

## **MODULE 4**

### **Community-Based Practice and Research: Collaboration and Sharing Power**

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Contemporary public health is dedicated to a community orientation and the premise that community-based activities are essential to sound practice and research. The central importance of community as a public health value is clearly reflected in the 2001 Public Health Code of Ethics and its accompanying statements. Five of the Code's twelve principles and six of its eleven key assumptions address the nature of community, the interdependence of individuals and groups, the links between communities and the environment, and the role of communities in public discourse and collaboration with public health organizations.<sup>1</sup> Defining public health as "what we, as a society, do collectively to assure the conditions for people to be healthy,"<sup>1</sup> the authors of the Code declare that effective public health practice and research depend on informed community trust and participation.

The practical ethical issues in community-based practice and research are as wide-ranging as community life itself. Many important ethical questions depend upon the meaning of community, but the word typically has no clear, consistent usage in public health, either as a social concept or as an ethical value. Moreover, identifying the key characteristics and rightful members of any particular community may raise ethical and political questions even before one considers the community's appropriate roles in assessment and priority setting, research, intervention, or public health policy.

This essay begins with an examination of some common definitions of community, community participation, and community representation, and considers the ethical presuppositions that lie behind the ways the terms are often used in public health. It then reviews how surveillance activities that focus on a given community may identify important public health problems and disparities within the larger population, and discusses the vital role of community members' own views and health concerns in assessment and priority setting. Next the essay reviews the tensions inherent in community-based practice by considering the ideals and experience of community-oriented primary care. Finally, it will address the increased emphasis on community participation in research and the challenge of applying research findings to interventions and ongoing practice in the participant communities.

#### **Defining Community and Communities**

The term *community* comes from the Latin root for "common" or "shared". The most general meaning of community is a group of people united by their common features. However, there is no agreement on precisely which common features create community, and the key features of even an established community may seem to vary when viewed by group members as opposed to outsiders.<sup>2</sup>

The theoretical public health literature on community is generally based in sociology. Early sociological efforts to describe communities focused on the importance of shared values and shared experience. Sociologists typically define a community in terms of group norms, personal relationships, and members' clear roles and expectations of each other. Health promotion researchers have identified six such aspects of community:<sup>3</sup>

- membership (a sense of belonging and clarity of roles)
- common symbol systems (language, religious rituals, national symbols)
- shared values and norms (from shared experience or handed-down belief)
- mutual influence of its members (based in communication)
- shared emotional bonds (a sense of personal connectedness)
- shared needs and a shared commitment to meeting them (a sense of "us" that transcends personal interests).

This set of characteristics also has parallels in the concept of the religious community of faith, which is characterized by fellowship, shared values, spiritual and emotional bonds, and mutual support. Many social scientists and ethicists maintain that human beings naturally seek community and are eager to experience the meaning and personal fulfillment that true community offers.

The use of the term community in public health practice often differs dramatically from the somewhat romanticized sociological notion seen in theoretical literature. Often the term is used to refer to a group of people from the same geographic location or catchment area (e.g., the westside community). It may also refer to a group with a common racial or ethnic background, socioeconomic status, religion, profession, health condition, or who share some other important experience (e.g., the African-American community, the indigent community, the Greek Orthodox community, the medical community, the HIV/AIDS community, or the women veterans' community). Public health agencies and practitioners typically use the word to refer to individuals and groups linked by one or more characteristics that, however vaguely defined, give them recognizable common needs and interests of concern to public health.

Often the intent of identifying a group as a community determines what features will be emphasized and who will be counted as a community member. Although self-defined communities figure prominently in the work of many public health agencies and professionals, many so-called communities are more rightly just "target populations", constructs defined by the goals of a particular public health project or mandate (e.g., sexually active teenagers; households within 3 miles of a toxic waste site; the mentally ill homeless) rather than any natural social grouping. The description of a community targeted for public health practice or research may also be based on allegedly objective and readily measurable classifications, such as socioeconomic or demographic profiles, specific health conditions, or risk factors for disease. But because even these characteristics can be too complex to measure or verify, many projects define their communities of interest in terms of surrogate measures (i.e., income below 200% of poverty level, families of children enrolled in the local school district) or by arbitrary geopolitical boundaries (zip code, county, tri-state area) established by governments' or funders' priorities rather than characteristics that members of the resulting cohort would recognize as important to their identity.

Even within a "true" sociological community, professionals' views of the important relationships and commonalities among individuals and groups may be quite different from the views of the individuals

and groups themselves. Insiders typically see important distinctions between themselves and others who public health professionals might link as a community. For example, similarities of linguistic and ethnic heritage may link Hispanics of many national backgrounds, but their differing political and economic interests and cultural differences can significantly affect the cohesion of the “Hispanic community” as viewed from the inside. Similarly, the “public health community” of practitioners, researchers, and academics may appear splintered to insiders who emphasize such differences as discipline, professional training, and area of work. A true community can be quite diverse, because people of vastly different backgrounds can often create and maintain a sense of community when they have a common cause or a common adversary against which to define themselves and their goals. However, as common goals are met or the perceived benefits of solidarity fade, such a community may become divided or even dissolve. Because of the many forces that can affect a group’s cohesiveness, community should be seen as a dynamic phenomenon in which change is both natural and expected.

Many people may consider themselves members of more than one community, or may fall under definitions of membership in several communities of interest to public health. Beginning with membership in a household, individuals are often formal or informal members of self-identified communities based in professional activities and the workplace, religious or spiritual beliefs and practice, sexual orientation, political affiliations, civic and charitable service, athletic activities, academic institutions or experience, social organizations or hobbies. Many individuals’ community affiliations overlap and serve parallel interests. However, different communities’ values and their expectations of members may also conflict, challenging individuals with multiple loyalties to choose sides or live with unresolvable ethical tension. Conflicting loyalties can be a risk for public health professionals when the goals and methods of public health practice challenge the traditions or beliefs of their religious, ethnic, or other value-oriented community. However, public health professionals who can successfully reconcile these tensions in their own lives can be quite valuable as interpreters and change agents who can negotiate the conflicts and facilitate understanding where others cannot work effectively.

Some uses of the term community in public health contexts are themselves ethically problematic. “The community” is often used as shorthand to refer to outsiders to public health — “them” in relation to public health professionals’ “us”. This phrase can serve as a useful reminder that public health activities always take place in a community context and that professionals must always be aware of the community’s response. However, it can also imply an adversarial or hierarchical relationship between public health professionals and the people they serve, a perspective that conflicts with the stated goal of collaborative, participatory public health. At times, it can also carry negative implications of the community’s ignorance, misunderstanding, and apathy as opposed to the professionals’ skills and knowledge and dedication to society’s welfare.<sup>4</sup>

An even more ethically dangerous phenomenon is that public health practitioners and researchers may consciously or unconsciously use the concept of community as a marketing strategy to promote activities, perceptions, and goals to a target population. Referring to a cohort as a community can create the impression of underlying community values, norms, and expectations that hide “a giant reinforcement schedule.”<sup>5</sup> Use of the term community and its accompanying sense of mutual values and responsibility to encourage behavior change or acceptance of certain health values has been criticized as being cynically manipulative when it substitutes marketing and implied peer pressure for real moral and psychological support.<sup>5</sup>

## **Community as a Public Health Value: Communitarianism and Public Health Ethics**

The meaning of community as a central value in public health is at least as complex as its definition in practice. The preamble to the Public Health Code of Ethics states that one of the key principles “that follow from the distinctive characteristics of public health ...is the interdependence of people ... (which) is the essence of community.”<sup>1</sup> Community is an essential value for public health because “the health of individuals is tied to their life in the community.”<sup>1</sup> In this light, public health theorists and practitioners typically interpret the good of the community and the good of the individual as interdependent.

