Health Bulletin

A publication of the Population Reference Bureau

Number 3

Working With the Community for Improved Health

By Kristina Gryboski, Nancy V. Yinger, Ricardo H. Dios, Heidi Worley, and Fariyal F. Fikree

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The suggested citation, if you quote from this publication, is: Kristina Gryboski et al., "Working With the Community for Improved Health," *Health Bulletin* 3 (Washington, DC: Population Reference Bureau, 2006). For permission to reproduce portions from the *Health Bulletin*, contact PRB at permissions@prb.org, or at the address above.

Editor: Ellen Carnevale
Design: Michelle Corbett, Population Reference Bureau
Production: Jon Howard, JH Design, Inc.
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Acknowledgments

The authors gratefully acknowledge the reviewers, Judi Aubel, Susan Rifkin, and Nina Wallerstein, for their invaluable comments. The authors thank Ellen Carnevale for her editorial guidance, and Lori Ashford, Marya Khan, and Rachel Nugent for their useful suggestions.

Working With the Community for Improved Health

In the world's poorest countries, the top three risk factors leading to disease, disability, or death are undernutrition; unsafe sex; and unsafe water, sanitation, or hygiene.[1] The underlying causes of these risks are complex, stemming from social, political, and economic conditions that contribute to vulnerabilities. Poverty and discrimination due to gender, ethnicity, age, or area of residence generate unhealthy living conditions and create barriers to the use of health services and information.

Although advances in health have contributed to improvements in quality of life worldwide, persistent health problems remain in developing countries, particularly for poor, marginalized, and rural populations. Neonatal mortality, preventable childhood illnesses, and adolescent reproductive health issues deserve special attention because of their global burden and the gross inequities inherent in their persistence. For example, an estimated 4 million deaths occur during the first 28 days of life, accounting for 38 percent of all deaths to children under 5 globally.[2] In children under 5, vaccines have been successful in preventing illness and death across a broad spectrum of diseases—polio, measles, and pertussis—but diarrheal disease remains a leading cause of preventable death to these children. Reproductive health issues—unmet need for family planning, unplanned pregnancies, or lack of knowledge of HIV—and access to reproductive health services significantly affect future population growth and women's autonomy.

Cost-effective interventions are available to address many pressing health problems. For example, community-based health and nutrition programs, if done on a large scale, have shown that an investment of $10 per child yields a 2 percent reduction in underweight per year.[3] But these interventions must be accessible to people where they live. Technological interventions can also be cost effective, but may take a narrow disease-focused approach.

Sustaining healthy populations and creating a context that facilitates health may require a broader perspective, such as that embodied in community participation. But some health specialists think that community participation is time-consuming and does not really improve health outcomes. Participatory processes can be protracted and progress toward health goals delayed, requiring heavy time and resource investments that may not be matched by the achievement of desired results.

This *Health Bulletin* explores community participation in health, using five case studies of participatory processes and their role in instigating important health and well-being benefits. This *Bulletin* is the third in a series that seeks to understand and convey the important qualitative issues that determine health status—disparities, communication, and community participation.

What Is a Community?

The term "community" has many interpretations. Some public health programs use the term to refer to groups that have a common health risk, but those individuals may or may not perceive themselves as part of that community. In the social sciences, community generally refers to groups that have some sense of shared identity and belonging, often within a

geographic and political context. Communities have common values, traditions, interests, institutions, and experiences. They also have social networks and systems within and beyond their boundaries, such as mutual-help traditions and social safety nets, which build support and cooperation. At the same time, communities often include differences—in status, access to resources, and power among individuals and groups. A person may identify with several communities.

Communities are complex and dynamic; therefore, community participation must be tailored to a given situation. Conditions both within and outside the community, such as existing political and economic structures that support public participation, or public knowledge about health conditions, affect a community's readiness to act.

What Is Community Participation?

Community participation as a development strategy has a long history. It was central to the "Health for All by the Year 2000" framework proposed in 1978 by the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF), and adopted by 150 United Nations member states. Decades of prior experience using a medical service approach had not sufficiently improved health or alleviated health inequities. The "Health for All" strategy specified the potential for communities to be actively involved in health development to improve their health conditions.[4] Since then, the concept of community participation has been interpreted and applied in various ways by donors, governments, and nongovernmental organizations (NGOs).

Over the years, community participation has evolved to include a variety of methods and approaches, some focusing on activities, others on processes. One set of "empowerment" approaches stems from the fundamental principles of community participation, and focuses on processes that enable intended program beneficiaries to define, implement, monitor, and evaluate programs that address self-defined needs.[5] A recent review by WHO on the effectiveness of these more-generalized empowerment approaches to improve health recommended that the most effective strategies are those that build on and reinforce true participation to ensure autonomy in decision-making and a sense of community. Those empowerment approaches that enable community members to focus on changing the local or external conditions that cause ill health can have the greatest impact.[6]

Community participation is defined in this *Health Bulletin* as a process that increases a community's capacity to identify and solve problems. Such participation can lead to equitable and sustainable improvements in health. When communities have this capacity, health programs may be more effective because solutions to health problems are based within that community's social structures, and accountability systems ensure that services are suited to the sociocultural context. The WHO review concluded that empowerment strategies, of which community participation is one, are promising in their ability to produce both empowerment outcomes and health impacts, with demonstrable added value to individuals and communities.[7]

Communities have a range of assets that can contribute to health outcomes—health knowledge, planning and management capacities, mobilization and communications experience, and collaborative spirit. An assets-based approach holds that each community boasts a unique combination of assets—individuals, families, local associations, organizations, and institutions.[8] This approach is different from the more-traditional method of health program planning that focuses on problems, needs, risk factors, deficiencies, or weaknesses in the community.[9] Assets-based community development is internally focused and relationship driven, and acknowledges traditions of organizing and planning.[10]

Planning and management—a community's capacity to analyze health problems, understand the views of differing groups in the community, solve problems, create action plans, access and coordinate information, leverage resources, and monitor and evaluate progress—are key to community-based health programs. A community's leadership structure should embody diverse interests, equity with special attention to disenfranchised groups, group facilitation, conflict resolution, and participatory learning methods. Successful leaders are visionary, energetic, and committed. Effective collaboration involves advocacy, negotiation, and nurturing partnerships toward a common goal. If these capacities and assets are not present in the community, skills building can help transfer knowledge to the community.

By partnering with communities and learning from them, health workers can increase their ability to respond to community priorities and perceptions and build upon community strengths (in this *Bulletin,* the term "health workers" is defined as health professionals external to the community).[11] This process can lead to increased sustainability if it empowers diverse members of communities, especially the most vulnerable and least powerful, to mobilize and gain access to social, economic, and political resources, and to achieve policy changes that improve their condition.[12] Although participatory processes are costly because of the length of time they require, the results can be more sustainable over the long-term.[13]

Community-based health programming grows out of an egalitarian perspective honed in the 1960s. The best-known example comes from Brazilian educator Paulo Freire. He was a catalyst of a "popular education" learning method in which individuals and groups analyzed the social-structural causes of individual and community problems.[14] Freire targeted the least powerful members of society to take action to transform their oppression into more

equitable systems through access to information. In Freire's approach, a facilitator uses participatory, problem-based methods to foster analysis and solution seeking. The facilitator is a co-learner who assists the dialogue rather than directs it. Programs that apply these learning principles use a variety of qualitative techniques suitable for low-literacy populations, such as traditional entertainment, to engage a community dialogue on problem and asset identification, and in ongoing self-evaluation of progress toward goals.[15]

Other approaches—community organizing and social mobilization—use similar principles that recognize that inherent tensions and inequities in systems must be openly analyzed and discussed in order to improve social, political, and economic conditions.[16] Community organizing is important when the solution must be community-driven and community-wide, or when systemic barriers such as lack of resources must be overcome. For example, setting up systems of emergency transportation and referral of complications for obstetric emergencies requires the participation of local community members and leaders in design and implementation. In Uganda, for example, the "Rescuer" project ensures that trained birth attendants have radio communication to call for help, and that local transport can be obtained on short notice.[17] In Sierra Leone and Ghana, community leaders collaborated with the local transport workers' union to set up a roster of vehicles for emergency transportation.[18]

Yet at times, efforts to employ a community participation approach miss the mark. Attempts to engage or cultivate representative community leaders may selectively or subconsciously ignore or subvert the natural community organization. Even when such efforts are done openly, they may lack legitimacy among community members. Moreover, community leaders' decisions do not always reflect the needs and preferences of all community members. Some leaders may abuse their position and undermine the legitimacy of health services by working toward their own interests. Also problematic is the use of health authorities who are charged with developing activities that pursue external health targets, but ignore community culture and traditions. The policy context can also facilitate or hinder community participation efforts (see Box 1).

Although the theoretical foundation for community participation is clear, impact across sectors remains unclear. In this *Bulletin*, we will examine a range of approaches that community-level health programs have taken to implement participatory methods, and the evidence of such outcomes as impact and sustainability.

Community Participation and Health Outcomes

Establishing a direct connection between participation and health outcomes is challenging because of the complexity of the social processes involved and the difficulty of measuring progress quantitatively. One challenge lies in defining variables to characterize a community's participatory processes and mechanisms. Gradations of control and skills such as those developed by Susan Rifkin and colleagues are useful for assigning numerical rankings for statistical analysis.[19] However, with few exceptions, most health programs designed to include a participatory component have been evaluated only on health outcomes.

While few programs have used rigorous evaluation designs, such as randomized controlled trials, to determine health outcomes, some participatory programs have monitored the use of health services and preventive health behaviors, and have found increased equity in access to services as well as reductions in the incidence of infectious disease.

Programs that build on cultural strengths such as mutual-help traditions, and that create partnerships between communities and health services, have docu-

Box 1

Factors That Support Community Participation

- Recognition by policymakers, health services, and communities of the right and duty of people to participate in public and community affairs.
- A political and administrative system that promotes and accepts decentralization and regional/local authority for decisionmaking on health policy, resource allocation, and programs; and implements these reforms with transparency and accountability.
- A health care delivery system in which the institutions, service providers, and managers are flexible; genuinely committed and supportive; responsive to regional/local needs in collaborative and creative ways; and include the community through such mechanisms as institutional boards, advisory groups, health committees, and community education programs.
- Structures, norms, and traditions in health institutions and in communities that promote inclusiveness, transparency, and accountability.
- Responsible, responsive, and efficient media, information, and communication systems within and between communities and at various government levels.
- A citizenry with sufficient awareness, knowledge, and skills in social organization and health-related issues (or a foundation for building them), community self-help traditions, and norms of mutual support.
- Adequate timeframe for facilitators to work together with communities to build/enhance capacity and provide support in needed technical areas.
- Supportive facilitation that enables power sharing and communication among stakeholders and actively includes marginalized groups.
- Community perceives that participatory actions are meaningful and lead to prompt, visible improvements.

