. New interventions or previously unappreciated causal links can be identified through the community’s knowledge of local circumstances. The speed and efficiency of the project can be enhanced by rapidly engaging partners and participants and identifying new sources of information.
3. **Implementation and change**—Improvements can be made in the way research findings are used to bring about change (e.g., through new or improved services, policy or funding changes, or transformation of professional practices), and capacity for change and the maintenance of long-term partnerships can be expanded.
4. **Ethics**—Engagement creates opportunities to improve the consent process, identify ethical pitfalls, and create processes for resolving ethical problems when they arise.
5. **The public involved in the project**—The knowledge and skills of the public involved in the project can be enhanced, and their contributions can be recognized (possibly through financial rewards). These efforts foster goodwill and help lay the groundwork for subsequent collaborations.
6. **Academic partners**—Academic partners can gain enhanced understanding of the issue under study and appreciation of the role and value of community involvement, which sometimes result in direct career benefits. In addition, new insights into the relevance of a project and the various benefits to be gained from it can result in increased opportunities to disseminate its findings and their wider use.
7. **Individual research participants**—Improvements in the way studies are carried out can make it easier to participate in them and bring benefits to participants.
8. **Community organizations**—These organizations can gain enhanced knowledge, a higher profile in the community, more linkages with other community members and entities, and new organizational capacity. These benefits can create goodwill and help lay the groundwork for subsequent collaborations.



9. **The general public**—The general public is likely to be more receptive to the research and reap greater benefits from it.

The author of the review acknowledged that there can be costs associated with community engagement (e.g., increased time and other resource needs, the need to develop new skill sets, increased expectations) but contended that these are more than outweighed by the positive impacts and generally can be addressed over time through training and experience (Staley, 2009).

## USEFUL CONCEPTS FOR THE PRACTICE OF COMMUNITY ENGAGEMENT

The social science and public health fields provide us not only with useful definitions of community and ideas about community engagement but also with a wealth of concepts that are relevant to the practice of engagement. Here, we explore some of the most important.

### Culture and Community Engagement

One of the more useful of the hundreds of definitions of culture is this one from the anthropologist Christie Kiefer (2007): “a complex integrated system of thought and behavior shared by members of a group — a system whose whole pattern allows us to understand the meanings that people attach to specific facts and observations.” Culture shapes identities and fosters notions of community, and it shapes how individuals and groups relate to each other, how meaning is created, and how power is defined. Furthermore, culture shapes ideas about partnership, trust, and negotiation. Therefore, culture shapes the process of community engagement, and effective engagement requires an understanding of culture (Blumenthal et al., 2004; Dévieux et al., 2005; Silka et al., 2008).

In particular, researchers and practitioners need to understand the cultural dynamics of specific groups and institutions in order to build relationships, identify ways to effectively collaborate, and build respect and trust. This is an ongoing effort for all involved in the community engagement process (Harrell et al., 2006; Minkler et al., 2004; Shoultz et al., 2006; Sullivan et al., 2001). Communities are not homogeneous entities; they are made up of diverse groups with different histories, social structures, value systems, and cultural understandings of the world.

There is no question that culture and health are intimately connected. Indeed, culture influences perceptions of illness and suffering, methods of disease prevention, treatments for illness, and use of health services. Both medical and public health literature recognize the connection between health and culture (Airhihenbuwa, 2007; Fisher et al., 2007; Krumeich et al., 2001; Resnicow et al., 1999), but the solution to bridging cultural boundaries is often presented as acquiring “cultural competency,” or having knowledge of a group’s cultural differences and typical behaviors or beliefs. This is inadequate, however. As anthropologists have demonstrated, culture is dynamic and complex, and cultural competence is more than identifying how a group is thought to differ from prevailing standards or norms of behavior and belief (Carpenter-Song et al., 2007). Focusing on the meanings that individuals share and on the explanatory models they use to discuss their health problems provides a richer understanding of these individuals and can yield a cultural understanding that is rooted in their real lives rather than in stereotypes. This meaning-centered approach can also help reveal how community conditions are determined by social, economic, and political forces rather than simply by individual choices (Carpenter-Song et al., 2007; Kleinman et al., 2006; Kumagai et al., 2009; Silka et al., 2008).

To achieve successful collaboration with a community, all parties involved need to strive to understand the point of view of “insiders,” whether they are members of a neighborhood, religious institution, health practice, community organization, or public health agency. Key to developing such understanding is recognizing one’s *own* culture and how it shapes one’s beliefs and understanding of health and illness (Airhihenbuwa, 2007; Hahn, 1999; Harrell et al., 2006; Kleinman, 1980; Minkler, 2004). For example, community-engaged programs and research often involve people from universities or health institutions working with community groups in areas labeled “low income” or “at risk.” Acknowledging diversity in background, experience, culture, income, and education and examining how society produces privilege, racism, and inequalities in power should be central to the process of community engagement. Such an approach can help partners better understand and address the roots of health issues and guard against reproducing repressive patterns within their partnerships (Chávez et al., 2008; Chavez et al., 2007; Jones et al., 2000; Krieger et al., 1999; Yonas et al., 2006).