Unfortunately, public health’s community orientation is often misunderstood by ethicists trained in the principle-based frameworks of bioethics, which presume a certain natural conflict between the needs, interests, and goals of individuals and those of society at large. In mainstream bioethics, the principle of respect for autonomy requires that health professionals recognize and honor the right of individual patients to be self-determining, unless respecting one individual’s rights would violate the rights of another. Many bioethicists likewise emphasize the need for health practitioners and policy makers to avoid unduly restricting the rights of individuals in the just distribution of health-related benefits and burdens across society. In this context, critics of policies that seek community-oriented goals mistakenly label public health as “utilitarian”, in reference to the ethical framework that promotes the goal of the “greatest good for the greatest number” with less concern for individual rights than for social benefit.

While public health is not officially linked to any specific ethical theory or school of thought, its community orientation has many parallels to the philosophy of communitarianism. Communitarianism developed in the 1980s in response to a perceived overemphasis on individual rights.<sup>6</sup> Like public health, communitarian theory maintains that individuals are ultimately inseparable from community life, and that no one person and no one community can ever be completely self-determining. In contrast to more familiar ethical frameworks’ presumption of a natural antagonism between individuals and society—and particularly the state—communitarianism recognizes that human beings need *both* autonomy and social relationships. Communitarians insist that while individuals make their own moral choices, their moral commitments and values are shaped by community norms and experiences.

Traditional bioethics often interprets public health’s concern for community to be anti-individual, and its models for public health reflect a tension between individuals and society in which benefit is often a zero-sum game. For example, seatbelt legislation is often identified as a case in which the state enforces a paternalistic limitation of individual rights (to drive unrestrained) in pursuit of a greater social good (fewer collision-related injuries and lower related costs to society). In contrast, a communitarian approach to this issue focuses not only on the individual’s direct benefit from using seat belts, but also on the benefit that the individual enjoys as a member of a community that reduces driving-related injuries and deaths.<sup>7</sup> Communitarian models of ethical analysis are still relatively new, but a communitarian perspective on human dignity, social relationships, and community values can also suggest new approaches and strategies for resolving ethical controversy in public health practice and research.

## **Community Participation and Representation**

Ethical community-based practice and research depend not only upon a clear understanding of community and identification of the community’s interests but also on the way in which community participation and representation are understood. Community participation in public health appears both

as a grass-roots phenomenon linked to political activism and as a practical organizational effort to involve individuals and communities in promoting and protecting their own health. Just as there is no standard definition of community, the meaning of *participation* is ambiguous in many contexts where the term is often used. Community participation is commonly understood as the involvement of the community in the planning, organization, operation, administration, financing, and control of a project or enterprise. However, the goal of grass-roots community participation is not simply involvement, but rather the redistribution of power that deliberately includes traditional “have-nots” in the sharing of information, setting of priorities and policies, allocation of resources, and distribution of benefits and services.<sup>5</sup>

An early governmental step toward the promotion of community participation in public health programs came in the Economic Opportunity Act of 1964, which provided federal grants to state and local public and private non-profit agencies for community action projects, and which required “maximum feasible participation” by community members. Subsequent efforts to evaluate the effects of community participation in funded projects were frustrated by the wide variability in the definition, format, and implementation of relevant programs nationwide, and proponents of mandatory communication in federally funded activities were largely unable to respond when government requirements were cut back or eliminated. Moreover, the early efforts at engaging community participation in governmentally funded public health activities were criticized by grass-roots activists as mere tokenism that did not get the public very far up the “ladder of citizen participation,”<sup>8</sup> and which permitted “maximum feasible manipulation” of lay people rather than promoting partnership or citizen control.<sup>9</sup>

The concept of partnership or shared governance has been increasingly important in the literature on community participation over the past decade. The fundamental ethical challenge of authentic partnership and true sharing of authority with community groups lies in overcoming the significant disparity in power between community members and public health professionals, who have specialized knowledge, technical skills, and institutional or governmental support. Establishing a partnership requires mutual trust, which is built only over time and after visible results have been achieved. Sustaining a partnership in which collaborators have significantly different degrees of access to power typically requires ongoing financial, political, and community support, reinforced by demonstrated positive outcomes from the collaborative project. Important characteristics of authentic collaboration include the six “R’s” of participation: recognition, respect, role, relationship, reward, and results.<sup>10</sup> Without these components, the community is likely to discount the professionals’ sincerity and disengage from the project.

Because many communities of greatest interest to public health are precisely those whose members have limited technical skills, knowledge and access to power, promoting community participation in public health activities has necessarily involved professional efforts to empower individuals and the community at large. Empowerment relates to a person’s ability to affect his or her own situation. Individual, organizational, and community empowerment are interrelated in the development of social support and interpersonal, social, and political skills. Increasingly public health efforts to empower communities are also dedicated to capacity building, which typically involves the education, development, and support of community members who will then have the specialized knowledge, skills, and abilities to carry out the roles previously played by public health practitioners from outside the community. Capacity building creates a cadre of individuals who both understand the needs and values of the community as only members can and understand the theories and methods of public health that can help meet those community needs appropriately. The ethical advantage of capacity building is also

an important practical strength, as community members are ultimately able to work effectively toward their own goals without the potentially overpowering presence of public health professionals.

The effectiveness and ethical quality of community participation in any public health activity are also dependent upon the authenticity of the individuals and groups representing the community of interest. In theory, community representatives are able to provide insight into the norms, values, experiences, questions, objections, and appreciation of the community they represent, expanding, correcting, and ideally validating the approach taken by public health professionals in practice and research. Community representatives ideally serve as a bridge between their respective communities and the public health professionals with whom they work, representing the community to the professionals and the professionals back to their communities. However, in the same way that public health professionals often define communities based largely on the reason for engaging specific groups, professionals often identify community representatives in light of the purposes they are expected to serve. Even sincere efforts to include community representation in public health activities may result in tokenism if the primary purpose of inclusion is simply to satisfy external requirements for community participation or to secure the approval of proposed projects.

Engaging community representatives in a public health project is subject to logistical and ethical problems similar to those described in defining a community. Public health professionals who seek input from “average” members of the communities they serve may not be able to recognize the significant differences among members of even a small community, especially if that group is unfamiliar to or quite different from the professionals themselves. In an effort to identify “authentic” community members, public health professionals often look for individuals who are recognized as leaders or spokespersons for their group. However even identifying these individuals requires both an understanding of how the community perceives its own essential characteristics and recognizes who speaks for the community in its interaction with others. It also requires understanding of the group’s organizational and power structures. In more than a few situations, the official leaders of a given community have only titular or symbolic positions while others hold the true power or command the real respect of its members.

Similarly, an individual’s authority in one area of community affairs may not translate into authority in another, and an acknowledged community leader from an unrelated area may not provide the desired access to the group’s needs and views related to public health. Even powerful community leaders may be intimidated by health professionals whose work they may not fully understand and whose language and approach are unfamiliar. In order to maximize the effective participation of community representatives, it is essential for them to receive careful orientation to the project and to get to know its organizers. Ongoing education about the work in which they will be involved and its larger context can further empower community representatives, particularly when it is coupled with an active role for the community in defining its own needs and strengths, a process discussed below. Nonetheless, public health professionals should avoid the temptation to pick the most visible community members for multiple projects, as the repeated participation of a select few may not only exacerbate existing power differentials within a community, it may also create career community participants who are increasingly estranged from and resented by the group they are intended to represent.