Sources: J. David L. Zakus and Catherine L. Lysack, "Revisiting Community Participation," *Health Policy and Planning* 13, no. 1 (1998): 1-12; Judi Aubel, *Communication for Empowerment: Strengthening Partnerships for Community Health and Development* (New York: UNICEF, 1999); and Ranjani K. Murthy and Barbara Klugman, "Service Accountability and Community Participation in the Context of Health Sector Reforms in Asia: Implications for Sexual and Reproductive Health Services," *Health Policy and Planning* 19, suppl. 1 (2004): 178-86.

mented dramatic reductions in child mortality and improved preventive health practices. For example, the Navrongo Health Research Center in northern Ghana saw nearly a 60 percent decrease in deaths among children ages 2 to 5 when traditional leaders and communities were engaged in planning and delivering health services, and when community health nurses were relocated from subdistrict health centers to rural villages, trained in local outreach, and given motorbikes and medicines. In northern India, immunization coverage increased from 50 percent to 90 percent after communities participating in the Local Initiatives Program mobilized resources in urban and rural settings. More than 600 village committees trained over 2,000 community health volunteers to map community needs and manage and monitor service delivery.[20]

Working respectfully with the "gatekeepers" of cultural norms using participatory communication and learning approaches can result in important improvements in health knowledge and behavior. In Senegal, a program coordinated by the Christian Children's Fund, an international NGO, in collaboration with the Ministry of Health in two districts in the Thiès region, recognized the important role of grandmothers in deciding family health matters, and engaged them to improve the nutritional advice and support they gave to mothers and children. Almost 90 percent of women reported optimal postpartum infant feeding practices, as supported by grandmothers' advice, compared with only 50 percent of women in nonproject villages.[21]

Participatory programs can also create social change by building advocacy skills. Box 2 highlights an example of local-national policy dialogue in the Philippines. Advocacy skills can also empower particular population groups. In Calcutta, the Sonagachi program helped commercial sex workers increase their ability to protect themselves from sexually transmitted infections (STIs) and HIV. The program has shown an increase in the use of condoms and a reduction in HIV prevalence rates compared to other regions. The program bolstered women's leadership skills and facilitated the creation of an advocacy movement to improve women's status, while fostering sustainability. This program has expanded to other regions.[22]

Box 2

Building Skills to Facilitate Advocacy in the Philippines

In 2004, the Population Reference Bureau established a national coalition in the Philippines to assist communities and policymakers in addressing complex development priorities—health services, poverty alleviation, environmental protection, and sustainable livelihoods. The coalition, SIGUE, uses approaches that simultaneously integrate population, health, and environment (PHE) issues. SIGUE, which in the local language means "agreement and desire to move forward," promotes regular dialogue at the national level, researches integrated development options, and provides support to a larger network of entrepreneurs who are using integrated approaches throughout the country.

The coalition works with its members and community leaders to document successful PHE projects, promote champions who have led these efforts, and create opportunities for others to apply integrated approaches. One local midwife, for example, received national acclaim for her efforts to link family planning with environmental conservation, while a mayor received two prestigious national awards—the *Gawad Galing Pook* award and the Rafael M. Salas Population and Development Award—for groundbreaking approaches in the integration of reproductive health, family planning, and environment in local governance. The coalition has hosted two annual National Conferences on PHE that have encouraged communities and decisionmakers to integrate PHE efforts into their work.

What Is Participation?

A handful of researchers have analyzed the characteristics and nature of participatory processes to determine which elements are critical and sustainable for health improvement. Elizabeth Whitmore argues that the key to participation is the extent to which participants have decisionmaking power.[23] Rifkin and colleagues posit that three characteristics of participation are important to health outcomes: Participation should be active, voluntarily chosen, and hold the possibility of being effective.

Based on in-depth studies of three community-based programs in Asia, Rifkin characterized three approaches that health planners use to define community participation based on different assumptions about how decisions should be made to improve health:

- In the *medical approach*, decisions are solely in the hands of health professionals who direct community members to carry out actions to support health services or to make environmental improvements. They direct the community to act based on their professional knowledge, but do not build the community's self-development.
- In the *health services approach*, communities contribute to health care by giving human resources, materials, and/or money. Health professionals interact with the community through community health workers (CHWs), who act as brokers between community members and health services under the supervision of health professionals. In this approach, health professionals largely control decisions about health care delivery, and oversee the CHWs who represent the community.
- In the *community development approach*, the community identifies structural causes (social, political, and economic) of health problems in their community and acts collectively to create solutions.[24]

The community development approach holds the most promise for strong community involvement in all aspects of health programming. The critical elements of community participation are detailed in Box 3.

Communities vary in their ability to participate in health programs, but community participation can increase over time, depending on where the community and the project begin. Many studies have shown the importance of building community-level capacity for participation in program design, and accountability systems, and have provided evidence that working solely through hierarchical structures without facilitating a wider process of community inclusion may lead to a lack of community participation and resistance, especially among disadvantaged groups.[25]

Community Participation Program Development Continuum

To better understand how participatory processes influence health and well-being outcomes in communities, we highlight five case studies in which participatory elements of health programming contributed to health and other results. These case studies will be presented based on a modified version of the analytical framework proposed by several researchers.[26]

The model, presented in Figure 1 (page 6), has four levels of participation:

- At the *low level* of participation (participation score = 1), involvement of the community is minimal to none because the community lacks certain basic skills, the sociopolitical environment creates obstacles to participation, or communities are simply not given opportunities to participate.
- At the *moderate level* (participation score = 2), communities are aware of the health program and issues; may assist in needs assessment, planning, or implementing activities at the direction of the professional health workers; and may or may not be aware of program evaluation results. Decisions remain with the professional health workers.
- At the *high level* (participation score = 3), community members are involved in all aspects of program management, advocate for their own needs, make decisions in partnership with professional health workers, and are involved in project evaluation.
- At the *highest level* (participation score = 4), community members are directly involved in making decisions about all aspects of program management, resource allocation, and process and outcome evaluation. At this level, equity and inclusiveness are present in all areas of the project, including representative leadership.

Judi Aubel points out that the lowest level is the least complex to implement, and may be the most appropriate when rapid implementation is needed, during epidemics or disasters, for example.[27] The moderate level may also be appropriate to implement rapidly if the community already has the capabilities consistent with that level. Both the moderate and high levels are feasible when funders have specified health goals that would benefit from a longer involvement to build community capacity for sustaining the program. Such goals might include reducing maternal mortality or increasing vaccination coverage. The highest level of participation requires an elevated level of community skills, supportive policies, and structures that encourage coordination between the health sector and other sectors (such as the economic, education, and agriculture sectors), and flexibility about which health improvements to prioritize.

Other factors also influence the feasibility of implementation at different levels. For example, the political, economic, and social context may inhibit participation if there is a history of repression. Participatory processes can create tensions and conflicts when existing structures and norms are inequitable, and facilitators must be prepared to resolve conflicts and protect vulnerable groups from backlash.

Box 3

Elements of Community Participation

The Community Possesses:

- **Health Knowledge**—basic technical information on causes, prevention, and treatment of health problems.
- **Planning and Management Skills**—analysis of assets and problems, understanding views of different community groups, gender analysis, problemsolving, action planning, coordination, evaluation, information access, and resource mobilization.
- **Facilitative Leadership and Communication Skills**—responsive leadership, representation of diverse interests, equitable approaches to including disenfranchised groups, group facilitation, conflict resolution, and participatory learning methods.
- **A Commitment to Collaboration**—advocacy, negotiation, partnership cultivation, and journalist/media relations.

Health Workers Possess:

- **Health Knowledge**—credibility as a provider of advice and service.
- **Knowledge of the Community**—understanding community perspectives on health, and identification of community resources and strengths; and respecting community members regardless of wealth and/or education.
- **Planning, Communication, and Collaboration Skills**—dialogue facilitation, participatory analysis and planning, mutual respect and learning, cultural competence, consensus-building, problemsolving, advocacy, and cross-sector collaboration.
- **Facilitation and Mentoring Skills**—working in partnership, acting as a catalyst by stimulating analysis of assumptions held in the community.

Source: Judi Aubel, *Communication for Empowerment: Strengthening Partnerships for Community Health and Development* (New York: UNICEF, 1999).

Figure 1

Community Participation Program Development Continuum

	1 (low)	2 (moderate)	3 (high)	4 (highest)
Equity/ Inclusiveness	Health professionals assume leadership for program activities. Community leaders are primarily or exclusively men who represent traditional power structures.	Community leaders involved in program activities rely heavily on direction from health professionals and rarely have input in program decisions. Community leaders are aware of interests of various community groups.	Community leaders and representatives work in partnership with health professionals to participate in decisions. Community leaders regularly confer with representatives of all community groups (ethnic, women, poor) to include their perspectives in decisionmaking.	Communities create a representative process for community leadership positions. Women and other vulnerable groups play a strong role in health program initiatives.
Management	Health professionals identify needs, and develop and manage health services. Communities depend primarily on resources provided by the health system to carry out activities. Health professionals generally direct community contributions and input.	Community members have basic needs-assessment, planning, and/or implementation skills. Decisions are largely made by health professionals who provide guidance and make primary decisions about program activities and resource use.	Community members have strong needs-assessment, planning, management, and resource mobilization skills. Communities may be able to advocate for their needs, mobilize and access human and other resources from institutions outside the community. Communities make decisions in partnership with health professionals through ongoing mechanisms. Health professionals provide ongoing support and guidance to strengthen community capacity and preventive health knowledge.	Community members are highly skilled in all phases of community health needs assessment, planning, and management. Communities effectively mobilize and access resources, advocate for their needs, and create partnerships to collaborate within and outside the community. Community members have strong knowledge of preventive health practices. Community members play a lead role in identifying program priorities.
Process and Outcome Evaluation	Communities have no opportunity to give feedback about the program and are not aware of program evaluation design or results.	Evaluators and health professionals make decisions about evaluation design and interpretation of results. Evaluators may explain the process to community members whose perspectives regarding evaluation design may be included. Results may be presented to the community.	Communities are active in deciding what to evaluate, and/or in gathering and interpreting information to evaluate program effectiveness. Mechanisms are developed to facilitate community collaboration with health professionals and evaluators to improve activities. Communities receive technical advice and ongoing support for evaluation.	Communities are active in evaluating effectiveness of programs and deciding how to make improvements. Communities seek advice on their own initiative from health professionals and access evaluation expertise as needed.

Sources: Judi Aubel, *Communication for Empowerment: Strengthening Partnerships for Community Health and Development* (New York: UNICEF, 1999); Susan B. Rifkin, Frits Muller, and Wolfgang Bichmann, "Primary Health Care: On Measuring Participation," *Social Science and Medicine* 26, no. 9 (1988): 931-40; Alvarez Reyes et al., "Methodology to Describe Community Health Participation" (in Spanish), *Cuban Public Health Journal* 22, no. 1 (1996): 5-6; and United Nations Development Program (UNDP), Office of Evaluation and Strategic Planning, *Who Are the Question Makers? A Participatory Evaluation Manual* (New York: UNDP, 1997).

Experiences From the Field

While endorsement of participatory health development has been strong since the 1970s, few programs have rigorously evaluated the health outcomes of participatory efforts. The following five programs were chosen because they have evidence of impact and highlight the links between participation and health. And the Nepal case study is one of a few examples of a project that was developed explicitly to evaluate the influence of participatory processes on health. These programs also make it easier to understand the differing elements of participation across a variety of health issues.