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Done well, the community-engaged approach can enable partnerships to develop programs and research “in ways that are consistent with a people’s and a community’s cultural framework” (Airhihenbuwa, 1995). When researchers and organizers work collaboratively with community organizations throughout a project, they can produce effective, culturally appropriate programs and robust research results.

## Community Organization

The practice and theory of community organizing provide useful insights into mobilizing the community to engage in health promotion. The foundation for community organizing is the principle of social action, bringing people together — often, but not exclusively, from the same neighborhood — to pursue a shared interest (Braithwaite et al., 1994).

When pursuing social action, a key question is who represents the community. Often, the most empowered members of a community will quickly move to the forefront, regardless of whether they are truly the most representative (Geiger, 1984). Similarly, engagement leaders may want to work with those who can most readily deliver what they want (such as research participants and data sources), but these persons may not be representative of the community. Facilitating community organization cannot be allowed to serve the needs of individual partners at the expense of the larger community (CARE: Community Alliance for Research and Engagement, 2009).

Community organizing is based on the principles of empowerment, community competence, active participation, and “starting where the people are” (Nyswander, 1956, as cited in Minkler, 2005, p. 27). As Labonte et al. (1996) state, imposing one’s own notions of health concerns over the community’s risks several disabling effects. These include being irrelevant to the community, creating feelings of powerlessness in the community, complicating individuals’ lives, and channeling local activism away from important challenges toward less important ones.

Community organizing recognizes that, in order to change, we all must feel a need for change, and that we are more likely to do so when we are involved in group learning and decision making (Minkler, 1990). An important element of community organizing is helping communities look at the

root causes of problems while at the same time selecting issues that are “winnable, simple, and specific” and that can unite members of the group, involve them in achieving a solution, and further build the community (Minkler, 1990).

## Community Participation

Community engagement requires participation of community members in projects that address their issues. Meaningful community participation extends beyond physical involvement to include generation of ideas, contributions to decision making, and sharing of responsibility. Among the factors that motivate people to participate are wanting to play an active role in bettering their own lives, fulfilling social or religious obligations, feeling a need for a sense of community, and wanting cash or in-kind rewards. Whatever people’s motivations, obtaining meaningful community participation and having a successful, sustained initiative require that engagement leaders respect, listen to, and learn from community members. An absence of mutual respect and co-learning can result in a loss of time, trust, resources, and, most importantly, effectiveness (Henry, 2011; Miller et al., 2005; Minkler et al., 2009).

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The “social exchange” perspective provides insight into motivations for participation; it uses the framework of benefits and costs to help explain who participates and why. From this perspective, organizations and individuals are involved in an “exchange system” and voluntarily share resources to meet their goals (Levine et al., 1961). Community members and organizations will participate if they perceive that the benefits of participation outweigh the effort required (Butterfoss, 2006; Butterfoss et al., 1993; Wandersman et al., 1987).

The potential benefits of participation for community members, academics, and health professionals include opportunities for networking, access to information and resources, personal recognition, learning, a sense of helping to solve community problems, improved relationships among stakeholders, increased capacity for problem solving, and contact with hard-to-reach populations (Butterfoss, 2006). Costs include the time and energy required to build relationships and other infrastructure and the lessening of control over initiatives (Staley, 2009).

Recently, literature has shifted from a focus on a social exchange model to other challenges and facilitators of community participation (Shalowitz et al., 2009). Some of these writings are based on experience rather than theory, but they may lead to the development of improved theories of participation (Michener et al., 2008; Williams et al., 2009).

Robert Putnam (2001) initiated an important debate about the degree to which Americans volunteer for and participate in group and community activities with the publication of *Bowling Alone*. In the book, Putnam argued that the willingness to volunteer and participate in public life waxes and wanes over time but that overall it has declined in recent decades. If there is indeed a trend away from civic engagement, it would affect efforts to engage communities in improving health.

Regardless of whether one agrees with Putnam's assessment, it is essential to recognize that the community's time is valuable and limited. Furthermore, developing relationships with individuals and community organizations, identifying common interests, and developing a shared sense of needs and shared ways to address those needs can take engagement leaders and stakeholders an enormous amount of time. Given the expanded roles that community members are being asked to play in the development of social programs and in research, we must consider how to compensate them for their participation, and we should involve them in this process.

The costs, benefits, and perceived risks of participation can sometimes be changed with collaborative planning and decision making. For example, academic partners have traditionally presumed ownership of any data or other tangibles resulting from research, but if the benefits of participation are to outweigh the costs and the principles of community engagement are to be met, the community should be involved early on in identifying what assets the research will produce and the rights of each partner to use those assets (see Yale Center for Clinical Investigation/Community Alliance for Research and Engagement, 2009).

