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.
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### About the Authors

**Kristina Gryboski**, a medical anthropologist, has worked for 15 years as a researcher, program manager, and instructor in global health. Her international experience as a technical adviser and co-author spans a broad range of topics, including maternal and child health, nutrition, gender, female genital cutting, HIV/AIDS, and family planning.

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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.
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. 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. 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. 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. 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. 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.

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. 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. 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. Assets-based community development is internally focused and relationship driven, and acknowledges traditions of organizing and planning.

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). 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. Although participatory processes are costly because of the length of time they require, the results can be more sustainable over the long-term.

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. 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

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**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.

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Rifkin and colleagues posit that in the environmental conservation, while a mayor received two prestigious national awards—for groundbreaking approaches in the integration of reproductive health, family planning, and environment in local governance. 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 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.

**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. 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.

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.

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**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.
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.  

**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.

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. 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.

## Figure 1
Community Participation Program Development Continuum

<table>
<thead>
<tr>
<th>Equity/Inclusiveness</th>
<th>1 (low)</th>
<th>2 (moderate)</th>
<th>3 (high)</th>
<th>4 (highest)</th>
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<tr>
<td>Health professionals assume leadership for program activities. Community leaders are primarily or exclusively men who represent traditional power structures.</td>
<td>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.</td>
<td>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 decision-making.</td>
<td>Communities create a representative process for community leadership positions. Women and other vulnerable groups play a strong role in health program initiatives.</td>
<td></td>
</tr>
<tr>
<td>Management</td>
<td>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.</td>
<td>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.</td>
<td>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.</td>
<td>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.</td>
</tr>
<tr>
<td>Process and Outcome Evaluation</td>
<td>Communities have no opportunity to give feedback about the program and are not aware of program evaluation design or results.</td>
<td>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.</td>
<td>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.</td>
<td>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.</td>
</tr>
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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.

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 mortality, 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. 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, Maharashtra. 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.

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
possibilities of the new HBNC intervention. 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:

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

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).

**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).

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 standpipes.

**Figure 4**

<table>
<thead>
<tr>
<th>Participation score = 8</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Equity</strong></td>
</tr>
<tr>
<td>• Participatory interven-tions are a core philosophy of the implementing agency.</td>
</tr>
<tr>
<td><strong>Management</strong></td>
</tr>
<tr>
<td>• The intervention was home-based.</td>
</tr>
<tr>
<td>• 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.</td>
</tr>
<tr>
<td>• Village health workers played a key role in delivery of the intervention.</td>
</tr>
<tr>
<td><strong>Evaluation</strong></td>
</tr>
<tr>
<td>• Reduction in neonatal mortality was significant.</td>
</tr>
<tr>
<td>• Project has served as a model for other areas of the country and other countries.</td>
</tr>
</tbody>
</table>

Photo removed for copyright reasons.

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.

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

### Figure 5
Outcomes of KWA Water Program Compared With Control Area

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


### Figure 6
In Brief: KWA Water Program

<table>
<thead>
<tr>
<th>Participation score = 8</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Equity</strong></td>
</tr>
<tr>
<td>• Women were involved in decisionmaking and program implementation.</td>
</tr>
<tr>
<td>• 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.</td>
</tr>
<tr>
<td><strong>Management</strong></td>
</tr>
<tr>
<td>• Village panchayats took leadership in implementing and managing latrines and standpipes.</td>
</tr>
<tr>
<td>• Women implemented well chlorination and were given training on how to construct latrines.</td>
</tr>
<tr>
<td>• 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.</td>
</tr>
<tr>
<td><strong>Evaluation</strong></td>
</tr>
<tr>
<td>• Community members did not participate in the process and outcome evaluation.</td>
</tr>
</tbody>
</table>
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.

Young Nepali women face a range of disadvantages. Illiteracy among girls ages 10 to 19 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.

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.

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 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.
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 activ-

Figure 7
Differences in Community Participation Between Intervention and Control Sites in Nepal