These programs showcase the potential of participatory approaches for contributing to a reduction in the global burden of neonatal mortality, child morbidities, culturally circumscribed health conditions, and environmental health issues.

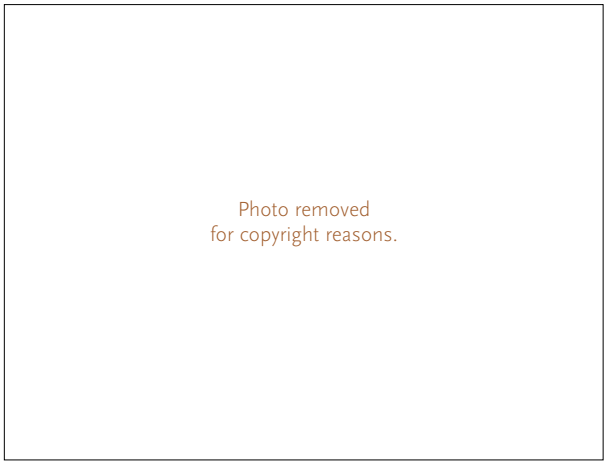
Each case study received a "participation score." This score is the sum of the scores in each of the three essential processes—equity/inclusiveness, management, and process and outcome evaluation—described in Figure 1. This score could be as high as 12. The scores are not value judgments on the programs. A higher score does not imply a better project or an improved health outcome; only a higher degree of participation. Figure 15 (page 18) presents the participation scores for each case study in each of the essential processes.

Case Study:
Addressing Neonatal Health in India: The Society for Education, Action and Research in Community Health

Background

Like most developing countries, India has been able to reduce infant mortalilty, going from 90 deaths per 1,000 live births in 1990 to 64 per 1,000 live births in 2005. However, most often, improvement has occurred mostly in the post-neonatal stage; neonatal mortality (within the first 28 days) remains high. With a neonatal mortality rate (NMR) of 43 deaths per 1,000 live births, India lost 1 million newborns in 2000—27 percent of the world total.[28] Half of these newborn deaths are due to neonatal infections.

SEARCH (Society for Education, Action and Research in Community Health) is a nongovernmental organization in rural Gadchiroli, Maharastra.[29] The founders of SEARCH based their work on the social philosophy of Mahatma Gandhi. They have medical education from India and training in public health from Johns Hopkins University in the United States. Since 80 percent of babies in rural India are born at home, SEARCH decided that the risks to neonatal health and survival must be addressed in that setting. Building on research already completed, and on their strong positive reputation in the community since the late 1980s, SEARCH conducted a field trial of a new home-based neonatal care (HBNC) package in Gadchiroli. This package provided low-cost, primary care to neonates using the skills, capacities, and assets available in villages.[30]



Since 80 percent of babies are born at home in rural India, community-level interventions are key to their survival.

Participatory Approach

SEARCH's work has three objectives: to provide health care to local populations, to offer training and education in health, and to conduct research to shape health policies. The staff state as a principle that research should take place with the participation of local people—"Research, not *on* people, but *with* people."

In this context, the SEARCH staff identified neonatal survival as a problem, and worked to convince the community (particularly the men) to adopt it as a priority. Community consultation was a key ingredient for success: "Neonatal care was not a high priority for the adult males who usually articulate community needs." Families generally had a fatalistic outlook toward newborn death; SEARCH staff had to sensitize them to the needs and

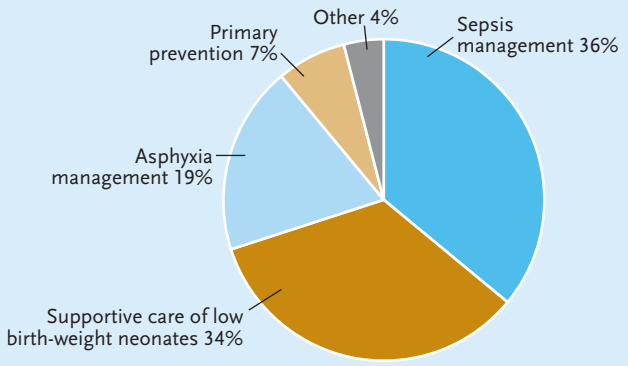
Figure 2

The Community Health Action and Research Approach of SEARCH

Live close to communities
↓
Listen to their health problems
↓
Provide appropriate health care for the immediate needs
↓
Conduct quality anthropologic and epidemiological studies on the health problems with the involvement of local people
↓
Dialogue with communities and inform them about the evidence
↓
Based on the evidence and the dialogue, select a priority problem for solving
↓
Develop a low-cost solution, appropriate to the rural setting that empowers local people in solving their health problem
↓
Design and conduct field trials with scientific rigor
↓
The local community benefits from interventions, resulting in improved health
↓
Publish to inform the scientific community
↓
Demonstrate the model and the evidence to policymakers
↓
Influence health policy—nationally and internationally
↓
Go back to communities for a dialogue on the next problem

Figure 3

Reduction in Neonatal Mortality During SEARCH Intervention, 1996-2003



Source: Abhay T. Bang et al., "Neonatal and Infant Mortality in the Ten Years (1993 to 2003) of the Gadchiroli Field Trial: Effect of Home-Based Neonatal Care," *Journal of Perinatology* 25, suppl. 1 (2005): S92-107.

possibilities of the new HBNC intervention.[31] Thus, the initial impetus for the project came from SEARCH leadership, who then consulted with and convinced the villagers to conduct the HBNC trials in their homes. The elected village council *(gram panchayat)* and the women's groups *(mahila mandals)* in each village were asked to sign a resolution to support participation in the study, and all the villages signed. Clearly, the initial decision-making and choice of intervention did not originate in the community; however, SEARCH's successful history of working to improve people's health led to a participatory action research process.

The SEARCH team has a clear system for carrying out their work. Figure 2 demonstrates how they articulate that process.

The SEARCH goals clearly and explicitly reach beyond the borders of Gadchiroli. The SEARCH team also uses sophisticated scientific methods to test their intervention models, which may not be highly participatory. The study design compared intervention and control groups to clearly identify changes in health status resulting from the project.

The HBNC package improved neonatal care through trained village health workers and trained birth attendants in 53 villages. The package involved:

- Educating new mothers about health;
- Providing immediate care to newborns, including resuscitating newborns who are not breathing regularly after birth;
- Supporting breastfeeding and maintenance of infant body temperature;
- Providing increased vigilance for problems in preterm and low birth-weight infants;
- Recognizing danger signs that suggest serious newborn infections and treating them with antibiotics; and
- Giving village health workers the ability to dispense antibiotics in family homes—previously the exclusive domain of doctors in health care facilities.[32]

Outcomes

By the program's third year, newborn mortality had fallen by an impressive 60 percent in the intervention areas, and there was a significant reduction in various newborn and maternal illnesses. After 10 years, these results were sustained. SEARCH's analysis shows that the neonatal mortality rate in the intervention area declined from 62 deaths per 1,000 births in 1993-1995 to 25 per 1,000 births in 2001-2003. During the same 10-year period, the NMR in the control area increased from 58 deaths per 1,000 births to 64 deaths per 1,000 births. Reductions occurred for early NMR (a 64 percent decline), and late NMR (an 80 percent decline). The total reduction in neonatal mortality during the

intervention (1996 to 2003) was due to three major interventions: sepsis management, supportive care of low birth-weight neonates, and asphyxia management (see Figure 3).

The SEARCH process has saved lives and has influenced newborn health projects in India and other countries. The intervention occurred in the community and depended on care delivered in the home by village health workers and family members. Its success depended on local participation that increased over time. However, the program was originally conceived based on needs identified by SEARCH, not derived from the community. The evaluation was not designed to assess community participation, but rather to understand the change in health status. From the outset, SEARCH implemented activities with a health goal in mind. Community participation was most evident in the details of intervention design and implementation, especially the key role of village health workers in the delivery of the intervention.

Since the original pilot intervention almost 10 years ago, SEARCH continues to implement and monitor neonatal interventions in the region, providing a longer horizon to judge the effectiveness of home-based neonatal care interventions (see Figure 4).[33]

Figure 4
In Brief: SEARCH

Participation score = 8	
Equity	• Participatory interventions are a core philosophy of the implementing agency.
Management	• The intervention was home-based. • The elected village council *(gram panchayat)* and the women's groups *(mahila mandals)* in each village signed a resolution to support participation in the study. • Village health workers played a key role in delivery of the intervention.
Evaluation	• Reduction in neonatal mortality was significant. • Project has served as a model for other areas of the country and other countries.

Case Study: Improving Water and Sanitation in India

Background

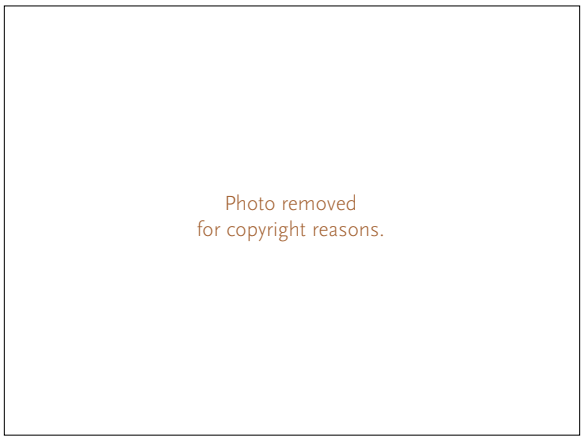
Prior to the late 1980s, the Indian state of Kerala faced two problems: seasonal drought and drinking water salinity in coastal regions. Drinking water wells became contaminated because of their proximity to latrines, leading to a high rate of child morbidity. Thus, the need for potable water was acute in rural areas, especially in the summer months.

Low awareness about safe water handling and use (such as boiling water before drinking) was a key problem, despite a literacy rate of about 90 percent for both men and women and a relatively good, accessible health care system. The state has a history of strong grassroots organizations, and active village-level democratic institutions *(panchayats)*. These assets provided a good starting place for a solution.

Participatory Approach

In the late 1980s, the Dutch and Danish governments supported water and sanitation programs to improve latrines and piped water. The program was implemented by the Kerala Water Authority (KWA), a government corporation. Although the community was not involved in the needs assessment, KWA staff worked with the *panchayats* and other grassroots organizations to implement the project and manage latrines and piped water (standpipes).[34]

KWA did emphasize community participation in deciding on the location of the standpipes. Out of concern that "elites" would use their influence to choose the standpipe locations, the KWA staff aimed for a transparent and democratic process, and involved the community in mapping each ward to show the proposed location of the



Clean water is essential for good health. In Kerala, India, a creative mapping process brought clean water to the community in a way that actively involved women in decisions.

standpipes and the location of all houses (indicating differing income groups), roads, schools, hospitals, and childcare centers. The maps were displayed in the *panchayat* offices, and community members were invited to give suggestions or voice objections. There were open meetings to air disagreements or concerns. As a result, many of the original standpipe locations were changed.

Because women generally perform most of the water collection, the KWA staff sought their participation in decisions and implementation. Women implemented well chlorination, and local women masons were trained on how to construct latrines, further contributing to their incomes. Locals became trainers in health awareness. The program worked with schools and village-level workers *(anganwadis)*—who provided care and gave meals to children under India's Integrated Child Development Scheme—to disseminate health information through children to their families.