### **Constituency Development**

Developing a constituency, or developing relationships with community members who have a stake in and support public health and health care, involves four "practice elements":

- Know the community, its constituents, and its capabilities.
- Establish positions and strategies that guide interactions with constituents.
- Build and sustain formal and informal networks to maintain relationships, communicate messages, and leverage resources.
- Mobilize communities and constituencies for decision making and social action (Hatcher et al., 2008).

These four elements, which provide a simple, useful framework for thinking about the requirements of community engagement, will be revisited in Chapter 4's discussion of the organizational support required for community engagement.

### Capacity Building

Building capacity to improve health involves the development of sustainable skills, resources, and organizational structures in the affected community. For engagement efforts to be equitable, effective, and sustainable, all stakeholders must be ready for collaboration and leadership. Thus, building capacity also includes fostering shared knowledge, leadership skills, and an ability to represent the interests of one's constituents. Because capacity building is deeply rooted in the social, political, and economic environment, it cannot be conducted without an understanding of the specific environment in which it will take place (Eng et al., 1994). When carried out with context in mind, capacity building is an integral part of community engagement efforts, necessary for challenging power imbalances and effectively addressing problems.

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### Community Empowerment

The theoretical roots of "empowerment" as a critical element of community engagement can be traced back to Brazilian educator Paulo Freire (Freire, 1970; Hur, 2006). As articulated by Kenneth Maton (2008), empowerment is "a group-based participatory, developmental process through which marginalized or oppressed individuals and groups gain greater control over their lives and environment, acquire valued resources and basic rights, and achieve important

life goals and reduced societal marginalization.” Ideally, empowerment is both a process and an outcome of community engagement.

Empowerment takes place at three levels: the individual, the organization or group, and the community.

Empowerment takes place at three levels: the individual, the organization or group, and the community. Empowerment at one level can influence empowerment at the other levels. Furthermore, empowerment is multidimensional, taking place in sociological, psychological, economic, political, and other dimensions (Fawcett et al., 1995; Hur, 2006; Maton, 2008; Rich et al., 1995). Community-level empowerment “challenges professional relationships to communities, emphasizing partnership and collaboration rather than a top-down approach” (Wallerstein, 2002, p. 74).

Empowerment theory stresses that no external entity should assume that it can bestow on a community the power to act in its own self-interest. Rather, those working to engage the community should, when appropriate, offer tools and resources to help the community act in its own interest. This could include helping to channel existing sources of community power in new ways to act on the determinants of health. Kretzmann et al. (1996) note that communities are usually assessed in terms of their problems, but they point out that this demeans and disempowers the community, relegating its members to the roles of dependents and recipients of services. They advocate for assessing communities in terms of their own assets, resources, and resourcefulness (Kretzmann et al., 1996).

### Coalition Building

Community engagement often involves building coalitions, defined by Cohen et al. (2002) as “a union of people and organizations working to influence outcomes on a specific problem” (p. 144). The goals of a coalition might range from sharing information and resources to advocating for specific policy changes (Cohen et al., 2002). Increasingly, funders have supported the building of coalitions for improving community health (Butterfoss et al., 1993; Green et al., 2001a; Hill et al., 2007).

The motivation to create coalitions comes from the recognition that they can accomplish what each partner cannot accomplish alone. Political science literature suggests that:

- Coalitions require that each party believe it needs help to reach its goals.
- The goals and perspectives of the members of a coalition will not all be shared. However, the coalition requires sufficient common ground that the parties can agree over time on a purpose, set of policies, and strategies.
- Coalitions require continuous and often delicate negotiation among their participants.
- The distribution of power and benefits among the members of a coalition is an ongoing concern; all members need to believe that, over time, they are receiving benefits that are comparable to their contributions (Sofaer, 1993).

Coalitions can help the engagement process in a number of ways, including maximizing the influence of individuals and organizations, creating new collective resources, and reducing the duplication of efforts. The effectiveness of coalitions has been evaluated on two distinct bases: how well the members work together, and what kinds of community-level changes they bring about. While noting that the research literature is inadequate for determining which factors are associated with the effectiveness of coalitions, Zakocs et al. (2006) suggest six possibilities: formalization of rules/procedures, leadership style, participation of members, diversity of membership, collaboration, and group cohesion.

Based on their review of the literature on coalitions, Butterfoss et al. (2002) developed community coalition action theory, which provides 23 practice-based propositions that address processes ranging from the formation of coalitions through the institutionalization of long-lasting coalitions. These propositions, which shed light on how to create and support effective long-term alliances, will be discussed in greater detail in Chapter 4.

