

Selection
Procurement
Distribution
Use
27 Managing for rational medicine use
28 Investigating medicine use
29 Promoting rational prescribing
30 Ensuring good dispensing practices
31 Community-based participation and initiatives
32 Drug seller initiatives
33 Encouraging appropriate medicine use by consumers
34 Medicine and therapeutics information
35 Pharmacovigilance

## CHAPTER 31

# Community-based participation and initiatives

Summary	31.2
31.1 Introduction	31.2
31.2 The power of advocacy groups and community-based organizations	31.3
31.3 What does community participation mean?	31.3
31.4 Why promote community participation?	31.4
31.5 Community participation and initiatives to improve pharmaceutical management	31.5
<i>Promotion of preventive health care • Improvement of availability of medicines and supplies • Management of outreach services • Management of facility-based health services • Promotion of appropriate medicine use</i>	
31.6 Health professionals' contribution to the process	31.10
31.7 Facilitating community participation in health programming	31.10
<i>Community needs assessment • Local decision making and participatory planning • Community organization and leadership • Participatory monitoring</i>	
31.8 Creating an enabling environment	31.14
References and further readings	31.15
Assessment guide	31.16

### ILLUSTRATION

Figure 31-1 Framework for appropriate Community Drug Management for Childhood Illness 31.6

### BOXES

Box 31-1	Tips for helping in participatory mapping	31.11
Box 31-2	Assessing management of medicines for childhood illnesses and adult malaria in the community	31.12
Box 31-3	Steps in participatory planning	31.13

### COUNTRY STUDIES

CS 31-1	Community case management successes	31.7
CS 31-2	Community health workers appropriately treat pneumonia in Senegal	31.8
CS 31-3	The Bamako Initiative in Benin, Guinea, and Mali	31.9
CS 31-4	Creating an enabling environment in the community to encourage tuberculosis treatment compliance	31.14

## SUMMARY

Community participation in health care is important because of the recognized value of locally tailored approaches, as well as the need for increased community financing to supplement government expenditures. For example, the Alma Ata Declaration of 1978 focused on primary health care as the best way to achieve healthy communities, and the deployment of community health workers was viewed as a key component in that strategy. More recently, the concept of community case management has evolved to respond to international recommendations to deliver community-level treatment for common, serious childhood infections. Many activities of questionable value, however, carry the label of “community participation,” which can reflect negatively on the whole field. This chapter summarizes the essential elements of a successful community participation program, with a focus on pharmaceutical management.

Community participation may involve—

- Contributing—community members contribute money, labor, or materials.
- Consulting—members are asked for their views and are informed of project plans.
- Managing—members actively participate in making decisions and in controlling resources.

When all three levels of participation are present, communities are full partners in providing services.

Full partnership in decision making means that health development is defined in terms of people’s real needs and priorities; community economic, human, and orga-

nizational resources are mobilized; and mechanisms are created to increase people’s access to information, knowledge, and skills and to help them make their goals and priorities known.

Community participation can improve pharmaceutical management through—

- Advocating for access to health care
- Promoting preventive health care
- Improving the availability of medicines and supplies
- Managing outreach services
- Managing facility-based health services
- Promoting appropriate medicine use

Formal health care professionals play a key role in facilitating community participation. They act as motivators; as supporters to the community in establishing strong organizations for community-based activities; as resource persons by establishing links between the community, government agencies, and other organizations; and as trainers and supervisors, building capacity within the community.

Community participation rarely emerges on its own. It succeeds best within an enabling environment, which includes—

- Political commitment to the concept of participation
- Interest in decentralization of health services
- Existence of a health structure
- Commitment to developing people’s managerial capabilities

### 31.1 Introduction

The failure of traditional top-down development approaches to eradicate poverty and improve the living conditions of the poor has led to increased interest in popular participation in development. For the first decade or so after the Alma Ata World Conference on Primary Health Care, many governments in developing countries took initiatives to expand community participation in the promotion and delivery of basic health services, including medicines. This expansion represented a response to the increasing trend toward decentralization and recognition of the value of locally tailored approaches, as well as an acknowledgment of the need for increasing levels of community financing. In the 1990s, however, countries were finding it difficult to sustain community-based health programs, especially with the increased focus on centrally run vertical programs such as those

focused on HIV/AIDS. But renewed interest in community-based approaches has resulted from countries seeking the most effective ways to accomplish the Millennium Development Goals.

Community participation can have an impact on health care, from policy to patient. At a higher level, community organizations and civil society groups have influenced policies—especially those related to the HIV/AIDS pandemic. At a more local level, a community-based focus creates a new form of governance for public health systems and alters the relationship between providers and users of health care services. Health professionals are being called upon to adopt new approaches and to work in partnership with communities: in sharing knowledge and skills, jointly deciding on plans for health care, and seeking to develop and strengthen the community’s capacity to care for itself.