The potential barriers to the effective involvement of community representatives often make it appealing to find health professionals from specific backgrounds to interpret the needs of targeted communities. In many ways this practice can provide a natural bridge between the professionals and the groups they

hope to serve. However, depending on the individual's background and the nature of the project, the socialization of professional training and work experience may distance professional members of a targeted community from the group's mainstream perspectives and even more so from its most vulnerable members. The difficulty of striking a balance in this regard argues for all but the smallest projects to include multiple representatives of any targeted community, in order to include a broader and ideally more representative spectrum of its voices. It also emphasizes the need for professionals to become more educated about the communities they serve in order to recognize important community characteristics and more easily overcome the barriers to community participation.

Since the end of the 1990s, two initiatives intended to improve the access of an increasingly multi-ethnic population to effective health services have also shown promise for increasing community participation in public health activities. The first is cultural competence education for professionals. Standards of cultural competence and related professional education are intended to improve public health professionals' recognition and understanding of the role of culture in health-related activities and the history, beliefs, values, and practices of members of the communities they serve. Concern for cultural competence was originally directed toward ethnic, religious, and linguistic differences in direct patient care, but increasingly the concept is being extended into social and political action and the organizational development of services and programs that accommodate communities' cultural differences.<sup>11</sup>

The second initiative is based in new federal standards for language assistance for people who use governmentally funded health-related services. These standards are aimed at institutions and agencies that provide health services, directing them to provide various forms of language assistance to individuals whose limited proficiency in English may be a barrier to their effective care.<sup>12</sup> The standards also apply in other settings where limited English proficiency affects some groups' access to health-related services. By facilitating communication and improved mutual understanding, language assistance and cultural competency programs should foster public health professionals' engagement of the diverse communities they serve and improve their ability to recognize changing community needs. Language assistance programs, in particular, should also expand many community groups' awareness and understanding of public health activities and ability to participate in them more fully.

### **Community Surveillance, Assessment, and Priority Setting**

Characterizing the health of the population through epidemiologic surveillance and identifying its health needs through formal assessment are essential public health activities that depend heavily on health professionals' presuppositions about distinctions and similarities among communities. Basic health statistics can be significantly affected by whether and how the larger population is analyzed by subgroups. Interpreting the meaning of such statistics, and identifying appropriate public health responses to them can also be affected by whether the members of the subgroups share community values or experiences. For example, the high low birth weight and infant mortality rates for the United States as a whole are often regarded as an embarrassing puzzle in light of national expenditures on prenatal and perinatal medical care. When national rates are evaluated by racial/ethnic group, socioeconomic status (SES), and age, the problem can be seen to affect young African-Americans of lower SES most severely, but the rates for all groups of African-American women are disproportionately higher than for their counterparts' from other racial/ethnic groups. In seeking to understand this disturbing phenomenon, public health researchers and women's health advocates have recently emphasized such potential causes as the experience of institutionalized racism and its associated stress

over possible biological or medical factors. Defining and measuring the experience of institutionalized racism and associated stress requires not only the observational and analytic skills of behavioral scientists and social epidemiologists, it demands the participation of the communities being studied and insight into community members' interpretation of their experiences.<sup>13</sup>

Community health professionals have long recognized that community members view health and illness and their respective causes differently than do practitioners and researchers. Even when community members and professionals identify the same health problems, needs, and resources, their emphases often differ. Professionals' emphasis on organizations and the delivery of service typically contrasts with community members concern for social, economic, and interpersonal issues. Knowledge of community members' subjective experience is considered essential for a comprehensive view of a community's health status, both in terms of the lived meaning of surveillance data and the importance attributed to specific health problems in daily life. But because of difficulties in involving the community at large in assessment and the logistical and ethical difficulties of identifying and engaging community representatives in the process, community assessment may be left largely to professionals in all but major projects or when funding guidelines require community participation.

In practice, community assessment and priority setting are twin components of health planning that inevitably affect each other. Formal assessment is typically based on an overview of a community's strengths and needs that effectively establishes some general priorities before the evidence is gathered, but funding for community projects requires data to support their feasibility and likely community benefit. Community members who enter into the assessment and planning process are typically much less concerned with developing and analyzing comprehensive and well-documented data and much more interested in action, change, and the provision of services. Maintaining community involvement in planning and priority setting often requires public health planners to balance their professional responsibility to use sound research methods and the need to provide meaningful opportunities for community participation that will keep community members interested and active in the process.

The best-known and most ambitious community-based priority-setting project in the United States, the Oregon Health Plan, illustrates both the ethical strengths and limitations of community involvement in planning for health services.<sup>14</sup> The Oregon Health Plan was the result of Oregon's 1989 revision of Medicaid in response to the state's growing number of uninsured residents. Under the plan all state residents who met federal poverty guidelines were eligible for Medicaid coverage, but fewer conditions and fewer types of treatment were covered under the revised system. In order to clarify which conditions and interventions should be covered under the plan, the state created the eleven-member Oregon Health Services Commission to develop a prioritized list that would be the basic benefits package. The Health Services Commission was created in part in response to the efforts of Oregon Health Decisions, a civic organization responsible for grass-roots education and community outreach centered around health care rationing. Between 1983 and 1984, Oregon Health Decisions conducted 300 community forums and town hall meetings designed to raise awareness of the practical and ethical issues related to health care rationing. The process involved some 5000 Oregonians and led to the 1984 Citizen's Health Care Parliament, which outlined the values that its participants believed essential to an acceptable rationing plan. In 1989 the Health Services Commission continued the community-based discussion in town hall meetings in every county across the state, discussing with participants how to allocate health care resources consistent with community values. The Commission subsequently used its findings to create a list of 709 condition-treatment pairs for which priority for coverage was based largely on the values and preferences expressed in the community forums.



From the outset the Oregon Health Plan was both hailed and criticized from many directions, but analysis of the priority list and the way in which it was developed received particularly strong criticism from some ethicists and community advocates. In particular, they pointed out that the community values and preferences that informed the prioritizing of coverage were not necessarily the values and preferences of Oregon's Medicaid-eligible population. The community forums and town meetings at which rationing, priorities, and values were discussed were typically attended by health care providers, and other educated, middle class Oregonians. Although organizations representing Medicaid patients took part in the discussions, only 5% of the participants were actual Medicaid recipients. Despite efforts to schedule sessions at convenient times for all community members and to publicize the meetings actively, members of the lower socioeconomic groups most affected by Medicaid's restructuring did not participate. Questions about the community that the Plan was meant to serve, the willingness and ability of health professionals and educated citizens to speak for the poor, and how the Commission might have engaged more participation from members of Oregon's lower socioeconomic groups continue to pose a serious challenge to health planners and the establishment of community-based practice.

### **Community-based practice**

Community-based practice, particularly the delivery of health services, is distinguished by both logistical and ethical aspects. Logistically, community-based practice is rooted in a particular, defined community, whose needs and goals define the purpose and activities of the practice. Ethically, community-based practice is committed to honoring the values and culture of the defined community being served and to shared governance of the practice itself. Community-based practice in this sense means the strategic and sustained cooperation of public and private health and social service agencies, neighborhood associations, local funders, businesses, schools and universities, consumer advocacy groups, public officials, and public agencies, which provide the resources and key players needed to maintain a comprehensive approach, a community focus and shared control, an epidemiological understanding of the community's health and well-being, and responsive and flexible interventions that recognize the importance of improving the health of both individuals and the community as a whole.