## THE ETHICS OF COMMUNITY ENGAGED RESEARCH

Debates about the ethics of clinical research are not new (Chen et al., 2006; Emanuel et al., 2000; Levine, 1988), but community-engaged research (CEnR)



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raises additional questions and challenges. Community engagement is about relationships between and among communities, researchers, and research institutions. What ethical code should we use to assess the conduct of those relationships, and how should that code be monitored and enforced? As CEnR has become more prevalent and more varied, this fundamental question has generated a number of specific questions and ideas (Khanlou et al., 2005; Silverstein et al., 2008).

A well-accepted ethical code concerning research that involves living human beings already exists, and a regulatory process based in this code has been developed for all federally funded “human subjects research.” The need for this ethical code stems from the nature of research — by definition, that which is being researched has not yet been “proven.” Accordingly, there is uncertainty about the results of research activities, including the possibility of harm to participants. In this ethical framework, studies are understood to fall into two general categories: those that present minimal risk to participants, and those that may subject participants to more than minimal risk (see Common Rule 45 CFR [Code of Federal Regulations] 46.102(h)(i)).

All federally funded research that involves living people requires review by an institutional review board (IRB); the people who serve on IRBs and review research have a responsibility to ensure that risk to participants is minimized. The issues that IRBs consider include the risks to participants, the procedures for collecting and protecting research data, the strength of the scientific design, and the process by which individuals give their informed consent to participate in research.

Should there be a process for determining whether a CEnR collaboration is based on trust and whether each partner has successfully fulfilled his or her responsibilities to the other partners and to the project? If there should be such a process or similar processes, should they be the responsibility of the IRB? In their reviews, IRBs typically have not considered many activities and principles of community engagement. For example, although IRBs may require letters of support from community partners, they are not concerned with how well the researcher knows the community or whether trust has been established. Once research has been approved, the IRB will not typically obtain community input for its regular reviews of research protocols. Furthermore,

studies demonstrate that IRBs generally do not incorporate the principles of CEnR into their considerations, even for studies that are community engaged (Flicker et al. 2007), and some have questioned whether the current IRB system is appropriate to provide oversight for all forms of CEnR (Brugge et al., 2003; Malone et al., 2006; Ross et al., 2010a, 2010b, 2010c; Shore, 2007). Finally, the majority of IRBs do not want to take on this additional task, and researchers and others are wary of “IRB mission creep” as these boards take on more and more regulatory responsibility (Center for Advanced Study, 2004).

The Yale University CTSA’s Community Alliance for Research and Engagement (CARE) Ethical Principles of Engagement Committee (2009) developed an expanded set of principles that is relevant to this discussion. The committee’s view is that ethical review applies “not only to individual research subjects but also to interactions between the research partners” (p. 2). The committee explains: “Each partner has certain responsibilities. Among the most important of these is that each should recognize the other’s needs and empower the other to assert its unique rights within the relationship” (CARE, 2009, p. 9).

Part of ethical conduct is developing a legitimate and serious dissemination plan for the findings of the proposed research that will meet the needs of both communities and researchers. In addition to its emphasis on ethical and empowering practice among partnership organizations, the CARE Committee extends the principles and protections of the Belmont Report to communities:

University Researchers should involve Community partners as early as possible in discussions about the potential uses of all data to be collected, including a dissemination plan for the sharing of the research findings with the wider [non-academic] Community, and should develop a process for handling findings that may reflect negatively and thus cause harm to one or both partners (CARE, 2009, p. 3).

Others have called for ethical review to consider the risks and benefits for both individual participants and entire communities and are asking whether it should be required that communities, as well as individuals, consent to research. This issue is particularly relevant for research into the relationship between the environment and health because the discovery and dissemination of environmental information may affect the well-being of an entire community (Brown et al., 2006; Gbadegesin et al., 2006; Shore,

2006; Wing, 2002). There is also uncertainty about the roles and authority of community advisory boards and what ethical principles, if any, govern these boards (Blumenthal, 2006; Gilbert, 2006; Quinn, 2004).

Developing a comprehensive list of ethical questions for CEnR is challenging because the purpose, approach, and context for such research varies greatly from one project to another (Green et al., 2001b; Israel et al., 1988). As both the volume and range of CEnR activities that focus on health expand, ideas about the ethical review of such research, both inside and outside the health field, will continue to develop.

## MODELS AND FRAMEWORKS FOR THE PRACTICE OF COMMUNITY ENGAGEMENT

In addition to the concepts just summarized, the literature provides models and frameworks for understanding health promotion and health research that can be helpful in the practice of community engagement. We cover a number of those here.

### The Social Ecological Model of Health

The social ecological model conceptualizes health broadly and focuses on multiple factors that might affect health. This broad approach to thinking of health, advanced in the 1947 Constitution of the World Health Organization, includes physical, mental, and social well-being (World Health Organization, 1947). The social ecological model understands health to be affected by the interaction between the individual, the group/community, and the physical, social, and political environments (Israel et al., 2003; Sallis et al., 2008; Wallerstein et al., 2003).