This chapter presents some of the key features of community participation in the promotion and delivery of basic health services, including pharmaceutical management. The chapter draws on the experiences of many community-based health programs, among them the Bamako Initiative, which promoted community management and financing of basic health services, including medicines, and the rise of community case management, which is a strategy to deliver community-level treatment for common, serious childhood infections. The chapter also describes how community volunteers and private-sector outlets can improve access to quality medicines and services. Although some of the interventions described are not specific to medicines, they relate to improving the availability and use of medicines to improve health outcomes.

Although many methods of community participation are possible, no clear-cut or universally applicable methods exist. Participation varies from one country to another and even from one community to another within the same country, depending on socioeconomic and political contexts. Because communities are not homogeneous, this chapter provides broad guidelines for increasing community participation. The terms *community*, *users*, *consumers*, and *beneficiaries* are used interchangeably.

### 31.2 The power of advocacy groups and community-based organizations

Increased advocacy from various groups, such as multi-lateral organizations, bilateral donors, nongovernmental organizations at all levels, and civil society organizations, has brought about pressure to change policies and push pharmaceutical issues onto national and international health care agendas. Issues that are receiving more attention include the need for new health technologies and medicines for tuberculosis (TB), malaria, and HIV/AIDS, including pediatric formulations of antiretrovirals (ARVs) and laboratory technologies, such as more sensitive TB diagnostics, that are suitable for developing countries. In particular, the HIV/AIDS pandemic put into motion an advocacy movement that has significantly influenced issues on a worldwide scale.

The profound impact of the AIDS pandemic resulted in a unique alliance of activists and people living with the infection acting as advocates within their communities. In 1983, an advocacy group in Brazil created a nongovernmental organization to fight AIDS, a year after the first case had been diagnosed there, and additional groups followed. In addition to increasing prevention efforts and treatment in poor and remote communities, Brazilian activists are credited with assuring adequate funding for ARVs and contributing to the country's successful pricing negotiations with pharmaceutical manufacturers (Homedes and Ugalde 2006). In 1987 in New York City, the AIDS Coalition

to Unleash Power (ACT UP) was formed as a community activist group dedicated to influencing AIDS-related policy. They were the most visible example of how involvement at the community level and from people living with HIV/AIDS could greatly affect public policy and issues such as ARV access and affordability that ranged far beyond their New York roots. Since 1998, the Treatment Action Campaign (TAC) and its allies in South Africa have led a lengthy and very visible public campaign to improve access to ART through the public health sector.

Today, organizations around the world work to mobilize community support and action not only to improve the lives of local families touched by HIV/AIDS, but to keep AIDS issues—especially access to ARVs—high on the public agenda. For example, the International HIV/AIDS Alliance ([www.aidsalliance.org](http://www.aidsalliance.org)), which was founded in 1993, works with community organizations in more than forty developing countries to strengthen the local response to HIV-related disease, and includes supporting community engagement for antiretroviral therapy (ART). The HIV/AIDS Alliance produces many resources and tools to improve the effectiveness of the community effort. A resource is also available for how to involve communities in the national AIDS response (International Council of AIDS Service Organizations [ICASO], AfriCASO, and International HIV/AIDS Alliance 2007).

### 31.3 What does community participation mean?

Although wide consensus exists on the central role of community participation in primary health care, the concept has varying definitions and different interpretations. In its *World Health Report*, the World Health Organization (WHO) defined communities as “groups of people living near each other, or with various social connections, and often with a shared sense of purpose or need” (WHO 2004). In practice, however, “community” may be conceptualized differently depending on the context. In general, the definition includes clients or users of health services as well as the providers of health services and medicines in the locality. An analysis of community participation suggested that the definition of community differs according to the actual level of participation (Murthy and Klugman 2004).

Community participation is best defined as a cumulative process through which beneficiaries develop the managerial and organizational capacity to increase control over the decisions that affect their lives. Therefore, community participation means that members have a strong voice in all issues that affect the well-being of the community at large. A high level of community participation implies the involvement of difficult-to-reach population groups, as well as the nongovernmental organizations that represent their

interests. The process of community participation can help these marginalized groups become better organized and more involved in decisions pertaining to their health.

When national government policies call for the decentralization of health-sector services, increased community participation is one way to help build capacity and ensure quality of services because management responsibility shifts to the local level. In this situation, however, civil society groups must advocate for the community to policy makers to ensure that the process of decentralized responsibility works effectively.