Figure 5

Outcomes of KWA Water Program Compared With Control Area

Percent of population who:	Intervention Area	Control Area
Judged the water quality to be good or satisfactory	60	40
Used new piped water	39	25
Filtered water before drinking	37	3
Indicated they would fix the standpipe if the caretaker was not available	56	37
Reported the latrine was used by children	85	44
Reported that water was available to flush the latrine	99	44
Expressed satisfaction with the project	75	30

Source: Sankaran Manikutty, "Community Participation: So What? Evidence from a Comparative Study of Two Rural Water Supply and Sanitation Projects in India," *Development Policy Review* 15, no. 2 (1997): 115-40.

Figure 6

In Brief: KWA Water Program

Participation score = 8	
Equity	• Women were involved in decisionmaking and program implementation. • The community participated in mapping each ward to show the proposed location of the standpipes in relation to homes and key village buildings, and gave feedback on proposed locations.
Management	• Village *panchayats* took leadership in implementing and managing latrines and standpipes. • Women implemented well chlorination and were given training on how to construct latrines. • The program worked with schools and village-level workers *(anganwadis)* —who provided care and gave meals to children under India's Integrated Child Development Scheme—to disseminate health information through children to families.
Evaluation	• Community members did not participate in the process and outcome evaluation.

Outcomes

Outcomes were measured through structured surveys and semistructured interviews with villagers, as well as through observation by the project evaluators. Random sampling was used to select two villages, and respondents (one-half men and one-half women) were also chosen randomly for each ward of the community. The results were compared to two randomly selected villages in another local program as a control group (see Figure 5). The program in the control area was designed by engineers without community participation, did not include latrine construction, and did not build health awareness of the community. In both programs, the *panchayat* was expected to draw from overall tax revenues to recover costs of each standpipe in the villages.

The project had several similarities to SEARCH. First, the KWA water project stands out for its representative and inclusive nature (see Figure 6), even though it did not involve the community in the initial needs assessment. The program built on community knowledge to make the design more locally appropriate, equitable, and feasible. Raising health awareness was integrated into local institutions to help generate demand and understanding before the latrines were complete. Second, the community perceived a benefit to participation, felt ownership and responsibility for the water and sanitation improvements, and made efforts to maintain and fix them. Kerala's high literacy rates and local democratic institutions favored a participatory approach that helped prevent elite domination. Women, who often have little decisionmaking power in the villages, participated in the decisionmaking as well as in implementation. Third, community members did not participate in the process and outcome evaluation. Other water and sanitation programs in Asia with similar elements of community participation—such as involving the community and women in all phases of decisionmaking—had similar results.[35]

Case Study:
Adolescent Reproductive Health in Nepal

Background

Few rigorous efforts have been undertaken to evaluate the success of participatory processes in adolescent reproductive health programs. EngenderHealth and the International Center for Research on Women (ICRW), in collaboration with Nepali partners, designed and conducted a research project in Nepal between 1998 and 2003 to improve adolescent reproductive health within target communities, while at the same time evaluate the influence of participatory approaches.[36]

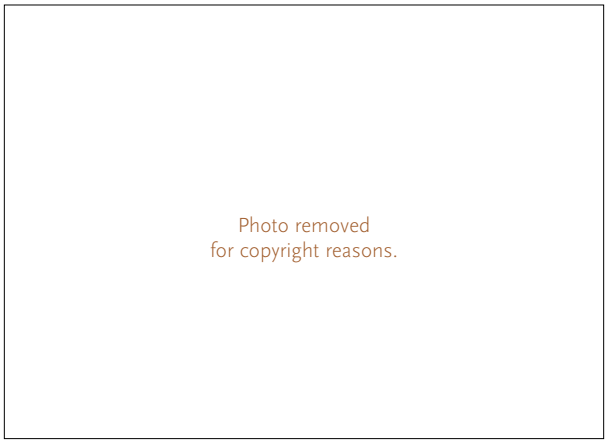
Young Nepali women face a range of disadvantages. Illiteracy among girls ages 10 to19 is 51 percent, compared with 26 percent among boys. Marriage is nearly universal, with girls marrying, on average, at age 16. Demographic and Health Survey data indicate that 52 percent of girls have begun childbearing by the age of 20, an important contributing factor to the country's high maternal mortality. At 539 maternal deaths per 100,000 live births, Nepal has the highest maternal mortality ratio in South Asia.[37]

Little sex education is provided in schools, and reproductive health is not openly discussed in families. Girls have less access than boys to formal institutional structures, such as schools and health care systems. As a result, girls do not receive accurate health information through formal communication networks. Furthermore, the design and delivery of appropriate services for adolescents have been constrained by traditional beliefs. Because of these inadequate or ineffective services and information, young people in Nepal may experience negative reproductive health consequences, including unplanned pregnancies and HIV/AIDS.

Participatory Approach

The project goals did not emerge directly from a felt need in the community. EngenderHealth and ICRW worked with local NGOs to choose rural and urban communities for the intervention and control groups. The study directors assumed that community participation would grow over time. Community members were researchers during parts of the monitoring and evaluation processes.

The project team defined community participation more broadly than just involvement by youth, and made efforts to engage the whole community because youth are strongly controlled by adults. Thus, adult approval and buy-in was essential for achieving youth participation and the desired behavior change. Moreover, changing adult behavior and attitudes is equally, if not more, essential for changing the fundamental factors affecting young people's reproductive health.



In Nepali communities where youth and parents helped design and implement programs, the reproductive health outcomes were better than in communities that used a more traditional approach.

The adolescent reproductive health project was set up with a quasi-experimental study design pairing the participatory approach for research, intervention, monitoring, and evaluation at two intervention sites with a more traditional approach at two control sites. The intervention and control sites each encompassed one rural and one urban area. The two rural sites, each with about 200 households, were located near the Nepali-Indian border. They were selected because they had a secondary school, a range of health service providers including at least one NGO, and access to a main road and electricity. The two urban communities, consisting of approximately 300 households each, were drawn from middle-class suburbs on the outskirts of Kathmandu. They met the basic criteria described above, although in an urban environment this included a more-developed infrastructure and a wider range of options for transportation, schooling, employment, health services, and leisure activities.

Figure 7 (page 12) highlights the differences between how the project operated in the control and intervention sites. Youth reproductive health (YRH) services were offered in both places, but in the intervention sites the community had input into the design and implementation.

Outcomes

Baseline, endline, and process data were collected. The baseline data also served as formative research and provided the basis for the initial needs assessment. Quantitative, qualitative, and participatory methods were employed to gather detailed information on the reproductive health knowledge and practices of young people from a range of perspectives, as well as on the broader social and cultural context that shapes and defines the sexual and reproductive experiences of Nepali youth.

During the project, it became obvious that participation does not mean the same thing in rural and urban

settings. Achieving and maintaining youth and community participation in an urban area is a much more difficult and challenging task than it was in rural areas, for several reasons. In rural areas, a sense of community is prevalent, while in urban areas, the boundaries of "community" are more artificially designed, especially given the greater diversity of urban residents. Urban residents are generally better off financially than rural populations and may not consider themselves in need of the benefits offered by NGO-initiated programs. Moreover, the demands of urban life may leave a person little time to invest in participatory processes; also, participatory activi-

Figure 7

Differences in Community Participation Between Intervention and Control Sites in Nepal

Project Element	Intervention Sites (rural and urban)	Control Sites (rural and urban)
Baseline data collection and needs assessment	• Extensive baseline • Extensive needs assessment • Quantitative, qualitative, and participatory methodologies	• Matching baseline • Limited needs assessment • No participatory methodologies
Intervention framework	• Youth reproductive health defined to include health risk factors, socioeconomic determinants, and social and normative constraints	• Youth reproductive health defined to include only basic health risk factors
Structures and mechanisms	• Structure: Participatory Action Committee consisting of community adults and Adolescent Coordinating Teams of community youth set up early and maintained throughout with increasing authority and decisionmaking • Mechanisms: Frequent creation of task forces, consultative committees, engagement with leaders and stakeholders	• No participatory structures or mechanisms
Intervention design	• Involvement of community in action planning process through sharing and discussion of the needs assessment • Creation of task forces to prioritize and design feasible and desirable interventions	• Interventions designed by professional project team with no community participation
Intervention components	• Package of 8 linked and coordinated intervention components including: direct health programs (adolescent friendly services, peer education and counseling, and education); and indirect programs (adult education and peer counseling, youth development, social norms, economic livelihoods)	• Three components (adolescent friendly services, peer education and counseling, and teacher training) conducted separately
Implementation style	• Participatory • Consultative • Substantial decisionmaking power for community adults and youth	• Didactic • Nonparticipatory
Attention to diversity, differentials, and disadvantaged	• Focus on differentiated needs of disadvantaged population a major program component (gender, rural vs. urban, wealth, ethnicity, marital status)	• Limited attention to differentials
Monitoring and evaluation	• Extensive tracking of implementation processes • Extensive endline evaluation • Quantitative, qualitative, and participatory methodologies	• Matching monitoring and endline measurement with quantitative methods only • No participatory methodologies

Source: Sanyukta Mathur, Manisha Mehta, and Anju Malhotra, *Youth Reproductive Health in Nepal: Is Participation the Answer?* (Washington, DC: EngenderHealth and ICRW, 2004).

ties may be a less attractive source of social expression or cohesion.

The extensive research efforts carried out by EngenderHealth, ICRW, and their Nepali partners revealed that the participatory approach led to more positive results in the broader, more contextual factors that influence YRH—as well as capacity building, empowerment, and sustainability—than in the basic reproductive health outcomes. Figure 8 illustrates these findings.

The participatory approach set the stage for future improvements in YRH in the Nepali context, including age at marriage, initiation of childbearing, prenatal care, institutional delivery, and increased male awareness of the reproductive health needs of women. For example, the proportion of young women seeking antenatal care for a first pregnancy increased from less than one-half to about two-thirds, whereas the control group showed a slight decline.[38]

For basic reproductive health outcomes, the participatory approach was generally more effective than the traditional approach, although not consistently so. For example, results were more positive at the intervention sites on only some of the measures of knowledge of sexually transmitted infections or HIV/AIDS. For some measures (such as contraceptive use), the results were mixed at both sets of sites. However, results on the communication of reproductive health concerns and understanding of sexuality were consistently more positive at the intervention sites. In particular, data from the intervention sites underscore the importance of peers and social networks as critical sources of service provision for young people.

A number of fundamental contextual changes were evident at the intervention sites, including increased secondary schooling for girls and more places to socialize for young men and, in particular, young women. Other changes included higher demand for information and services and better, more specific, in-depth understanding of YRH issues among both youth and adults.[39]

The indicators for education and empowerment showed stronger results than for health outcomes.[40] As in the cases of SEARCH and KWA Water, the project was inclusive and equitable in design and implementation. In contrast, however, the Nepal project used participatory methodologies in all aspects of data collection—needs assessment, and process and impact evaluations, which made this case more truly participatory than SEARCH and KWA Water. However, all three projects imposed externally derived health goals that had to be negotiated with the community.