The social ecological model understands health to be affected by the interaction between the individual, the group/community, and the physical, social, and political environments.

Both the community engagement approach and the social ecological model recognize the complex role played by context in the development of health problems as well as in the success or failure of attempts to address these problems. Health professionals, researchers, and community leaders can use this model to identify factors at different levels (the individual, the interpersonal level, the community, society; see Figure 1.2) that contribute to poor health and to develop approaches to disease prevention and health promotion that include

action at those levels. This approach focuses on integrating approaches to change the physical and social environments rather than modifying only individual health behaviors.

Stokols (1996) proposes four core principles that underlie the ways the social ecological model can contribute to efforts to engage communities:

- Health status, emotional well-being, and social cohesion are influenced by the physical, social, and cultural dimensions of the individual’s or community’s environment and personal attributes (e.g., behavior patterns, psychology, genetics).
- The same environment may have different effects on an individual’s health depending on a variety of factors, including perceptions of ability to control the environment and financial resources.
- Individuals and groups operate in multiple environments (e.g., workplace, neighborhood, larger geographic communities) that “spill over” and influence each other.
- There are personal and environmental “leverage points,” such as the physical environment, available resources, and social norms, that exert vital influences on health and well-being.

To inform its health promotion programs, CDC (2007) created a four-level model of the factors affecting health that is grounded in social ecological theory, as illustrated in Figure 1.2.

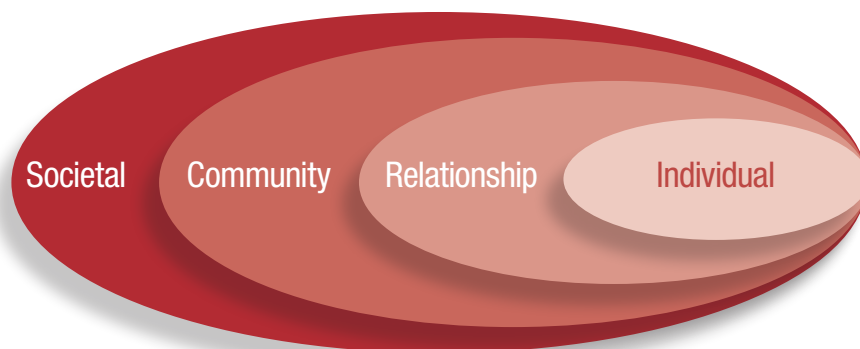


Figure 1.2. The Social-Ecological Model: A Framework for Prevention

The first level of the model (at the extreme right) includes individual biology and other personal characteristics, such as age, education, income, and health history. The second level, relationship, includes a person's closest social circle, such as friends, partners, and family members, all of whom influence a person's behavior and contribute to his or her experiences. The third level, community, explores the settings in which people have social relationships, such as schools, workplaces, and neighborhoods, and seeks to identify the characteristics of these settings that affect health. Finally, the fourth level looks at the broad societal factors that favor or impair health. Examples here include cultural and social norms and the health, economic, educational, and social policies that help to create, maintain, or lessen socioeconomic inequalities between groups (CDC, 2007; Krug et al., 2002).

The CDC model enables community-engaged partnerships to identify a comprehensive list of factors that contribute to poor health and develop a broad approach to health problems that involves actions at many levels to produce and reinforce change. For example, an effort to reduce childhood obesity might include the following activities at the four levels of interest:

- **Individual:** Conduct education programs to help people make wise choices to improve nutritional intake, increase their physical activity, and control their weight.
- **Interpersonal relationships:** Create walking clubs and work with community groups to introduce healthy menus and cooking methods. Promote community gardening groups.
- **Community:** Work with local grocery stores and convenience stores to help them increase the amount of fresh fruits and vegetables they carry. Establish farmers' markets that accept food stamps so that low-income residents can shop there. Work with the city or county to identify walking trails, parks, and indoor sites where people can go to walk, and publicize these sites. If the area needs additional venues for exercise, build community demand and lobby for new areas to be built or designated. Work with local employers to develop healthier food choices on site and to create other workplace health programs.

- **Society:** Advocate for the passage of regulations to (1) eliminate soft drinks and high-calorie snacks from all schools, (2) ban the use of trans-fatty acids in restaurant food, or (3) mandate that a percentage of the budget for road maintenance and construction be spent on creating walking paths and bike lanes.

Long-term attention to all levels of the social ecological model creates the changes and synergy needed to support sustainable improvements in health.