While few practices achieve this combination of ideals, across the country, diverse broad-based community partnerships such as Healthy Cities/Communities, Healthy Start, Ryan White Planning Councils, comprehensive community initiatives, and community health worker/promotora programs have made some inroads.\* One of the most successful models of community-based practice, community-oriented primary care (COPC), attempted to integrate community participation with clinical primary care and the basic features of public health. The history of COPC, which was quite popular in the United States in the 1980s, illustrates the ethical ideals as well as several ethical tensions inherent in community-based practice.

COPC was originally developed in 1940s South Africa by Drs. Sidney and Emily Kark and further developed in Israel. COPC was based upon the idea that decision making for health needs to hinge on an epidemiological understanding of the principal factors influencing health, including social, biological, and cultural characteristics and the natural and man-made environment. The Karks taught that health interventions should target both the individual and the community as a whole, and that the community should be involved in the promotion of its own health. In 1982 a U.S. Institute of Medicine

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\* See Best Practices sheet for general references on such programs.

(IOM)-sponsored conference on COPC defined the essential elements of COPC as (1) complementary use of epidemiology and clinical practice; (2) a defined target population, for whose health improvement COPC service takes responsibility; (3) defined health interventions based on epidemiological findings; (4) community involvement in its own health promotion; and (5) accessibility without financial, social, cultural, geographic, and other barriers to care.<sup>15</sup> Attracted to this model because of its comprehensive, democratic approach, many practitioners worldwide introduced COPC into public health practice, particularly in clinics for the indigent.

Over the past 20 years, however, COPC in the United States has come to be understood largely as a primary care medical practice with a geographically defined service area, where resource allocation and program design decisions are based at least in part on periodic health needs assessments. A few years after it defined a active role for communities in COPC, IOM reduced its definition of COPC to four key tasks performed by professionals: (1) defining and characterizing the community; (2) identifying the community's health problems; (3) modifying programs in response to health needs; and (4) monitoring the program's impact. Not surprisingly, today most U.S.-based COPC practices do not take a comprehensive approach to health that encompasses social, cultural, and environmental determinants, or target interventions to the health of the community as a whole (as compared to a large number of individuals). Similarly, although community health centers and other such practices may have consumer representation on advisory or governing boards, COPC practices today do not incorporate any significant degree of community involvement. Moreover, financial, geographic, cultural, and other barriers to access to health care continue to present tremendous challenges to indigent communities across the United States even where COPC programs exist.

The shift in COPC's ethical commitment to community participation and a holistic approach to community health may be the result of the persistent U.S. belief that health problems can be corrected by the delivery of professional health and social services and Americans' dedication to medical experts and institutions. Moreover, the dominant biomedical model of health and illness still overlooks the importance of connections among individuals for both creating and solving health problems, and doubts the wisdom or feasibility of sharing authority or responsibility with a given community for the promotion of its own health. And, perhaps most importantly, as the U.S. population grows more diverse and more mobile, the concept of "community" remains difficult to define in theory or practice, making community engagement particularly difficult to achieve. The original vision of COPC might well be highly effective if implemented faithfully, but the interaction of practical and ethical restrictions on its goals makes such implementation unlikely for the near future.

### **Community-Based Research**

The ethical issues in public health research, as in all human health-oriented research, relate primarily to the tensions between the real and potential benefits that research offers participants and the possible harms that the investigation may cause them.<sup>†</sup> Like epidemiologic surveillance, public health research attempts to answer questions related to the health of populations that may have markedly different answers for different communities. Nonetheless, presumptions about the similarities and differences between communities on which research agendas are built can pose ethical challenges for investigators and communities. The history of public health research is indelibly stained by the U.S. Public Health Service's 40-year study of untreated syphilis among poor, uneducated African-American men in Macon

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<sup>†</sup> Module 3 addresses the ethics of public health research in more detail.

County, Alabama, under the premise that the “Negro” biological response to syphilis was different from that of Caucasians.<sup>‡</sup> Despite national ethical standards that required the informed consent of participants over the four decades of the trial, researchers in the Tuskegee Syphilis Study betrayed the trust of the community and deceived individual participants by portraying the study as special medical attention.

Since the late 1960s, regulatory authorities have sought to protect research participants from study-related harms by through reinforced standards of informed consent for individuals enrolled in research protocols. In the late 1980s, however, AIDS activists demanded greater access to the therapeutic options offered only in drug trials. Their claims began a shift in the interpretation of informed consent from a largely defensive right to refuse experimental intervention to a positive right to be involved in research protocols as an informed partner.<sup>16</sup> Since the late 1990s federal regulations have reflected this new attitude, as evidenced by the substance and the language of new policies. Both governmental agencies and many researchers have abandoned use of the implicitly passive “research subject” in favor of the more active “research participant.”

“Participatory research” has gained particular currency for community-based studies. In the mid-1990s, international AIDS researchers faced significant ethical conflict in reconciling U.S. standards of individual informed consent with the accepted paternalism of medicine in most developing countries.<sup>17</sup> Some proposed models of community consent in which community leaders were asked to speak on behalf targeted participants.<sup>18</sup> Often the community members recruited for drug studies had no understanding of the western concept of self-determination and who respected the authority of community leaders to make important decisions in the group’s interests. For many ethicists this practice raised the crucial dilemma of how to respect individuals who do not believe in autonomy without supporting the potential exploitation use of vulnerable persons whose own interests might differ from those of their larger community. Although U.S. federal funding commits international research to U.S. ethical standards, the ethical controversy surrounding community consent remains largely unresolved, particularly with respect to privately funded drug studies.

In the United States, communities have begun to seek partnership with researchers in addressing health problems that they both recognize. Researchers, in turn, have realized the benefits of community participation in defining important research questions, implementing protocols, and interpreting results. The National Institutes of Health has increasingly called for protocol design to be consistent with the goals of participatory research, and recommends that applicants for certain federal funding consult published guidelines from the University of British Columbia on participatory research.<sup>19</sup> These guidelines highlight the importance of community involvement and partnership in health promotion research and define five basic categories for evaluating partnership and community participation:

- the **characteristics** of the participant community of interest;
- the **origins** of the research question and the **community’s support** for it;
- whether the research will **foster self-determination** among community members and **facilitate collaboration** with external resources;
- whether the community and the researchers can **learn about each other** during the process; and
- whether the participant community will **benefit from the research outcomes** and how.

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<sup>‡</sup> Module 2 discusses the history and legacy of the U.S. Public Health Service’s Tuskegee Syphilis Study in detail.

These criteria speak to the potential for researchers and communities to serve their mutual needs and link traditional concepts of research protection with new interpretations of collaborative trust.

## **Conclusion**

New attention to community in theory and practice offers the promise for a public health that is of the people and by the people as well as for the people. Integrated community-based efforts at surveillance, intervention, and research close an important circle for health professionals by bringing a wider range of knowledge, skills, and resources to bear on complex public health concerns and deepening broad commitment to solutions by involving people in decisions that affect them. For community-base research and practice to be successful, however, public health professionals must be alert to its inherent tensions and use conflicts to gain a greater understanding of how to balance the many worldviews, goals, and strategies at play. A strong mutual commitment to power-sharing and the collaborative process, and honest approach, careful attention to relationship, and the pursuit of “win-win” outcomes can go a long way to overcoming the may obstacles that remain.