The continuous and strategic engagement of youth and adult community members was substantially more successful in increasing skills, capacity, and empowerment among youth and adult community members at the intervention sites than at the control sites. As a result, improved skills and capacity, along with more local ownership and authority, have laid the foundations for sustainability (see Figure 9). In particular, diffusion of information and support through social networks is playing a strong role in spreading knowledge and ideas beyond individuals directly targeted by the interventions.

Figure 8

The Impact of the Participatory Approach in Nepal

Outcomes of Interest	Intervention Sites	Control Sites
Sustainability	++++	–
Capacity building and empowerment	++++	–
Broader normative and institutional factors	++++	+
Reproductive health outcomes contextually relevant in Nepal	++++	++
Service availability and access	+++	+
Basic reproductive health outcomes	++	+

++++ Very strong positive effect
+++ Strong positive effect
++ Moderate positive effect
+ Weak positive effect
– Undetermined effect

Source: Sanyukta Mathur, Manisha Mehta, and Anju Malhotra, *Youth Reproductive Health in Nepal: Is Participation the Answer?* (Washington, DC: EngenderHealth and ICRW, 2004).

Figure 9

In Brief: Adolescent Reproductive Health

Participation score = 8	
Equity	• Participatory Action Committee consisting of community adults and Adolescent Coordinating Teams of community youth set up early and maintained throughout with increasing authority and decisionmaking.
Management	• Extensive baseline and needs assessment using quantitative, qualitative, and participatory methodologies. • Involved the whole community in adolescent reproductive health. • Project team assumed that the "highest level" of partnership cannot, and does not have to, be activated at every stage with every activity.
Evaluation	• Community members were researchers during parts of the monitoring and evaluation processes. • Goal of evaluating the influence of community participation in health outcomes.

Case Study:
Family Surveillance in Peru: Working Together to Reduce Risks

Background

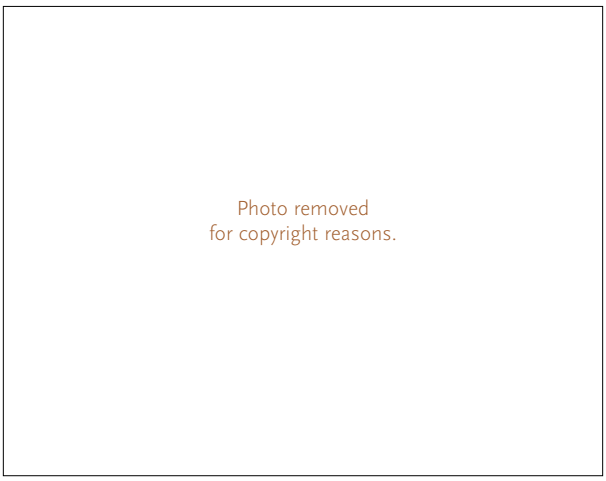
Since 1992, the National University of Trujillo in Peru has implemented the UNI Trujillo Project in partnership with local health workers and community leaders.[41] Undertaken in the Moche district of northern Peru, the intervention is building a new prevention approach to health services by addressing the multidimensional nature of health problems. The project shifts attention from the incidence of illness and injury to a more holistic perspective of the person who is or might become sick or hurt. Using the UNI (*Una Nueva Iniciativa,* "a new initiative") framework developed by the W.K. Kellogg Foundation, the project follows three principles: promote services that meet all the health needs of the population; encourage the participation of community leaders in the design and implementation of health care services; and develop services that address the family context and not just the immediate health needs of individuals.[42]

The project was designed to operationalize the concept of "Whole (or Total) Care," with the full engagement of health service providers, the target population, community leaders, and researchers. Moche is located four miles from the city of Trujillo. The population is composed of low-income, native-born citizens, and migrants from rural highlands. Before the project began, health services were curative and fragmented, and covered only 40 percent of the population. Patients received only targeted interventions, without any effort to identify the full set of health risks or conditions that were key, though often subtle, aspects of their health status.[43]

Participatory Approach

The UNI Trujillo project took a participatory approach from the beginning, involving the community in discussions about the "Whole Care" principles and giving participants a chance to understand a modern framework for health care and the time to think about better ways to manage their own health. Community leaders from all local groups, including women, played strong roles in decisionmaking and community activities. Mixed teams of health workers and community members defined the actions to improve their health status and conducted activities.

The UNI Trujillo program's initial design for specific activities was open-ended: Everything was negotiable except the UNI principles. The UNI program became well known for its "endless workshops" to explore problems, set priorities, and propose activities. The design



A project in rural Peru worked with health providers and community members to redefine health care goals and successfully changed the way services were delivered.

required surveys, focus group interviews, and other qualitative and quantitative data collection. As the local teams gathered and reviewed the data, they became increasingly aware of problems in the local health conditions and services (see Box 4).[44]

The Kellogg Foundation provided strong technical support. Critical feedback, policy impact analysis, and strategies for empowering local resources, among others, were addressed at several international workshops for the project's technical team. Similarly, the project team worked to strengthen the capabilities of community members. Many of the project's tools and procedures grew out of questions asked by the community leaders.

The primary intervention grew out of the community's expressed desire to improve the health status of its children, to protect them from health risks. Communities initially conceptualized and implemented an integrated

Box 4

A Key Turning Point

While collecting data, local teams were surprised to learn from a survey that Moche babies were no longer being born in Moche, even though the community is very proud of its heritage. Instead, babies were being born in the nearest city because of parents' lack of trust in Moche's health services. This simple finding became the turning point for dramatic changes in the local maternal and childcare facilities, including reclaiming an unused local facility that had been donated to the Ministry of Health. The community used that building to redesign maternal and child health services, developing the first community-designed maternity clinic in the country, complete with a well-organized waiting room and a separate space for educational purposes.

"child protection" intervention that included key child health measures such as full immunization, breastfeeding through six months of age, regular height and weight checks, ability to manage diarrhea or acute respiratory infection, and ability to provide the appropriate nutrients according to the child's age. Community cohesion on the importance of child health was strong and evolved into a comprehensive approach that encompassed the health of the child within the family. The child protection package was thus expanded to address the needs of a healthy family in a holistic manner.[45]

The family protection package was both a major outcome and additional comprehensive intervention that sought to help families minimize health risks—or in the project's terminology, "achieve protection." This package was broad in scope and customized for each family, including educational activities. Services were prioritized according to an evaluation of health risks within households, such as a child under age 1, a pregnant woman, more than four children, a history of domestic violence, or alcoholism.

Health workers partnered with community leaders and researchers to identify the best means for addressing needs. Some situations required health service from medical personnel, but other problems, such as a father's drinking habits that harmed his family, became the responsibility of neighborhood organizations. Some preventive measures became the responsibility of the mother or another family member, while other issues needed the guidance of trained community health workers.

These efforts to relocate the focus of the local health services resulted in "Family Surveillance," an innovative approach carried out by neighborhood representatives in partnership with health workers. Neighborhood representatives developed these surveillance plans within the section of the community where they lived. Family surveillance included the family protection package described above as well as better integration of households into the health system through management of clinical records according to families, followup systems, and evaluation workshops.[46]

Outcomes

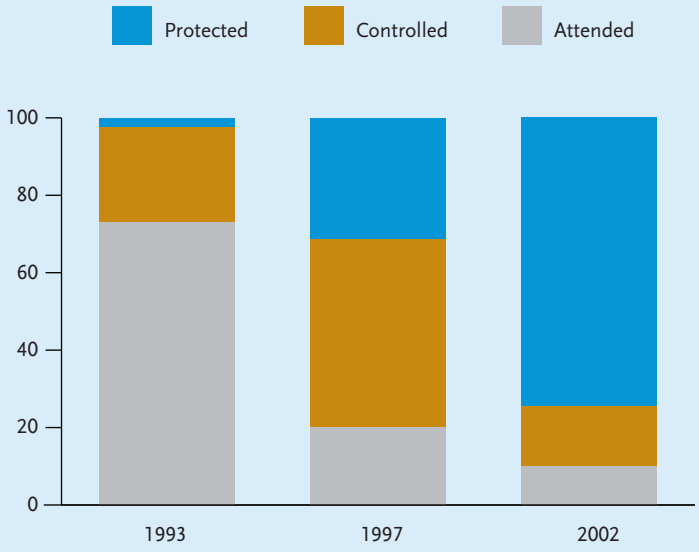
The major project outcome was a reorientation of health services from a focus on treating individual diseases to a family protection approach designed to promote an acceptable level of protection against prevailing local risks and diseases ("attended"). The goal of family surveillance was to monitor and address each family's health status in a holistic way. An evaluation of the health impacts of the family surveillance approach is still underway. However, Figure 10 shows a dramatic increase in the proportion of children "protected" against risk, along with a concomitant decline in those merely treated for specific diseases ("attended"). For example, in 1993 less than 10 percent of the children were "protected," and most of the children were "attended." As the project progressed, children who were "controlled" and "protected" increased, and by 2002, the level of "protected" had risen to over 70 percent.

These initiatives have buffered Moche from major diseases, such as malaria, dengue, and cholera, that have affected neighboring towns. Newborn survival has increased, and pneumonia and diarrhea in infants have declined (pneumonia went from 4.0 percent of all respiratory diseases in 1995 to 0.3 percent in 2000; severe diarrhea from 15 percent of all diarrheas in 1995 to less than 3 percent in 2000).[47]

The UNI Trujillo project employed a participatory process that was highly representative, with community leaders intimately involved (see Figure 11, page 16). In contrast to the SEARCH, KWA Water, or Adolescents projects, UNI Trujillo involved community members from the beginning in identifying priorities and developing the intervention package. Community participation was also high in the management and implementation aspects of the project, as it was in the other case studies. Community members also participated in program evaluation workshops. One limitation of the project's evaluation is the lack of a control group to contextualize the program's positive health and nonhealth results.

Figure 10

Level of Protection in Children Under Age 1 in Moche District, Trujillo, 1993–2002



Attended: Proportion of children under age 1 who received only curative health services.
Controlled: Proportion of children under age 1 who received curative and preventive health services.
Protected: Proportion of children under age 1 who received curative, preventive, and risk-reduction health services.

Source: Ricardo Dios et al., *Health Services Model Developed With the UNI Trujillo Project in Moche* (in Spanish), Universidad Nacional de Trujillo, 1998.

Figure 11

In Brief: UNI Trujillo

Participation score = 10	
Equity	• Community leaders came from all community subgroups. • Women played strong roles in community activities and decisionmaking. • Health professionals, community health workers, and community members were equally engaged in efforts to address health issues.
Management	• Formative research was conducted in conjunction with the community to gather relevant qualitative and quantitative data to assess the assets and needs of the community. • The project had a holistic child health approach that evolved into a holistic family health approach, integrating prevention, treatment, and risk-reduction services and tailored to each family's needs. • A "Family Surveillance" package (intervention) provided a collective approach to disease surveillance, education, prevention, and treatment. • Planning for and implementing the intervention package was time-consuming and required a lot of effort and consultation from all those involved.
Evaluation	• Community members participated in program evaluation workshops.

Figure 12

TOSTAN's Community-Based Education Model

Phase 1: Village committee is established to adapt and manage the program.