### The Active Community Engagement Continuum

The Active Community Engagement (ACE) continuum provides a framework for analyzing community engagement and the role the community plays in influencing lasting behavior change. ACE was developed by the Access, Quality and Use in Reproductive Health (ACQUIRE) project team, which is supported by the U.S. Agency for International Development and managed by EngenderHealth in partnership with the Adventist Development and Relief Agency International, CARE, IntraHealth International, Inc., Meridian Group International, Inc., and the Society for Women and AIDS in Africa (Russell et al., 2008). The ACE continuum is based on a review of documents, best practices, and lessons learned during the ACQUIRE project; in a paper by Russell et al. (2008) the continuum is described as follows:

The continuum consists of three levels of engagement across five characteristics of engagement. The levels of engagement, which move from consultative to cooperative to collaborative, reflect the realities of program partnerships and programs. These three levels of community engagement can be adapted, with specific activities based on these categories of action. The five characteristics of engagement are community involvement in assessment; access to information; inclusion in decision making; local capacity to advocate to institutions and governing structures; and accountability of institutions to the public (p. 6).

The experience of the ACQUIRE team shows that community engagement is not a one-time event but rather an evolutionary process. At each successive level of engagement, community members move closer to being change agents themselves rather than targets for change, and collaboration increases, as does community empowerment. At the final (collaborative) level, communities

and stakeholders are represented equally in the partnership, and all parties are mutually accountable for all aspects of the project (Russell et al., 2008).

### Diffusion of Innovation

Everett Rogers (1995) defined diffusion as “the process by which an innovation is communicated through certain channels over time among the members of a social system” (p. 5). Communication, in turn, according to Rogers, is a “process in which participants create and share information with one another in order to reach a mutual understanding” (p. 5). In the case of diffusion of innovation, the communication is about an idea or new approach. Understanding the diffusion process is essential to community-engaged efforts to spread innovative practices in health improvement.

Rogers offered an early formulation of the idea that there are different stages in the innovation process and that individuals move through these stages at different rates and with different concerns. Thus, diffusion of innovation provides a platform for understanding variations in how communities (or groups or individuals within communities) respond to community engagement efforts.

In Rogers’ first stage, *knowledge*, the individual or group is exposed to an innovation but lacks information about it. In the second stage, *persuasion*, the individual or group is interested in the innovation and actively seeks out information. In *decision*, the third stage, the individual or group weighs the advantages and disadvantages of using the innovation and decides whether to adopt or reject it. If adoption occurs, the individual or group moves to the fourth stage, *implementation*, and employs the innovation to some degree. During this stage, the usefulness of the innovation is determined, and additional information may be sought. In the fifth stage, *confirmation*, the individual or group decides whether to continue using the innovation and to what extent.

Rogers noted that the innovation process is influenced both by the individuals involved in the process and by the innovation itself. Individuals include innovators, early adopters of the innovation, the early majority (who deliberate longer than early adopters and then take action), late adopters, and “laggards” who resist change and are often critical of others willing to accept the innovation.

According to Rogers, the characteristics that affect the likelihood that an innovation will be adopted include (1) its perceived relative advantage over other strategies, (2) its compatibility with existing norms and beliefs, (3) the degree of complexity involved in adopting the innovation, (4) the “trialability” of the innovation (i.e., the extent to which it can be tested on a trial basis), and (5) the observability of the results. Greenhalgh et al. (2004) expanded upon these characteristics of an innovation, adding (1) the potential for reinvention, (2) how flexibly the innovation can be used, (3) the perceived risk of adoption, (4) the presence of a clear potential for improved performance, (5) the knowledge required to adopt the innovation, and (6) the technical support required.

Awareness of the stages of diffusion, the differing responses to innovations, and the characteristics that promote adoption can help engagement leaders match strategies to the readiness of stakeholders. For example, a community-engaged health promotion campaign might include raising awareness about the severity of a health problem (knowledge, the first stage in Rogers’ scheme), transforming awareness into concern for the problem (persuasion), establishing a community-wide intervention initiative (adoption), developing the necessary infrastructure so that the provision of services remains extensive and constant in reaching residents (implementation), and/or evaluation of the project (confirmation).