# Fact Sheet: Community-Based Practice and Research: Collaboration and Sharing Power

## Regulations and Guidelines

Legal mandates, professional guidelines, and organizational standards on community-based practice and research, including related ethical issues, are decentralized and generally not coordinated. Funders and contracting agencies often place program-specific conditions on use of grant or contract funds, or recommend that projects incorporate principles of community-based practice or research or related guidelines.

For example, many federally legislated funding streams require community representation, in some cases with fairly specific representation formulas. Among many other examples, required vehicles for community representation include the community-level Planning Councils mandated by Ryan White CARE Act for local distribution of federal HIV/AIDS funding, the governing boards of Community Health Centers, and the planning and coordinating Community Consortia required of each local Healthy Start infant mortality initiative. In another vein, in partnership with a number of other public health agencies, the Centers for Disease Control and Prevention have drafted a set of Public Health Performance Standards for state health departments, local health departments, and governing bodies like Boards of Health. Among other purposes, the standards are intended to improve performance and increase accountability. As collaboration with the community is included in the draft standards, it is more likely than ever that all governmental public health agencies will be held accountable for community collaboration.

With some exceptions that are related to new technologies, the ethical issues that arise in community-based practice and research today are not new. Most relate to the difficulty in defining a community, identifying its leaders and appropriate representatives, and recognizing and addressing the tensions inherent in sharing power, knowledge, and responsibility in the pursuit of community health benefits. In practice, individual public health professionals may find themselves unable to conform to all relevant mandates. More commonly, unwritten organizational norms or individual job descriptions may conflict with the approaches and tasks necessary to interact successfully with the community.

## Common terms

**Capacity building:** The provision and promotion of education and practical training within low- and unskilled communities, particularly with respect to essential health services. Capacity building is a strategy for community empowerment and fostering independence.

**Communitarianism:** An ethical theory that recognizes the dual human need for autonomy and social relationships, and emphasizes the role of communities' values and experiences in shaping individuals' moral commitments. Communitarianism developed in the 1980s in response to liberalism's emphasis on individual rights. Communitarians believe that individual rights must be balanced with communal responsibilities.

- Community:** A population or group defined by its common characteristics or experiences, particularly location or geographic origin; physical, behavioral, or personal characteristics (e.g., race/ethnicity, gender, age, sexual orientation, disability); beliefs, values, interests, norms or goals.
- Community assessment:** Evaluation of the strengths, abilities, needs and goals of a particular group, population, or geographic area, typically with the goal of intervention to improve services or minimize the harm caused by intervention elsewhere.
- Community governance:** Shared authority between communities and either private or public organizations over long-term issues of importance to the community, secured by a mutually desired outcome, such as funding, that depends of full community partnership.
- Community health:** The health of an identified group; organized practices intended to promote, protect, and preserve the health of one or more defined populations
- Community organizer:** Lay or professional person who works with one or more specific communities to define members' common goals, needs, problems and priorities, and design strategies and mobilize resources to achieve these goals and priorities.
- Community-oriented:** An integrated system of clinical primary care and public health, primary care (COPC) which emphasizes continuity of care and focuses on the whole community and its subgroups in needs assessment, planning and providing services, and evaluating outcomes. COPC's five essential features are: a clearly defined target population for surveillance, care, and evaluation; complementary roles of epidemiology and clinical care; defined programs based in epidemiologic assessment; involvement of the community in health planning and health promotion; and accessibility to services without geographic, financial, socio-cultural, or other barriers.
- Community participation:** The active involvement of the members of a community in the planning, creation, operation, and control of an organization, project, or service activity intended to benefit that community.
- Community representative:** An individual who participates in an organization, project, or service activity as a member of a specific identified group or population, both to provide the perspective and knowledge of the group to the organization or activity and to convey essential information about the organization or activity to the larger group.
- Culture:** As used here, a system of shared beliefs, values and behaviors and practices common to a particular group or population that results from group experience interpreted in light of beliefs about the purpose and meaning of life. With regard to health and well-being, culture includes ideas about definitions and causes of health and illness; beliefs about how to protect

and improve health; attitudes about when, how, and from whom to seek help; and appropriate ways of expressing (or not expressing) symptoms or suffering.

- Cultural competence: The knowledge, skills, and attitudes necessary to work effectively with persons from one or more cultures other than one's own. Since the late 1990s, many governmental and professional organizations have emphasized the need for cultural competence training to improve the ability of health-related organizations and individual health workers to provide high-quality services to diverse populations.
- Participatory research: Systematic inquiry with the active collaboration of the individuals or groups involved in or affected by the issue being studied, undertaken with the goal of education, intervention, and beneficial change.
- Oregon Health Plan: Oregon's 1989 revision of Medicaid in which all state residents who met federal poverty guidelines were eligible for Medicaid coverage, but with fewer conditions and fewer types of treatment covered. A list of 700 covered condition-treatment pairs and the priority for their coverage was based largely on values and preferences expressed by Oregon's citizens in community forums and public opinion polls conducted over several years.
- Shared governance: Collaboration of a broad range of stakeholders—public, private, governmental, lay, and professional, individuals and organizations—who take long-term joint responsibility to address issues of importance to the community.

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<sup>1</sup> <http://www.apha.org/codeofethics/ethics.htm>

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<sup>3</sup> Israel BA, Checkoway B, Schultz A, Zimmerman M. Health education and community empowerment: conceptualizing and measuring perceptions of individual, organizational, and community control. *Health Education Quarterly* 1994; 21(2):149-170.

<sup>4</sup> Durant J, Hansen A, Bauer M. Public understanding of the new genetics. In: *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*. T Marteau, M. Richards, eds. New York: Cambridge University Press, 1996, pp. 236-238.

<sup>5</sup> Jonas S. The question of community control. *American Journal of Public Health* 1971; 61 (10): 1934-1937

<sup>6</sup> The Communitarian Network, <http://www.gwu.edu/~ccps>

<sup>7</sup> Forster JL. A communitarian ethical model for public health interventions: An alternative to individual behavior change strategies. *Journal of Public Health Policy* 1982; .

<sup>8</sup> Arnstein SR. A ladder of citizen participation. *Journal of the American Institute of Planners* 1969; 35(4);15

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<sup>9</sup> Arnstein S. Maximum feasible manipulation. *City* 1970 (Oct/Nov): page numbers unavailable.

<sup>10</sup> Wolff T, Kaye G (eds.) *From the Ground Up: A Workbook on Coalition Building and Community Development*. Amherst, MA: AHEC/Community Partners, 1995.

<sup>11</sup> National Association of Social Workers. *NASW Standards for Cultural Competence in Social Work Practice*. Washington, DC: NASW, 2001. [http://www.naswpress.org/publications/standards/standards\\_cultural\\_competence/s01.html](http://www.naswpress.org/publications/standards/standards_cultural_competence/s01.html)

<sup>12</sup> Office for Civil Rights, U.S. Department of Health and Human Services. Title VI of the Civil rights Act of 1964; Policy Guidance Against National Origin Discrimination as it Affects Persons with Limited English Proficiency (65 Fed. Reg. 52762-52774).

<sup>13</sup> Reverby SM. More than fact and fiction: cultural memory and the Tuskegee Syphilis Study. *Hastings Center Report* 2001; 31(Sept-Oct): 22-28.

<sup>14</sup> Bodenheimer T. The Oregon Health Plan — Lessons for the nation (first of two parts). *New England Journal of Medicine* 1997; 337: 651-655; Crawshaw R. The Oregon Health Plan (letter). *New England Journal of Medicine* 1998; 338:395-396.