Phase 2: A group of participants enrolls in the educational program.

Phase 3: Each program participant selects one other person with whom to share knowledge.

Phase 4: Program participants organize a process of social mobilization. Participants identify subjects for public discussion to expose the entire village to the program. Discussion leaders seek the support of the community for denouncing harmful practices (including FGC).

Phase 5: If the community expresses support, its leaders conduct educational activities in neighboring villages. At intervillage meetings, support is sought from communities with whom family ties exist.

Phase 6: A group of villages organizes a public declaration to indicate their collective intention to abandon harmful practices.

Source: Nafissatou J. Diop et al., *The TOSTAN Program Evaluation of a Community-Based Education Program in Senegal* (New York: Population Council, GTZ, TOSTAN, 2004).

Case Study:
Abandoning Female Genital Cutting in Senegal

Background

TOSTAN, an organization based in Senegal, has achieved notable success in facilitating the abandonment of female genital cutting (FGC), a procedure that involves removing some or all of the external female genitalia.[48] Since 1997, over 1,000 villages in Senegal and Burkina Faso that were involved in TOSTAN's community-based participatory educational program have publicly declared an end to harmful traditional practices including FGC and early or forced marriages. In 1988, the organization started its activities in the Kolda region of Senegal, where nearly 60 percent of rural residents live below the poverty line and illiteracy affects 90 percent of the population. An estimated 88 percent of women in Kolda have experienced FGC. To address these and other challenges, TOSTAN began its work in 20 villages. The success of the program—and a resulting influx of resources—has led to its steady expansion.

Participatory Approach

Although best known for its work on FGC, TOSTAN's mission is broader—"to contribute to the human dignity of African people through the development and implementation of a non-formal, participatory education program in national languages."[49] TOSTAN's model starts as an education program with four modules: hygiene, problem-solving, women's health, and human rights. The model includes support for community mobilization and public declarations. (Public declarations are seen by TOSTAN to be an essential part of the process of social transformation, to enable people to renounce a traditional practice without fear of social stigma.) TOSTAN's participatory approach is based on the African tradition of participation and respectful consultation of all those concerned and affected by the implementation of any decisions or policy. In the TOSTAN model of community participation, villagers themselves determine their future (see Figure 12).

To the traditional African style of consultation, TOSTAN adds a modern view of women's empowerment and the role of literacy and education in achieving equity. Participants, mostly women, analyze their own situation more effectively and find the best solutions for themselves. TOSTAN's work on FGC evolved from its education approach—the participants decided to abandon FGC.

Outcomes

An evaluation by the Population Council highlights that TOSTAN's program followed all six phases of implementation outlined in Figure 12, and was consistent with the

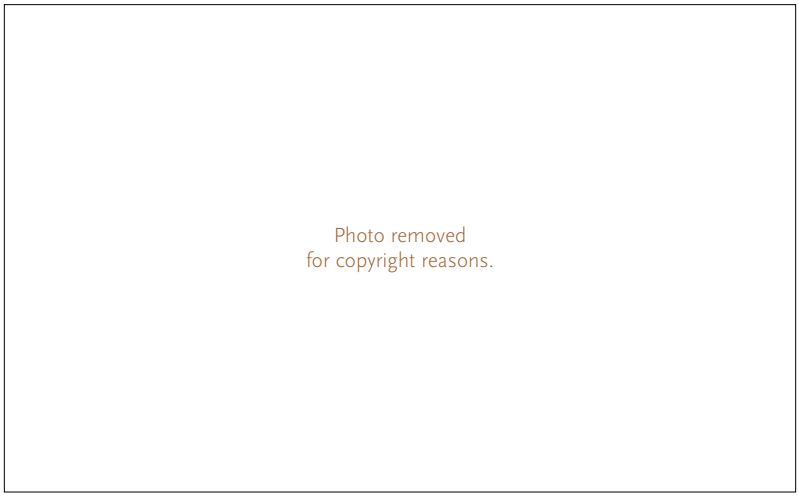
theory of social change in an African context, as articulated by TOSTAN leadership.[50] The Population Council assessed the health impacts in 20 of 90 villages in the Kolda region.[51] All women and men participating in the education program were interviewed before and after the intervention, and again two years later, to measure women's and men's awareness, attitudes, and behavior concerning reproductive health (RH) and FGC. For comparison, a group of women and men from 20 similar villages that did not receive the education program were interviewed at the same time.

According to the evaluation, TOSTAN's education program significantly increased the awareness of women and men about human rights, gender-based violence, FGC, and reproductive health. Awareness of human rights, violence, and FGC also increased in the control site, but to a lesser extent. The consequences of FGC were better known in the intervention villages, as were issues concerning contraception, pregnancy surveillance, and child survival. In general, women's knowledge improved more than men's, except for knowledge about sexually transmitted infections and HIV.

During this time, support for FGC declined in the region, possibly reinforced and accelerated by the TOSTAN program. Figure 13 presents results from the intervention group and the control group. After the education program, approval of FGC declined by 50 percent among the women who participated, and 40 percent among the partners (friends of the participant selected by the participant with whom to share information), highlighting a "trickle-across" effect. The evaluation also found a significant decline of 30 percent in the control group, although the level of approval remained higher than in the intervention group.

To test the impact of the program on community members' willingness to abandon FGC, the proportion of participants' daughters aged 0 to 10 years whose parents reported they had been cut was used as the primary outcome indicator. The prevalence of FGC reported among these daughters decreased significantly, from 7 in 10 at the baseline to 1 in 10 among participants, and 2 in 10 among participant-partners.

The TOSTAN intervention is highly participatory across the three aspects of this *Bulletin's* program development continuum—equity, management, and evaluation (see Figure 14). Like the other case studies, the TOSTAN program involves community leaders and seeks to affirm that all community members are represented and included. Community members participate in planning, management, and decisionmaking; and they provide evaluative feedback on the success of the program that determines the location of the next intervention. Like UNI Trujillo, TOSTAN involved the community in the needs assessment. TOSTAN scored slightly lower in terms of the community's participation in evaluation design and analysis.



As the result of participation in a community-based literacy project in rural Senegal, women became activists in efforts to abandon female genital cutting.

Figure 13
Results From Evaluation of TOSTAN's Intervention

	Intervention Group		Control Group	
Percent of population who(se):	**Baseline**	**Endline**	**Baseline**	**Endline**
Approved of FGC	72	16	89	60
Partner approved of FGC	65	14	86	54
Would cut daughters in future	71	12	89	54
% of girls ages 0-10 not cut	46	60	48	48

Source: Nafissatou J. Diop et al., *The TOSTAN Program Evaluation of a Community-Based Education Program in Senegal* (New York: Population Council, GTZ, TOSTAN, 2004).

Figure 14
In Brief: TOSTAN

Participation score = 11	
Equity	• Each program participant selected one other person with whom they shared what they learned. • Approach was based on the African tradition of participation and respectful consultation of all those concerned.
Management	• Intervention was nonformal community-based participatory education program. • Intervention added modern view of women's empowerment, and the role of literacy and education in achieving equity. • Public declarations were an essential component of intervention.
Evaluation	• Community members provided evaluative feedback on the success of the program that determined the location of the next intervention.

Figure 15

Community Participation Program Development Continuum Score

Essential Process	SEARCH (India)	Water (India)	Adolescents (Nepal)	UNI Trujillo (Peru)	TOSTAN (Senegal)
Equity/Inclusiveness	3	3	3	3	4
Management	3	3	2	4	4
Process and Outcome Evaluation	2	2	3	3	3
Total Participation Score	8	8	8	10	11

Note: The numbers represent the participation scores for each case study on each of the three essential processes. The scores are based on the Community Participation Program Development Continuum (see Figure 1, page 6), and were derived from a subjective determination of whether a project was low (1), moderate (2), high (3), or very high (4) in that process. The total participation score could be as high as 12.

Analysis of Levels of Community Participation

Each case study was scored according to the Community Participation Program Development Continuum, a subjective determination of whether a project was low, moderate, high, or very high in each of the three areas. A "1" corresponds to the lowest level and a "4" corresponds to the highest level of participation. The total participation score could be as high as 12.

As shown in Figure 15, TOSTAN scored the highest on community participation, with UNI Trujillo a close second. All five case studies were high on equity/inclusiveness, and TOSTAN, UNI Trujillo, and the Adolescents projects involved community members in needs assessments. Community participation was strong across all five case studies for program planning, management, and decisionmaking; and community members were key to program implementation. However, community participation in the design or analysis of program evaluation was lower except in the Adolescents project in Nepal, which was designed explicitly to evaluate community participation. The lack of participation in evaluation may have implications for long-term program sustainability. The key difference in total participation scores derived from the efforts of TOSTAN and UNI Trujillo to work on health goals identified by the community.

In some cases, community participation grew over time. In Nepal, for example, the project team assumed that the highest level of partnership cannot, and does not have to, be activated at every stage with every activity. Knowing that an intensive level of interaction may require resources, skills, and time beyond the capabilities of the project team or community, the project team recognized that community participation could increase over time. Given the existing power structures, capabilities, and community setup, it may not be realistic to expect the full partnership with youth or parents at the very beginning of a project. Moreover, it may even be unrealistic to assume that a full partnership can be achieved in the two- to three-year lifespan of most projects.[52] Indeed, evidence of an increase in community participation can be seen across all case studies, with the exception of TOSTAN (see Figure 16).

Community ownership of a health program derives from a strong participatory process and, at the same time, promotes the full integration of the program and its positive health benefits into the community. The KWA Water and TOSTAN cases both demonstrate such indicators of potential sustainability. In Kerala, community members felt responsible for the maintenance of the new standpipes. In the TOSTAN project, the community's efforts to expand to neighboring villages, where family ties were strong, ensured wider exposure of the educational messages and participatory processes.

In most of these communities, a degree of community mobilization and participation existed prior to the intervention, and helped program development. Where community capacities and assets relevant to health programming did not exist, skills training, such as the geographic resource mapping in the KWA project, was conducted as part of program implementation.

Program and Policy Implications

Policies and programs that include community participation can improve health. The five case studies in this *Bulletin* illustrate several general points about the relationship between community participation and health outcomes, as well as more effective ways to carry out participatory programming.

Health Impacts

Community participation can facilitate improved health status. For example, in SEARCH, after three years of the intervention, the main health outcome—neonatal mortality rate—had fallen by an impressive 60 percent compared to the control area, where the rate had increased. In the case of

KWA Water, key health indicators were better across the board in intervention areas, and in the case of two key indicators—water filtration and use of latrines by children—outcomes were dramatically different (for filtration, 37 percent compared with 3 percent; for use of latrines, 85 percent of children compared with 44 percent). And the TOSTAN intervention resulted in clear shifts in attitudes toward FGC, with approval of the practice declining by 50 percent in the intervention group. Findings from the Adolescents project showed that the proportion of young women seeking antenatal care for a first pregnancy increased from less than one-half to about two-thirds, whereas the control group showed a slight decline.