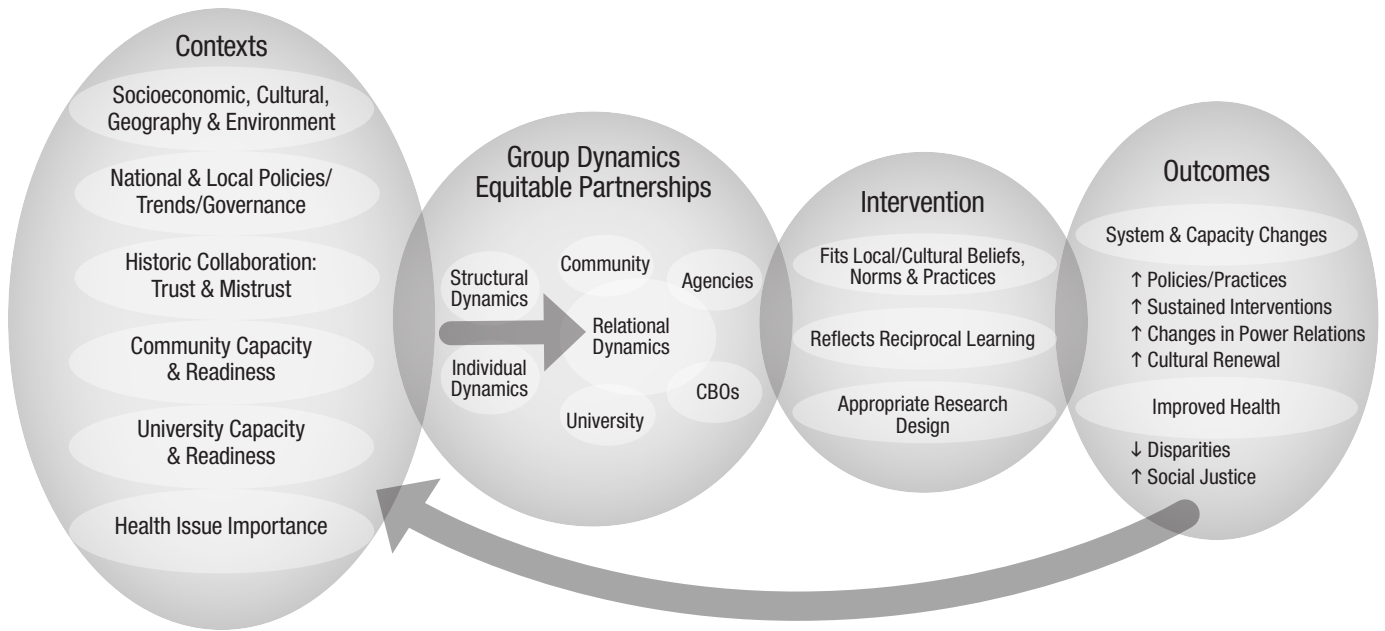
Awareness of the stages of diffusion, the differing responses to innovations, and the characteristics that promote adoption can help engagement leaders match strategies to the readiness of stakeholders.

### Community-Based Participatory Research

Community-based participatory research (CBPR) is the most well-known framework for CEnR. As a highly evolved collaborative approach, CBPR would be represented on the right side of the continuum shown in Figure 1.1 (page 8). In CBPR, all collaborators respect the strengths that each brings to the partnership, and the community participates fully in all aspects of the research process. Although CBPR begins with an important research topic, its aim is to achieve social change to improve health outcomes and eliminate health disparities (Israel et al., 2003).

Wallerstein et al. (2008) conducted a two-year pilot study that looked at how the CBPR process influences or predicts outcomes. Using Internet survey methods and existing published literature, the study focused on two questions: *What*





Contexts	Group Dynamics		Intervention	Outcomes
<ul style="list-style-type: none"> <li>• Social-economic, cultural, geographic, political-historical, environmental factors</li> <li>• Policies/Trends: National/local governance &amp; political climate</li> <li>• Historic degree of collaboration and trust between university &amp; community</li> <li>• Community: capacity, readiness &amp; experience</li> <li>• University: capacity, readiness &amp; reputation</li> <li>• Perceived severity of health issues</li> </ul>	<p><b>Structural Dynamics</b></p> <ul style="list-style-type: none"> <li>• Diversity</li> <li>• Complexity</li> <li>• Formal agreements</li> <li>• Real power/resource sharing</li> <li>• Alignment with CBPR principles</li> <li>• Length of time in partnership</li> </ul> <p><b>Individual Dynamics</b></p> <ul style="list-style-type: none"> <li>• Core values</li> <li>• Motivations for participating</li> <li>• Personal relationships</li> <li>• Cultural identities/humility</li> <li>• Bridge people on research team</li> <li>• Individual beliefs, spirituality &amp; meaning</li> <li>• Community reputation of PI</li> </ul>	<p><b>Relational Dynamics</b></p> <ul style="list-style-type: none"> <li>• Safety</li> <li>• Dialogue, listening &amp; mutual learning</li> <li>• Leadership &amp; stewardship</li> <li>• Influence &amp; power dynamics</li> <li>• Flexibility</li> <li>• Self &amp; collective reflection</li> <li>• Participatory decision-making &amp; negotiation</li> <li>• Integration of local beliefs to group process</li> <li>• Flexibility</li> <li>• Task roles &amp; communication</li> </ul>	<ul style="list-style-type: none"> <li>• Intervention adapted or created within local culture</li> <li>• Intervention informed by local settings and organizations</li> <li>• Shared learning between academic and community knowledge</li> <li>• Research and evaluation design reflects partnership input</li> <li>• Bidirectional translation, implementation &amp; dissemination</li> </ul>	<p><b>CBPR System &amp; Capacity Changes</b></p> <ul style="list-style-type: none"> <li>• Changes in policies/practices: <ul style="list-style-type: none"> <li>- In universities and communities</li> </ul> </li> <li>• Culturally based &amp; sustainable interventions</li> <li>• Changes in power relations</li> <li>• Empowerment: <ul style="list-style-type: none"> <li>- Community voices heard</li> <li>- Capacities of advisory councils</li> <li>- Critical thinking</li> </ul> </li> <li>• Cultural revitalization &amp; renewal</li> </ul> <p><b>Health Outcomes</b></p> <ul style="list-style-type: none"> <li>• Transformed social/economic conditions</li> <li>• Reduced health disparities</li> </ul>