<sup>15</sup> Conner E., Mullin F, eds., Institute of Medicine. *Community Oriented Primary Care: New Directions for Health Services Delivery*. Washington, DC: National Academy Press, 1982.

<sup>16</sup> Arras JD. Noncompliance in AIDS research. *Hastings Center Report* 1990, 20(Sept/Oct): 24-32

<sup>17</sup> Levine RJ. Informed consent: Some challenges to the universal validity of the western model. *Law, Medicine & Health Care* 1991; 19: 207-13.

<sup>18</sup> Weijer C, Goldsand G, Emanuel EJ. Protecting communities in research: current guidelines and limits of extrapolation. *Nature Genetics* 1999, 23: 275-280.

<sup>19</sup> University of British Columbia Institute for Health Promotion Research. Guidelines and categories for classifying participatory research projects in health promotion, in *Participatory Research in Health Promotion in Canada*. Ottawa, Ontario: Royal Society of Canada. [www.ihpr.ubc.ca/guidelines.html](http://www.ihpr.ubc.ca/guidelines.html)



## **Case Study 1: Providing Culturally Appropriate Services in a Changing Community**

**Our Covenant Health Center** is a 17-year old nonprofit clinic in an indigent, multi-ethnic neighborhood of a once-prosperous urban community. Our Covenant was founded as a free pediatric clinic by a consortium of churches after a sharp economic downturn left many area residents without jobs or health insurance. Through the leadership of a retired public health administrator and the volunteer efforts of other church members, the clinic grew steadily. After only a few years Our Covenant had expanded to provide a wide range of medical and social services for which patients paid on a sliding scale based on household income. By its 6th anniversary, Our Covenant had received funding from several private foundations and had hired a full-time administrator and several full- and part-time clinical staff. Our Covenant celebrated its 10th anniversary by moving into a renovated discount store building, which was donated by its owners to avoid a tax foreclosure.

The mission of Our Covenant Health Center is to provide community-based primary care for area residents, and the neighborhood has long viewed the clinic and its staff as important community assets. The 10-person board of directors includes 3 long-time community residents, and the community advisory board meets monthly to review operations and take part in planning. Both boards and the administration consider community capacity building to be one of Our Covenant's basic responsibilities. Two lay health workers were recruited from among neighborhood residents, and the veteran social worker/educator lives nearby. All three participate actively in the life of the community, visiting patients in their homes and conducting education and referral sessions.

Changing demographics have complicated Our Covenant's community-based efforts over the past few years. When the clinic was founded, the surrounding neighborhood and the clinic's patient population were a roughly equal mix of African-American and white Anglo families; today it is about 95% African-American. About 6 years ago, an influx of Mexican and Central American immigrants to the city brought new populations to the clinic. Soon the clinic needed Spanish interpreters to care for the many patients with limited English proficiency (LEP) coming from across the city. The administrator obtained private funding for 2 half-time bilingual clerks, but the availability of language assistance drew more LEP patients to the clinic, and their need for language assistance soon overwhelmed the bilingual staff members' abilities. To date the clinic has not had the money to hire additional interpreters or bilingual staff, and has relied instead on uncertified volunteers to translate.

After a month in which almost 60% of the patients spoke little or no English, the administrator concludes that the staff must be reconfigured to meet the clinic's current and projected need for bilingual services. She proposes that the social worker and one lay health workers each be made half-time, and that the clinic use the resulting salaries to hire a part-time bilingual social worker and a part-time Spanish-English interpreter. The board grudgingly agrees but the community advisory board objects. They insist that the social worker, an original member of Our Covenant's staff and neighborhood resident, should not be penalized for not speaking Spanish. The community advisory board points out clinic statistics that show that the majority of LEP patients come from outside the clinic's target population and that a growing number come from out of state. They propose that all patients from outside clinic's designated service area should be referred to other facilities.

- How should the board and administration respond to Our Covenant Health Center's changing patient population and the language assistance needs of the new patients seeking care there?
- How should new demand for services shape the clinic's approach to its community and original mission?

## Case Study 1: Discussion

This case addresses the dynamic nature of communities, the demographic and political variables used to define individual communities, and the how the need to tailor public health services to the cultural distinctions and differing needs of subgroups may affect an agency's structure and function. Discussion should focus on 1) how a public health entity defines the community it intends to serve, including the role that community members have in establishing such definitions; 2) how an identified community may include significantly different subgroups with apparently conflicting values and needs; 3) the meaning of cultural competence, its benefits and limits, and the practical ethical challenges of operating in a multi-cultural environment; and 4) the nature and limits of mission statements and concepts of organizational ethics.

### Background

No community organization can remain unchanged and be responsive to the needs of community dynamics. High rates of immigration have been a prominent feature of demographic change in the United States since the 1970s. Few areas of the country have been unaffected by the growth of Hispanic and Asian populations and the influx of immigrants with limited English proficiency (LEP). On a population level, this diversity has highlighted the role of culture in defining health needs and appropriate services, while on the individual level it has emphasized culture's influence on appropriate diagnosis and treatment. Public health agencies and community-based providers are increasingly responsible for meeting standards of cultural competence in treating the groups they serve, and for providing language assistance to LEP clients and patients.

Community organizations that serve growing immigrant populations may find their resources and identities strained as they attempt to meet immigrants' vast needs while meeting their original community missions. Moreover, long-term community residents may resent immigrants' use of already limited resources, straining the community relations essential to successful operations.

### Suggested Questions for Discussion

- What is the purpose of a mission statement for a community organization? When should a mission statement be changed and through what process? What external factors, internal features, and potential future needs shape the definition of a community organization and its services? What role should an organization's staff members play in defining, interpreting, and carrying out its stated mission?
- Are there valid grounds for a private, nonprofit primary care clinic to accept only specific groups of people as patients? *If so*, on what ethical grounds might a clinic such as Our Covenant refuse to treat certain individuals or classes of people? *If not*, why must a clinic treat everyone who seeks care? What are the limits of either position?
- Federal guidelines on language assistance call for health care providers to employ bilingual health professionals and/or certified interpreters. The guidelines insist that LEP patients' English-speaking family members should not be asked to translate for the patient and caregivers. What ethical and practical problems may use family members as translators cause? In addition to direct patient care, what other services and materials should available for LEP

members of a service community? If a charitable organization or agency does not receive federal funding, how should it view federal standards and guidelines on quality of care?

- How can public health organizations and health care providers encourage their employees to gain “cultural competence” without unintentionally promoting cultural stereotypes that may lead to discrimination? Can an individual be “culturally competent” with respect to a specific group *without* speaking or understanding the group’s primary language? Is being bilingual an adequate measure of cultural competence?

## Case Study 2: Community Representatives on the Institutional Ethics Committee

Smith County Hospital is a 450-bed public hospital that serves a large multiethnic industrial town and the surrounding unincorporated area. The hospital draws patients from three outlying ambulatory clinics that the county operates, an active obstetrics service, and its emergency department, which maintains a Level I trauma center.

Smith County Hospital is preparing for an upcoming site visit from the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO). Since the early 1990s, JCAHO has called for hospitals to have a mechanism, process, or service such as an institutional ethics committee (IEC) that considers and helps to resolve ethical issues that arise in the care of patients, particularly in the area of terminal illness and care of the dying. At the last accreditation visit one JCAHO reviewer spent over an hour discussing the hospital's new IEC and its policies and practices. The hospital was not cited for problems with its IEC, but the reviewer strongly recommended that the committee's membership be made more multidisciplinary and more representative of the hospital's constituents. Since then, the IEC's chair, a general pediatrician, has recruited new members from almost every area and profession in the institution, as well as a lawyer from the Smith County Attorney's office. However, the IEC chair, the hospital's administrator, and the county attorney disagree about whether to include lay community representatives on the committee. They have put the issue on the today's IEC meeting agenda for a vote.