Health Equity

Participatory programs often lead to improved equity in access to resources and services. Improvements in transparency and accountability can be made in local systems when communities gain knowledge of their rights and develop problemsolving strategies. Each of the case studies was strong on inclusiveness and in the equity aspects of program development. In the case of UNI Trujillo, genuine community participation allowed community members to address the issues important to them, and to use the technical capabilities of their health professionals to mobilize assets and resources. In the TOSTAN and the Adolescents cases, community-initiated changes that resulted from improved skills such as advocacy are pivotal for equity and sustainability. Participation is particularly important for the least powerful members of society, who are most at risk for inequitable and unjust treatment and have the lowest social and health status. Participation provides opportunities for not only new knowledge and skills but also for building confidence to act upon decisions about life improvements. Improved equity and inclusiveness contributes to program effectiveness, as shown in the KWA Water project, which capitalized on women's integral role in water collection and consumption.

Health Professionals

Community participation programs ask as much of health professionals as they do of citizens. Instead of designing and applying specific solutions to single health problems, professionals working under a participatory framework need to be able to communicate effectively with community members and view them as partners in creating solutions. In this context, health professionals need to learn new skills, such as adult learning approaches, conflict resolution, facilitation, cross-sector collaboration, cultural sensitivity, and participatory research and evaluation. In UNI Trujillo, program professionals respected the people with whom they worked and appreciated their cultural context, were cognizant of the benefit of learning from communities, gave communities decisionmaking authority, and changed course as circumstances evolved.[53] Program staff can facilitate rather than direct programs, and can strive for sustainability through community-driven decision and actions. Programs can ensure that communities participate in decisionmaking at all phases (design, implementation, and evaluation), and that the least powerful in communities are well-integrated and represented in leadership positions.

Health professionals must be willing to view health in a holistic way, not soley from a disease-oriented perspective. Many health issues have a societal context that directly or indirectly affects prevention and treatment, as TOSTAN highlights. The design of an intervention in partnership with the community may differ from a medically driven model. Indeed, communities can help identify and solve problems that health services cannot solve alone. Programs may need to adjust to differing contexts, such as differences between communities in rural and urban areas, when programs expand or when broader economic or political changes affect the community.

Trust can be a precursor to, as well as an outcome of, participation. Trust is not traditionally considered in health service design. The community participation process requires working at different paces during different phases. A significant time commitment is needed to build trusting relationships and to develop the skills of both communities and health professionals to work together. In the case of SEARCH, health professionals expanded the trust they had built with the community over many years. Programs that aim for community participation should help the community assess and build upon their current strengths and choose the best ways to improve the relevant skills they lack, through providing mentoring during implementation.

Figure 16

Deepening of Community Participation in Management Over Time

	SEARCH (India)	Water (India)	Adolescents (Nepal)	UNI Trujillo (Peru)	TOSTAN (Senegal)
Community participation in management	2 beginning, 3 end	2 beginning, 3 end	1 beginning, 2 end	2 beginning, 4 end	4 throughout

Research and Evaluation

Data from the case studies suggest that participatory approaches can support health outcomes. But the evidence base is still thin. The case studies show that community participation is a process rather than an intervention.[54] Thus, it is very difficult to define all the factors that contribute to the outcomes. Three projects—Adolescents, UNI Trujillo, and TOSTAN—used participatory processes in both the needs assessment phase of program management, as well as at the process evaluation stage. In addition, the Adolescents project was the only project to use participatory methods to conduct the project's impact evaluation. In general, however, most participatory programs have not been evaluated using scientific study designs such as prospective or case-control. Thus, the impact of community participation needs more research. Ideally, evaluations would be able to show comparisons between programs that use participatory approaches and those that do not by using case control studies.

Research needs to be undertaken to better define and analyze the community participation process, including:

- Better understanding of how community participation leads incrementally to changes such as increased equity and women's empowerment, and in turn how these changes affect health outcomes.
- Effective combinations of quantitative and qualitative methods. Traditional evaluations of programs usually use nonparticipatory methodologies, but a combination of approaches can yield important sources of information about program effectiveness and suggest connections between process and outcomes.
- More studies of cost-effectiveness and sustainability to understand the appropriate inputs needed for health improvements, and the timeframe needed to realize and sustain the outcomes. Future research should investigate the feasibility of scaling up and replicating community participation programs and the conditions needed, such as national policies and structures supporting participatory processes.
- More studies on the tradeoffs of a community participation approach; for example, how time spent in community meetings might take away from time spent in income-earning activities.

Is Community Participation Worth the Effort?

Community participation does yield important benefits in health because the process of involvement is in itself a valuable outcome for communities. Certain health problems are so grounded in community norms (FGC, for example), and their alleviation demands so much from community members and health professionals alike, that a participation component is essential. Community members can become agents of their own health improvement, through self-reflection on individual and community health problems or issues, and through action planning. Community participation approaches build local capacities and assets; health programs thus assume a more authentic nature that, in the long run, have a better chance of sustainability. It remains to be seen, however, whether community participation in identifying and prioritizing health problems at the outset is a determining factor of effective participation.

Nonetheless, community participation advances health equity, so that the disparities between wealthy and poor, and healthy and ill, are lessened in the struggle for global health improvement.

References

1. Majid Ezzati et al., "Selected Major Risk Factors and Global and Regional Burden of Disease," *Lancet* 360, no. 9343 (2002): 1347-60.
2. World Health Organization (WHO) estimates, based on data collected around 1999.
3. John B. Mason et al., "Community Health and Nutrition Programs," in *Disease Control Priorities in Developing Countries*, ed. Dean T. Jamison et al. (New York: Oxford University Press, 2006).
4. WHO Study Group, *Community Involvement in Health Development: Challenging Health Services*, WHO Technical Report Series No. 809 (Geneva: WHO, 1991); and K.W. Newall, "Health by the People," *WHO Chronicle* 29 (1975): 161-67.
5. Susan B. Rifkin, "A Framework for Linking Community Empowerment and Health Equity: It Is a Matter of Choice," *Journal of Health, Population, and Nutrition* 21, no. 3 (2003): 168-80.
6. WHO/EURO Health Evidence Network, "What is the Evidence on Effectiveness of Empowerment to Improve Health?" accessed online at www.who.int, on March 15, 2006.
7. WHO/EURO, "What is the Evidence on Effectiveness of Empowerment to Improve Health?"
8. James H. Price, Joseph A. Dake, and Ruthie Kucharewski, "Assessing Assets in Racially Diverse, Inner-City Youths: Psychometric Properties of the Search Institute Asset Questionnaire," *Family and Community Health* 25, no. 3 (2002): 1-9.
9. John P. Kretzmann and John L. McKnight, *Building Communities from the Inside Out: A Path toward Finding and Mobilizing a Community's Assets* (Chicago, ACTA Publications, 1993); and Price, Dake, and Kucharewski, "Assessing Assets in Racially Diverse, Inner-City Youths."
10. Kretzmann and McKnight, *Building Communities from the Inside Out*.
11. Judi Aubel, *Communication for Empowerment: Strengthening Partnerships for Community Health and Development* (New York: UNICEF, 1999).
12. Elizabeth A. Baker, Marilyn M. Metzler, and Sandro Galea, "Addressing Social Determinants of Health Inequities: Learning From Doing," *American Journal of Public Health* 95, no. 4 (2005): 553-55.
13. UNICEF, *We Will Never Go Back: Social Mobilization in the Child Survival and Development Programme in the United Republic of Tanzania* (New York: UNICEF, 1993); and Carmel Dolan and F. James Levinson, "Will We Ever Get Back? The Derailing of Tanzanian Nutrition in the 1990s," *Discussion Paper* 17 (Medford, MA: Tufts University School of Nutrition Science and Policy, 2000).
14. Paolo Freire, *Pedagogy of the Oppressed*, 20th ed. (New York: The Continuum Publishing Company, 1996).
15. Robert Chambers, *Whose Reality Counts? Putting the Last First* (London: Intermediate Technology Publications, 1997); David Werner, *Where There is No Doctor* (Berkeley, CA: Hesperian Foundation, 2003); Marisol Estrella and John Gaventa, "Who Counts Reality? Participatory Monitoring and Evaluation: A Literature Review," *Institute of Development Studies Working Paper* 70 (1998), accessed online at www.ids.ac.uk, on May 12, 2006; United States Agency for International Development (USAID), *Conducting a Participatory Evaluation: Performance Monitoring and Evaluation TIPS*, Number 1 (Washington, DC: USAID, 1996), accessed online at www.dec.org, on May 12, 2006; and Judi Aubel, *Participatory Program Evaluation: A Manual for Involving Program Stakeholders in the Evaluation Process* (Calverton, MD: MACRO International, 1999).
16. For community organizing, see: Saul Alinsky, *Rules for Radicals: A Pragmatic Primer for Realistic Radicals*, rev. ed. (New York: Vintage Books, 1989); and Valeria Stetson and Robb Davis, "Health Education in Primary Health Care Projects: A Critical Review of Various Approaches," CORE Group (1999), accessed online at www.coregroup.org. For social mobilization, see: UNICEF, *We Will Never Go Back: Social Mobilization in the Child Survival and Development Programme in the United Republic of Tanzania* (New York: UNICEF, 1993).
17. WHO, *Safe Motherhood Newsletter*, Issue 21 (Geneva: WHO, 1996); and F. Farah, "Making a Difference in Emergency Obstetric Care in Uganda," presentation at Safe Motherhood Technical Consultation in Sri Lanka, Family Care International, Oct. 18-23, 1997.
18. Prevention of Maternal Mortality (PMM) Network, "Situation Analyses of Emergency Obstetric Care: Examples from Eleven Operations Research Projects in West Africa," *Social Science and Medicine* 40, no. 5 (1995): 657-67.
19. Susan B. Rifkin, Frits Muller, and Wolfgang Bichmann, "Primary Health Care: On Measuring Participation," *Social Science and Medicine* 26, no. 9 (1988): 931-40.
20. Dara Carr, *Improving the Health of the World's Poorest People* (Washington, DC: Population Reference Bureau, 2004).
21. Judi Aubel, Ibrahima Touré, and Mamadou Diagne et al., "Senegalese Grandmothers Promote Improved Maternal and Child Nutrition Practices: The Guardians of Tradition Are not Averse to Change," *Social Science & Medicine* 59, no. 5 (2004): 945-59.
22. Smarajit Jana et al., "The Sonagachi Project: A Sustainable Community Intervention Program," *AIDS Education and Prevention* 16, no. 5 (2004): 405-14; N.J.D. Nagelkerke et al., "Modelling HIV/AIDS Epidemics in Botswana and India: Impact of Interventions to Prevent Transmission," *Bulletin of the World Health Organization* 80, no. 164 (2002): 89-96; and I. Basu et al., "HIV Prevention Among Sex Workers in India," *Journal of Acquired Immune Deficiency Syndrome* 36, no. 3 (2004): 845-52.
23. Elizabeth Whitmore, "Evaluation and Empowerment: It's the Process that Counts," *Networking Bulletin* 2, no. 2 (1991): 1-8.
24. Susan B. Rifkin, *Health Planning and Community Participation: Case Studies in Southeast Asia* (New York: Routledge, 1985).
25. J. David L. Zakus and Catherine L. Lysack, "Revisiting Community Participation," *Health Policy and Planning* 13, no. 1 (1998): 1-12; Lynne Miller Franco et al., *Social Participation in the Development of MHOs in Senegal* (Washington, DC: PHRplus, Abt Associates, 2005); Lydia Kapiriri et al., "Public Participation in Health Planning and Priority Setting at the District Level in Uganda," *Health Policy and Planning* 18, no. 2 (2003): 205-13;

Ranjani K. Murthy and Barbara Klugman, "Service Accountability and Community Participation in the Context of Health Sector Reforms in Asia: Implications for Sexual and Reproductive Health Services," *Health Policy and Planning* 19, suppl. 1 (2004): 178-86; Population Council India, "Broad Representation Supports Credibility of Village Committees," *OR Summary* 52 (Washington, DC: FRONTIERS, 2005); Ghazala Mansuri and Vijayendra Rao, *Evaluating Community-based and Community-driven Development: A Critical Review of the Evidence* (Washington, DC: World Bank, Development Research Group, 2003); and Jonathan Isham and Satu Kahkonen, "What Determines the Effectiveness of Community-based Water Projects: Evidence from Central Java, Indonesia, on Demand Responsiveness Services Rules and Social Capital," *Working Paper* 251 (College Park, MD: University of Maryland, Center for Institutional Reform and the Informal Sector, 2001).