Used with permission from Minkler et al., 2008.

Figure 1.3. CBPR Conceptual Model. A later version of this diagram can be found in Wallerstein et al. (2010)

*is the added value of CBPR to the research itself and to producing outcomes? What are the potential pathways to intermediate system and capacity change outcomes and to more distal health outcomes?* Through a consensus process using a national advisory committee, the authors formed a conceptual logic model of CBPR processes leading to outcomes (Figure 1.3). The model addresses four dimensions of CBPR and outlines the potential relationships between each. The authors identify:

“contextual factors” that shape the nature of the research and the partnership, and can determine whether and how a partnership is initiated. Next, group dynamics...interact with contextual factors to produce the intervention and its research design. Finally, intermediate system and capacity changes, and ultimately, health outcomes, result directly from the intervention research (p. 380).

Models such as these are essential to efforts to empirically assess or evaluate community engagement practices and disseminate effective approaches.

## **Translational Research**

NIH has created a new impetus toward participatory research through an increase in funding mechanisms that require participation and through its current focus on “translation” (i.e., turning research into practice by taking it from “the bench to the bedside and into the community”). Increasingly, community participation is recognized as necessary for translating existing research to implement and sustain new health promotion programs, change clinical practice, improve population health, and reduce health disparities. The CTSA initiative is the primary example of an NIH-funded mechanism requiring a translational approach to the clinical research enterprise (Horowitz et al., 2009).

The components of translational research are understood differently by different authors in the field. In one widely used schema, translational research is separated into four segments: T1–T4 (Kon, 2008). T1 represents the translation of basic science into clinical research (phase 1 and 2 clinical trials), T2 represents the further research that establishes relevance to patients (phase 3 trials), T3 is translation into clinical practice, and T4 is the movement of “scientific knowledge into the public sector... thereby changing people’s everyday lives” (p. 59) through public and other policy changes.

Westfall et al. (2007) have identified the lack of successful collaboration between community physicians and academic researchers as one of the major roadblocks to translation. They note that although the majority of patients receive most of their medical care from a physician in a community setting, most clinical research takes place in an academic setting (Westfall et al., 2007). Consequently, the results of clinical trials may not be easily generalized to real-world clinical practices.

One solution to this dilemma is practice-based research (PBR): engaging the practice community in research. PBR has traditionally been conducted in a primary care setting using a coordinated infrastructure (physicians, nurses, and office staff), although the recent emphasis on translation has contributed to the emergence of more specialized practice-based research networks (e.g., in nursing, dental care, and pharmacy). Like all efforts in engagement, developing PBR includes building trust, sharing decision making, and recognizing the expertise of all partners. PBR addresses three particular concerns about clinical practice: identifying medical directives that, despite recommendations, are not being implemented; validating the effectiveness of clinical interventions in community-based primary care settings; and increasing the number of patients participating in evidence-based treatments (Westfall et al., 2007). “PBR also provides the laboratory for a range of research approaches that are sometimes better suited to translational research than are clinical trials: observational studies, physician and patient surveys, secondary data analysis, and qualitative research” (Westfall et al., 2007, p. 405).

Like all efforts in engagement, developing PBR includes building trust, sharing decision making, and recognizing the expertise of all partners.

## CONCLUSION

The wide-ranging literature summarized above shares several major themes:

- There are multiple reasons for community-engaged health promotion and research.
- Community engagement must be conducted in a manner that is respectful of all partners and mindful of their need to benefit from collaboration.

- It is important to understand context (in all its complexity) as it affects health problems and the development of health solutions.
- We must recognize that community-engaged health improvement is a long-term, evolving process.

Chapter 2 covers nine principles of community engagement that are grounded in the preceding literature. Succeeding chapters develop practical applications and examples of the issues discussed in the first two chapters, specifically in the areas of planning and implementing CEnR and health promotion (Chapters 3 and 5), creating the management and organizational support necessary for community engagement (Chapter 4), using social networking for community engagement (Chapter 6), and evaluating community-engaged projects (Chapter 7).

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