The IEC chair introduces the topic by reporting on the JCAHO reviewer's comments from two years before that the IEC needed one or more people from the community to bring a lay perspective to the IEC's discussion. The chair notes that, from his experience with the community advisory board of the county's pediatric clinic, the hospital has contact with many knowledgeable and dedicated community people who would be interested in serving on the IEC.

The administrator and the county attorney, however, draw a clear distinction between community advisory boards and the IEC. First, they argue, the IEC deals with complex information about individual patients and medical procedures that lay people don't understand. They worry that it would slow discussion to have to explain all the detailed medical issues to community representatives. Second, the county attorney insists, the IEC discusses cases that involve extremely sensitive personal information. Lay people don't have the ethical commitment to patient confidentiality that health professionals do, he claims, and there is no guarantee that community representatives won't talk to their friends and family members about what they've heard, especially if they know the patient. Moreover, there is no guarantee that community members won't go to the media if they learn about something that they think is unethical. Third, insists the administrator, many of the staff already on the IEC are members of the hospital's community and have friends and family members who are patients in the county health care system. They can represent the community even better than someone from the outside because they understand the hospital as well as the community's perspective. Finally, he points out, JCAHO does not *require* community representatives. He proposes that if this year's site visitor asks they can simply report that the committee considered the idea and decided not to add community members at this time.

- How should the members of the Smith County General Hospital ethics committee determine whether to include community representatives? If they choose to include community representatives on the IEC, how should such members be selected?

## Case Study 2: Discussion

This case addresses the role of community representatives on decision-making bodies that affect the public welfare and in government organizations in particular. Discussion should focus on 1) how to define a lay persons' qualifications to serve on a given specialty board or committee; 2) how to define what constitutes representativeness for any given community; 3) why professionals may fear lay participation in public health practice; and 4) how to maximize community representatives' contribution to the overall goals of the groups they serve.

### Background

The Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) is a voluntary accreditation organization for hospitals and other in-patient health care facilities. JCAHO accreditation is required for such institutions to receive Medicare and Medicaid funding. Since the mid-1990s, JCAHO's standards have called for institutions to have a functioning multidisciplinary institutional ethics committee (IEC) to address ethical issues in patient care. JCAHO standards do not require hospital IECs to have lay community members the way that federal funding standards require community clinics to have community advisory boards, but they recommend that community representatives be included to provide insight into patients' perspectives on ethical issues.

Hospital IECs typically address ethical issues involved in caring for seriously ill and dying patients. Since the 1980s, IECs have served successfully to prevent and resolve ethical conflict between health care professionals and patients and their families. IECs often provide ethics education for hospital staff. They often help to write hospital policy related to medical care at the end of life (the use of advance directives and do-not-resuscitate orders, and withholding or withdrawing life support). Their best-known role, however, is in providing a setting for caregivers and patients and their families to work out controversial ethical issues in the care of specific patients. The IEC offers expert guidance on difficult ethical decisions, and most IECs provide an advisory opinion at the request of the person seeking consultation. Because many clinical ethical issues are highly personal and sometimes controversial, IECs observe strict guidelines on confidentiality. The qualifications for membership on IECs may vary between hospitals, but most members are chosen because of their clinical knowledge and professional dedication to good patient care.

### Suggested Questions for Discussion

- Defining Smith County General Hospital's community is essential for determining who might be a suitable community representative. Is it the entire population of people who live and work in Smith County? The population of indigent persons most likely to use the hospital? The Smith County residents whose taxes support the hospital financially? The patients who currently use Smith County General Hospital or its affiliated clinics?
- Which aspects of community life and which community perspectives might the IEC find useful in its consideration of ethical policy and practice? Given the size and multiethnic composition of Smith County, how many community representatives would be needed to represent the county's diversity? Could the authoritativeness of their views be confirmed? If so, how; if not, why not?

- What information and perspectives from the hospital might the IEC want community representatives to convey to the community? With which segments of the County's population might the IEC particularly want community representatives to be contact? How many representatives would be needed to represent the hospital to these groups?
- Can a health professional from a given community appropriately represent the interests and perspective of lay people from his or her community without being unduly influenced by professional attitudes and perspectives? If so, how can such professionals' best serve as "culture brokers?" If not, in what fundamental ways does the experience of health professions education and practice change people?
- What contributions might lay people make to the IEC beyond helping to satisfy JCAHO? What successful models of community representation might the IEC use in creating an effective system of lay membership? What institutional and interpersonal supports might certain lay members need to participate fully on the IEC?

### **Case Study 3: Community Participation in Epidemiologic Surveillance and Research Design**

Stillwater Springs is a small town about 45-minutes from the state capital. The town thrived during the early twentieth century as the home of one of the United States' most important lead mines, but the mine closed 30 years ago, and most of Stillwater Springs' residents left shortly thereafter. Over the past decade, however, a population boom and housing shortage in the capital city has brought many young families and retirees to Stillwater Springs because of its affordable housing and more relaxed rural lifestyle. In the past 5 years developers have built 3 new subdivisions at the edge of Stillwater Springs, several new businesses have opened, and voters recently passed a bond election to build a new elementary school. The capital city's newspaper has recently called Stillwater Springs one of the state's most promising communities for the future.

In the past several months, news reports about the end of an Environmental Protection Agency (EPA) Superfund cleanup at a lead mine in a nearby county have created controversy in Stillwater Springs. Many new residents have been surprised to learn that the town was an active lead-mining center for almost a century, and they worry that the nearby abandoned mine may expose them to health hazards. Most long-time residents can remember neighbors with seemingly unusual neurological conditions, but the town had no doctor for almost 20 years, and there is no county health department. Thus there are no central records detailing residents' health problems. Many parents insist that chronic underfunding and substandard programs are to blame for the school's poor academic ranking, but others privately suspect that chronic lead exposure may have resulted in mild mental retardation for some children. Although the mine is a frequent topic of conversation at community events, most residents don't know how to find answers to their concerns.

Brenda Curtis is a single mother of two young children and a resident of one of the town's new subdivisions. In college Brenda lived in an East Coast city where lead paint in old buildings posed a known health hazard, and she had worked on a lead poisoning education campaign as a community service project. From an EPA website Brenda learns that several old lead mines have been linked to elevated levels of heavy metals in the ground water and soil, and that people exposed to contaminated soil and water near old mines have been found to have unsafe blood lead levels. After reading that the risks of lead poisoning in mining areas are particularly high for preschoolers who spend a lot of time outside, Brenda takes her children to the pediatrician in the capital city for blood tests. Both children have slightly elevated levels of lead in their systems, but have no obvious symptoms of lead poisoning.

Armed with the children's test results and a packet of readings on lead poisoning from the Internet, Brenda goes door-to-door in her neighborhood, gathering signatures on a letter to the state health department's lead abatement program. The letter asks for an epidemiologic investigation of the community's health risks from lead, including blood testing of as many residents as possible, soil and water sampling, surveillance for neurological and developmental problems in area residents, and the creation of a database of all residents with high blood lead levels and their proximity to the mine. When the county newspaper reports on her effort, Brenda receives unexpected criticism from area business owners and residents concerned about the town's image and property values. The next week's paper carries a story on the EPA's 1985 decision that the Stillwater Springs mine did not meet the criteria to



be placed on the National Priority List of environmentally hazardous sites eligible for Superfund cleanup. The mayor of Stillwater Springs, who is often credited with the community's economic turnaround, is quoted in the article saying that the town is a safe and healthy place to raise a family.