26. Rifkin, Muller, and Bichmann, "Primary Health Care: On Measuring Participation"; Aubel, *Communication for Empowerment*; Alvarez Reyes et al., "Methodology to Describe Community Health Participation" (in Spanish), *Cuban Public Health Journal* 22, no. 1 (1996): 5-6; and United Nations Development Programme (UNDP), *Who Are the Question Makers? A Participatory Evaluation Manual* (New York: UNDP, 1997).
27. Aubel, *Communication for Empowerment*.
28. Joy E. Lawn, Simon Cousens, and Jelka Zupan, "4 Million Neonatal Deaths: When? Where? Why?" *Lancet* 365, no. 9462 (2005): 891-900.
29. Abhay T. Bang et al., "Methods and the Baseline Situation in the Field Trial of Home-Based Neonatal Care in Gadchiroli, India," *Journal of Perinatology* 25, suppl. 1 (2005): S11-17.
30. Bang et al., "Methods and the Baseline Situation in the Field Trial of Home-Based Neonatal Care in Gadchiroli, India."
31. Bang et al., "Methods and the Baseline Situation in the Field Trial of Home-Based Neonatal Care in Gadchiroli, India."
32. Zulfiqar A. Bhutta, Gary L. Darmstadt, and Elizabeth I. Ransom, *Using Evidence to Save Newborn Lives* (Washington, DC: Population Reference Bureau, 2003).
33. Robert L. Parker, "Guest Editorial for Journal of Perinatology Supplement on the Gadchiroli Field Trial," *Journal of Perinatology* 25, suppl. 1 (2005): S1-2.
34. Sankaran Manikutty, "Community Participation: So What? Evidence from a Comparative Study of Two Rural Water Supply and Sanitation Projects in India," *Development Policy Review* 15, no. 2 (1997): 115-40; and Isham and Kahkonen, "What Determines the Effectiveness of Community-based Water Projects."
35. Isham and Kahkonen, "What Determines the Effectiveness of Community-based Water Projects."
36. Sanyukta Mathur, Manisha Mehta, and Anju Malhotra, *Youth Reproductive Health in Nepal: Is Participation the Answer?* (Washington, DC: EngenderHealth and ICRW, 2004).
37. Ministry of Health (Nepal) et al., *Nepal Demographic and Health Survey 2001* (Calverton, MD: Family Health Division, Ministry of Health, New ERA, and ORC Macro, 2002).
38. Anju Malhotra et al., "Do Participatory Programs Work: Improving Reproductive Health for Disadvantaged Youth in Nepal," *Development Outreach* (Washington, DC: World Bank Institute, 2005): 32-34.
39. Malhotra et al., "Do Participatory Programs Work."
40. Mathur, Mehta, and Malhotra, *Youth Reproductive Health in Nepal*.
41. Ricardo Dios et al., *Health Services Model Developed with the UNI Trujillo Project in Moche* (in Spanish), Universidad Nacional de Trujillo (1988); "Exploding Myths, Finding Solutions to the World Health Care Crisis," Salzburg Seminar 395 (Battle Creek, MI: W.K. Kellogg Foundation, 2002); and Ricardo Dios, "Promotora Model," in *Community Health Workers and Community Voices: Promoting Good Health*, ed. Marguarite J. Ro, Henrie M. Treadwell, and Mary Northridge (Atlanta: Community Voices Publications, 2003): 15-22.
42. M. Kissil and Mario Chaves, *UNI Program: A New Initiative in Health Professionals' Education* (Battle Creek, MI: W.K. Kellogg Foundation, 1994).
43. Ricard Dios et al., "Towards a Local Health System in Moche: Initial Situation of the Health Services" (in Spanish), *Trujillo National University-UNI Trujillo Project, Production Series* 1 (1993), and 2 (1995).
44. Ricardo Dios et al., *UNI Trujillo Project Health System Model in Moche District: Advances in its Systematization* (in Spanish), accessed online at www/prouni.org, on May 25, 2006.
45. Ricardo Dios et al., "Towards a Local Health System in Moche: Integrated Child Care Unit," *Trujillo National University-UNI Trujillo Project, Production Series* 3 (1996).
46. Ricardo Dios, et al., *Family Monitoring System—Family Card* (in Spanish), Universidad Nacional de Trujillo (1999).
47. M. Madueño, J. Alarcón, and C. Sanabria, *Analysis of the Gap and Demand for Health Services to Assign Sector Investments at Medium Term* (in Spanish) (Lima, Perú: ABT, 2003); and Dios et al., *Health Services Model Developed with the UNI Trujillo Project in Moche*.
48. Nafissatou J. Diop et al., *The TOSTAN Program: Evaluation of a Community Based Education Program in Senegal* (New York: Population Council, GTZ, TOSTAN, 2004), accessed online at www.popcouncil.org, on April 3, 2006.
49. "About TOSTAN," accessed online at www.tostan.org, on May 15, 2006.
50. Diop et al., *The TOSTAN Program*.
51. The Supra Regional Project for the Elimination of Female Genital Cutting of GTZ funded implementation of TOSTAN's work in 90 villages in Kolda Region. The Population Council's Frontiers in Reproductive Health Program, with funding from USAID, evaluated the program in 20 villages.
52. Mathur, Mehta, and Malhotra, *Youth Reproductive Health in Nepal*.
53. Dios et al., "Building UNI Trujillo: Lessons Learned," in *The Voices of the Main Characters*, Vol. II (in Spanish), ed. M. Almeida, L. Feuerwerker, and M. Llanos (Sao Paulo, Brazil: HUCITEC, 1999): 59-66.
54. Susan B. Rifkin, "Paradigms Lost: Toward a New Understanding of Community Participation in Health Programmes," *Acta Tropica* 61, no. 2 (1996): 79-92.

Suggested Resources

Aubel, Judi. *Participatory Program Evaluation Manual: Involving Program Stakeholders in the Evaluation Process*. Washington, DC: USAID/Child Survival Technical Support, 2000. Available online at www.childsurvival.com.

Grabman, Lisa Howard, et al. *How to Mobilize Communities for Health and Social Change*. Baltimore: Johns Hopkins Bloomberg School of Public Health/Center for Communication Programs. Available online at www.hcpartnership.org.

JHPIEGO. *Igniting Change! Capacity-Building Tools for Safe Motherhood Alliances*. Baltimore: JHPIEGO, 2005. Available online at www.jhpiego.org.

Kidd, Ross, et al. *Understanding and Challenging HIV Stigma: Toolkit for Action*. Washington, DC: International Center for Research on Women, 2003. Available online at www.sara.aed.org.

Mansuri, Ghazala, and Vijayendra Rao. *Evaluating Community-Based and Community-Driven Development: A Critical Review of the Evidence*. Washington, DC: The World Bank, 2003.

McQueen, David V. "Strengthening the Evidence Base for Health Promotion," *Health Promotion International*, 16, no. 3, (2001): 261-68.

Minkler, Meredith, ed. *Community Organizing and Community Building*, 2d ed. San Francisco: Jossey Bass, 2005.

Murthy, Ranjani K., and Barbara Klugman. "Service Accountability and Community Participation in the Context of Health Sector Reforms in Asia: Implications for Sexual and Reproductive Health Services," *Health Policy and Planning* 19, supp. 1 (2004): 178-86.

Narayan, D. *Empowerment and Poverty Reduction: A Sourcebook*. Washington, DC: World Bank, 2002.

Pan American Health Organization (PAHO). *Healthy Municipalities, Cities, and Communities: Evaluation Recommendations for Policymakers in the Americas*. Washington, DC: PAHO2005. Available online at www.paho.org.

Pretty, Jules N., et al. *Participatory Learning and Action: A Trainer's Guide*, London: International Institute for Environment and Development, 1995.

Rifkin, Susan B., et al. *Partners in Planning: Information, Participation, and Empowerment*. London: Macmillan Education Ltd., 2001.

Sharma, Ritu R. *An Introduction to Advocacy Training Guide*. Washington, DC: Academy for Educational Development. Available online at www.sara.aed.org.

Wallerstein, N., et al. *Problem-Posing at Work: An Educator's Guide*. Alberta, Canada: Grassroots Press, 2004.

White Ribbon Alliance. *Awareness, Mobilization and Action for Safe Motherhood: A Field Guide*. Available online at www.whiteribbonalliance.com

Winch, Peter J., et al. *Qualitative Research for Improved Health Programs: A Guide to Manuals for Qualitative and Participatory Research on Child Health, Nutrition, and Reproductive Health*. Baltimore: Johns Hopkins Bloomberg School of Public Health, 2000. Available online at www.pdf.dec.org.

Recommended Websites

American Medical Student Association, Cultural Competence
www.amsa.org/programs/gpit/cultural.cfm

Eldis Participation Resource Guide
www.eldis.org/participation/index.htm

Harvard Medical School, Cultural Competency in Women's Health
www.hms.harvard.edu/coewh/cultural/modules/index.html

Institute of Development Studies (IDS) Participation, Power, and Social Change Team
www.ids.ac.uk/ids/particip/index.html

Participatory Learning in Action
www.iied.org

U.S. Agency for International Development (USAID), Participation at USAID: Stories, Lessons, Challenges
www.usaid.gov/about/part_devel/docs/anthtoc.htm

U.S. Agency for International Development (USAID), Flexible Fund, Community-Based Family Planning Strategies and Approaches Workshop (May 16, 2006)
www.flexfund.org/workshops/meeting_5_16_2006.cfm

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Youth in a Global World

A new policy brief from the Population Reference Bureau (PRB), *Youth in a Global World*, describes what it is like growing up in today's world, with a special focus on four major experiences in the lives of young people: schooling, health, marriage, and childbearing. Written by Rachel Nugent, director of PRB's BRIDGE (Bringing Information to Decisionmakers for Global Effectiveness) project, this brief highlights changes, cites trends, and suggests ways policies and programs could further improve the lives of today's youth. (June 2006)

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