<table>
<thead>
<tr>
<th>Project Element</th>
<th>Intervention Sites (rural and urban)</th>
<th>Control Sites (rural and urban)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline data collection and needs assessment</td>
<td>• Extensive baseline</td>
<td>• Matching baseline</td>
</tr>
<tr>
<td></td>
<td>• Extensive needs assessment</td>
<td>• Limited needs assessment</td>
</tr>
<tr>
<td></td>
<td>• Quantitative, qualitative, and participatory methodologies</td>
<td>• No participatory methodologies</td>
</tr>
<tr>
<td>Intervention framework</td>
<td>• Youth reproductive health defined to include health risk factors, socioeconomic determinants, and social and normative constraints</td>
<td>• Youth reproductive health defined to include only basic health risk factors</td>
</tr>
<tr>
<td>Structures and mechanisms</td>
<td>• 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</td>
<td>• No participatory structures or mechanisms</td>
</tr>
<tr>
<td></td>
<td>• Mechanisms: Frequent creation of task forces, consultative committees, engagement with leaders and stakeholders</td>
<td></td>
</tr>
<tr>
<td>Intervention design</td>
<td>• Involvement of community in action planning process through sharing and discussion of the needs assessment</td>
<td>• Interventions designed by professional project team with no community participation</td>
</tr>
<tr>
<td></td>
<td>• Creation of task forces to prioritize and design feasible and desirable interventions</td>
<td></td>
</tr>
<tr>
<td>Intervention components</td>
<td>• 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)</td>
<td>• Three components (adolescent friendly services, peer education and counseling, and teacher training) conducted separately</td>
</tr>
<tr>
<td>Implementation style</td>
<td>• Participatory</td>
<td>• Didactic</td>
</tr>
<tr>
<td></td>
<td>• Consultative</td>
<td>• Nonparticipatory</td>
</tr>
<tr>
<td></td>
<td>• Substantial decisionmaking power for community adults and youth</td>
<td></td>
</tr>
<tr>
<td>Attention to diversity, differentials, and disadvantaged</td>
<td>• Focus on differentiated needs of disadvantaged population a major program component (gender, rural vs. urban, wealth, ethnicity, marital status)</td>
<td>• Limited attention to differentials</td>
</tr>
<tr>
<td>Monitoring and evaluation</td>
<td>• Extensive tracking of implementation processes</td>
<td>• Matching monitoring and endline measurement with quantitative methods only</td>
</tr>
<tr>
<td></td>
<td>• Extensive endline evaluation</td>
<td>• No participatory methodologies</td>
</tr>
<tr>
<td></td>
<td>• Quantitative, qualitative, and participatory methodologies</td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Outcomes of Interest</th>
<th>Intervention Sites</th>
<th>Control Sites</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sustainability</td>
<td>++++</td>
<td>–</td>
</tr>
<tr>
<td>Capacity building and empowerment</td>
<td>++++</td>
<td>–</td>
</tr>
<tr>
<td>Broader normative and institutional factors</td>
<td>++++</td>
<td>+</td>
</tr>
<tr>
<td>Reproductive health outcomes contextually relevant in Nepal</td>
<td>++++</td>
<td>++</td>
</tr>
<tr>
<td>Service availability and access</td>
<td>++++</td>
<td>+</td>
</tr>
<tr>
<td>Basic reproductive health outcomes</td>
<td>++</td>
<td>+</td>
</tr>
</tbody>
</table>

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


**Figure 9**

In Brief: Adolescent Reproductive Health

<table>
<thead>
<tr>
<th>Participation score = 8</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Equity</strong></td>
</tr>
<tr>
<td>• 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.</td>
</tr>
<tr>
<td><strong>Management</strong></td>
</tr>
</tbody>
</table>
| • 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. 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.

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.

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 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).

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**

<table>
<thead>
<tr>
<th>Year</th>
<th>Protected</th>
<th>Controlled</th>
<th>Attended</th>
</tr>
</thead>
<tbody>
<tr>
<td>1993</td>
<td>10%</td>
<td>90%</td>
<td>0%</td>
</tr>
<tr>
<td>1997</td>
<td>50%</td>
<td>50%</td>
<td>0%</td>
</tr>
<tr>
<td>2002</td>
<td>70%</td>
<td>20%</td>
<td>10%</td>
</tr>
</tbody>
</table>

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.
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. 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. 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. The Population Council assessed the health impacts in 20 of 90 villages in the Kolda region. 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.
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. 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 stand-pipes. 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 problem-solving 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 contribute 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 decision-making authority, and changed course as circumstances evolved. 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 decision-making 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 solely 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.

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**Figure 16**

**Deepening of Community Participation in Management Over Time**

<table>
<thead>
<tr>
<th>Community participation in management</th>
<th>SEARCH (India)</th>
<th>Water (India)</th>
<th>Adolescents (Nepal)</th>
<th>UNI Trujillo (Peru)</th>
<th>TOSTAN (Senegal)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community participation in management</td>
<td>2 beginning, 3 end</td>
<td>2 beginning, 3 end</td>
<td>1 beginning, 2 end</td>
<td>2 beginning, 4 end</td>
<td>4 throughout</td>
</tr>
</tbody>
</table>
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. 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.
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Suggested Resources


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/anhttoc.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
Selected Publications From the Population Reference Bureau

All publications are on PRB's website, www.prb.org.

The World's Youth 2006 Data Sheet
This data sheet, *The World’s Youth 2006*, profiles today's youth, providing data on population, education, and health, with a special focus on sexual and reproductive health. Data are shown by world region and by country within region. Topics include: education, work, marriage and fertility, health behaviors, and use of health services. (2006)

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)

Promoting Healthy Behavior
This *Health Bulletin* aspires to help public health and other professionals better integrate behavior-change strategies into their public programs and policies. It examines the pivotal role behavior plays in the leading causes of death and disability and the prevention or mitigation of these causes. This report describes research-based frameworks used to understand and influence health-related behaviors, and presents case histories and lessons learned. (May 2005)

Improving the Health of the World’s Poorest People
For the more than 1 billion people living on less than $1 a day—one of every six people worldwide—health services and modern medicines are out of reach. This *Health Bulletin* highlights the extent of the rich-poor health divide, the factors that play a role in health disparities, and approaches for improving the health of the poor. (February 2004)

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