When the state's lead abatement program director receives the letter signed by over 300 residents of Stillwater Springs, she is impressed with their initiative, but finds little reason to believe that the town is different from the many small mining towns across the state. She remembers vaguely hearing that in the mid-1980s EPA inspectors found no immediate health threat from the Stillwater Springs mine and gave it a better hazard ranking score than several other mines in the state. Still, as the letter points out, the recent construction may have stirred up lead-contaminated soil on previously unused property, creating a new risk of exposure.

The lead abatement program director wants to be responsive to this community's request for professional assistance in identifying a potential health threat that falls within her department's expertise. However, she knows that such an evaluation may be opposed by town leaders and others with a financial stake in the community's growth and prosperity, since the presence of toxic levels of lead will make Stillwater Springs an undesirable location. Moreover, the director knows that the environmental testing and epidemiologic work necessary to assess the potential health threat in Stillwater Springs will not be possible under the Health Department's projected 5-year budget. Even if she can find funding in the future, beginning assessment and surveillance there may snowball into demand for similar projects in many other communities at a cost that the state cannot afford.

- What steps should the lead abatement program director take in response to the letter from the Stillwater Springs residents?

## Case Study 3: Discussion

This case deals with community perception of health risks and the responsibility of public health practitioners and agencies to address community members' requests for assistance in identifying, assessing, and reducing threats to their welfare. Discussion should focus on 1) how public health agencies set priorities for research into health risks and the targets of epidemiologic studies, given limited resources; 2) how local, state, and federal agencies interact with each other and the communities they serve to evaluate and address multifaceted health problems; 3) how the interests of, and perception of risks and benefits to, any given community may differ among community members, as well as between community members and public health professionals; and 4) how to maximize effective interaction between communities and public health practitioners in designing and carrying out epidemiologic surveillance and research.

### Background

Mining was an important industry in many parts of the United States in the 1800s through the mid-1900s. New mining technologies in the late 1800s permitted excavation of multilevel tunnels and extraction practices that resulted in environmental contamination not only at mine sites but also in surrounding areas. Water accumulated in mine shafts typically contains high levels of dissolved heavy metals. When active mines pumped out this water, it often contaminated local ground and surface water. The practice of crushing rock taken from mines, both to extract metal ore and to make gravel for road construction, often created clouds of heavy metal dust that the wind carried for miles. Because lead is an element that does not break down in the environment, water and soil contamination is common in many areas where mining ended a generation or more ago.

Exposure to lead is a recognized health hazard, especially for children ages 1 to 5. In addition to the risk that small children will eat lead-based paint chips, young children's frequent hand-to-mouth contact puts them at risk of ingesting lead dust. Most children with lead poisoning have had chronic, low-level exposure to lead that can cause developmental and behavioral problems, lower IQ, and learning disabilities. Adults chronically exposed to lead may have neurological problems. More rarely, high levels of lead can cause mental retardation, seizures, coma, and death. Pregnant women may pass lead through the placenta, affecting fetal neurological development and growth. Because chelation treatment for lead poisoning is difficult and cannot resolve previous neurological damage, prevention is emphasized over intervention. Many public health agencies have programs in lead poisoning prevention and lead abatement. Epidemiologic work related to lead poisoning is typically carried out by local, county, and state health departments and children's clinics and hospitals. Its goals are usually to identify exposed individuals and groups at risk of poisoning, track the rates and health consequences of exposure, and locate sources of lead exposure for abatement and other prevention measures.

The U.S. Environmental Protection Agency (EPA) is a federal agency created in the 1970s "to protect human health and to safeguard the natural environment — air, water, and land — upon which life depends." EPA administers the Superfund Program, which was created by Congress in 1980 to identify, evaluate, and clean up the country's worst sites of hazardous environmental contamination from various sources. Sites suggested for the National Priorities List (NPL) of hazards warranting federally funded clean-up are announced in the *Federal Register* for public comment; EPA investigators then visit the site

to assess and score it under the Hazard Ranking System. High scoring sites may be targeted for immediate action to safeguard the health of the affected area's residents. However, the NPL is intended to provide information to state and local agencies and the public about sites that appear to warrant clean-up, and does not assign responsibility for clean up or legal liability for any harm.

### **Suggested Questions for Discussion**

- How do public health professionals' views of health threats and evidence of harm typically differ from those of members of the communities they serve? How do these differences shape public health professionals' interpretation of community concerns and requests for assistance? How are such discrepancies resolved in policy and practice? What responsibility do public health professionals have to community members to explain their conclusions and justify their actions?
- How might a health department's decision to conduct an epidemiologic survey create moral and legal obligations for governmental action far beyond the scope of the initial evaluation? How might internal interests affect an agency's willingness to undertake even a pilot epidemiologic project?
- How might external forces and interests influence a public health agency's decision to undertake epidemiologic assessment of a possible environmental health problem? Why might a community prefer to live in ignorance of a potentially remediable environmental threat rather than identify the nature and extent of the potential problem? What actions can public health professionals take to foster cooperation among community members in order to achieve high-quality surveillance?
- When several governmental agencies have jurisdiction over a broad-based public health problem, how is authority established among them? What response can the state health department's lead abatement director expect from environmental health officials at the federal and county levels if she proceeds with an initial survey of lead contamination in Stillwater Springs?

## Tools for Best Practice and Policy Assessment in Community-Based Practice and Research

The prescribed avenues for public health professionals to address the ethical issues in community-based practice and research vary widely. Nonetheless, for any project it is essential to identify and understand the written and unwritten ethical norms and values by addressing such questions as:

- What community is the focus our attention for this project? What criteria have we (public health officials) used to define this group as a community? Do they see themselves as a community with common interests, needs, and values? What other affiliations or divisions may be important to them?
- What previous experience do we have with community? Who among us has the best relationship with this group and what is it based on? In what other contexts do we interact with members of this community and how do those interactions affect the current project?
- Who speaks for this community and how were these spokespeople identified? At what point did they first become involved in the project? What was their original role in the project? How often do we communicate with community representatives or other community members about this project? Are these means of communication formal, informal, or both? What are our respective goals in this communication? Do both the community representatives and we attempt to include a wide range of community perspectives in this communication?
- What is the goal of our project and how was that goal identified? What role did members of this community have in defining that goal and the means of achieving it? What experience does the community have with this issue? How does this project relate to the community's other health priorities? How could community members modify the project if they chose to do so?
- How will participation in this project directly benefit the community and its individual members? How will the community and its individual members be empowered by participation in the project? How will the community's ability to learn about and act on other health issues be affected by participation in the project?
- Do we have a formal or informal agreement with the community about the ways in which knowledge gained from the project, including research data, may be used and how it may be disseminated?

The extent to which legal mandates or “expert” guidelines address community-based practice and research is also quite variable. However, professional and community groups have published a wealth of material intended to guide or facilitate community-based practice and research, both in print and online. A selected list of these “best practice” resources follows.

### Selected Resources

Campus-Community Partnerships for Health. *Partnership Perspectives*. San Francisco, CA: CCPH, 2000. <http://futurehealth.ucsf.edu/ccph/html>

Centers for Disease Control and Prevention/ATSDR Committee on Community Engagement.  
*Principles of Community Engagement*. Atlanta, GA: Centers for Disease Control and Prevention, Public Health Practice Program Office, 1997.

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