A community's full partnership in the decision-making process implies—

- Definition of health development in terms of local needs and priorities
- Mobilization of the community's economic, human, and organizational resources
- Creation of mechanisms that help people increase their access to information, knowledge, and skills; voice their opinions; and make their goals and priorities known

Three distinct approaches to community participation reflect different degrees of participation (Fox 1993)—

1. *Contributing*: Community members provide money, labor, or materials for health projects.
2. *Consulting*: Community members are asked for their views and are informed of project plans in order to secure their commitment and contributions to construction, operation, and maintenance.
3. *Managing*: Community members actively participate in decision making and in controlling community resources and are engaged in project identification, planning, organization, implementation, monitoring, and evaluation.

Many health professionals have seen community participation as mainly “contributing” to health projects; that is, the community assists the professionals with contributions of labor, materials, or money but only rarely with ideas. In both the contributing and the consulting modes, communities are regarded mainly as beneficiaries of assistance. When communities are involved with managing as well, the three concepts become synergistic; community members, in partnership with outside development workers, are able to use their heads and their voices—as well as their hands—in the development and operation of facilities and services they can genuinely call their own.

Community participation is best measured by its contribution to overall health outcomes, not only in terms of quantifiable project outputs but also in terms of the process of participation itself, including—

- Community involvement in needs assessment, planning, management of resources, implementation of project activities, monitoring, and evaluation
- People's capacity to manage and organize themselves
- People's access to new skills, knowledge, and information
- Community organization and solidarity
- Relationships between users and providers of health services
- Political will, leadership, commitment, and resources
- Transparency in project management and accountability of health services toward the public being served

### 31.4 Why promote community participation?

It is at the community level that women, men, and children get drinking water; that wastes are controlled to prevent disease; that nutritional deficiencies are identified and actions taken. It is in communities and in households that people choose health care providers, that families make decisions about the use of their resources, that patients obtain and decide how to use medicines. Therefore, projects aimed at improving access to and use of basic health services, including essential medicines, cannot achieve their objectives and ensure sustainability unless a genuine partnership exists with communities.

The concept of community participation in health is based on the following principles—

- Participation in one's own health care is a basic right to which all people are entitled.
- When health services are linked to local perceptions of needs and are managed with the support of local people, those services are more likely to achieve their objectives and be sustainable.
- By actively participating in project planning and decision making, people gain confidence in their ability to change their situation and better their health status.
- By solving their own problems, people become more self-reliant.
- Where public health institutions are weak, community participation in management and financing can improve efficiency, increase public accountability, restore users' confidence, mobilize additional resources to complement government resources, and improve the quality of services.
- By encouraging people to become involved, projects can benefit from local skills and resources.
- When people know from the start that a project is theirs, they show a greater sense of responsibility for the management and maintenance of services and facilities than when projects are controlled by “outsiders.”

- The positive experience of planning, implementing, and managing a successful project leads to involvement in other development activities, resulting in a multiplier effect.
- Health, nutrition, and family planning outcomes can be significantly improved and sustained only when the strengthening of health services, including medicine supply, goes hand in hand with community awareness about public health issues and personal health care.

Community participation is crucial in promoting healthy lifestyles and better health management at the household and community levels.

### 31.5 Community participation and initiatives to improve pharmaceutical management

Community participation has a role in pharmaceutical management, including advocacy for health care as described in Section 31.2. Communities can also—

- Promote preventive health care
- Improve availability of medicines and supplies
- Manage outreach services
- Manage facility-based health services
- Promote appropriate medicines use

#### Promotion of preventive health care

Governments and households could save money if efforts were made to promote preventive health care as well as rational medicine use. Grassroots community networks can play a crucial role in promoting preventive care and encouraging therapy without medicines at home for minor illnesses.

The process by which health promotion is carried out, including the time and effort that go into developing a community's sense of ownership, is critical to a program's success. In Malawi, for example, as part of an effort to control malaria, village health committees began selling insecticide-treated nets (ITNs) for beds. The demand for ITNs was very high, and committees used the revenue to finance community improvements, such as drinking-water wells. In addition, malaria cases decreased by as much as half in some villages (Lewnes 2005).

#### Improvement of availability of medicines and supplies

In response to the problem of declining public resources for financing pharmaceutical and other recurrent costs, some communities have adopted cost-recovery and self-financing schemes in local health centers, dispensaries, and outreach services. The aim is to improve and extend services by gener-

ating sufficient income to cover some local operating costs, such as the supply of essential medicines, salaries of some support staff, incentives for health workers, and investment in community health activities.

Community cost sharing can be based on user fees, prepayment for services, local taxes, and various income-generating activities. Communities can also help pay health care costs by contributing labor or making direct financial contributions for the improvement and maintenance of health care infrastructure. Revolving drug funds are discussed in Chapter 13, while Chapter 12 covers community-based health financing.

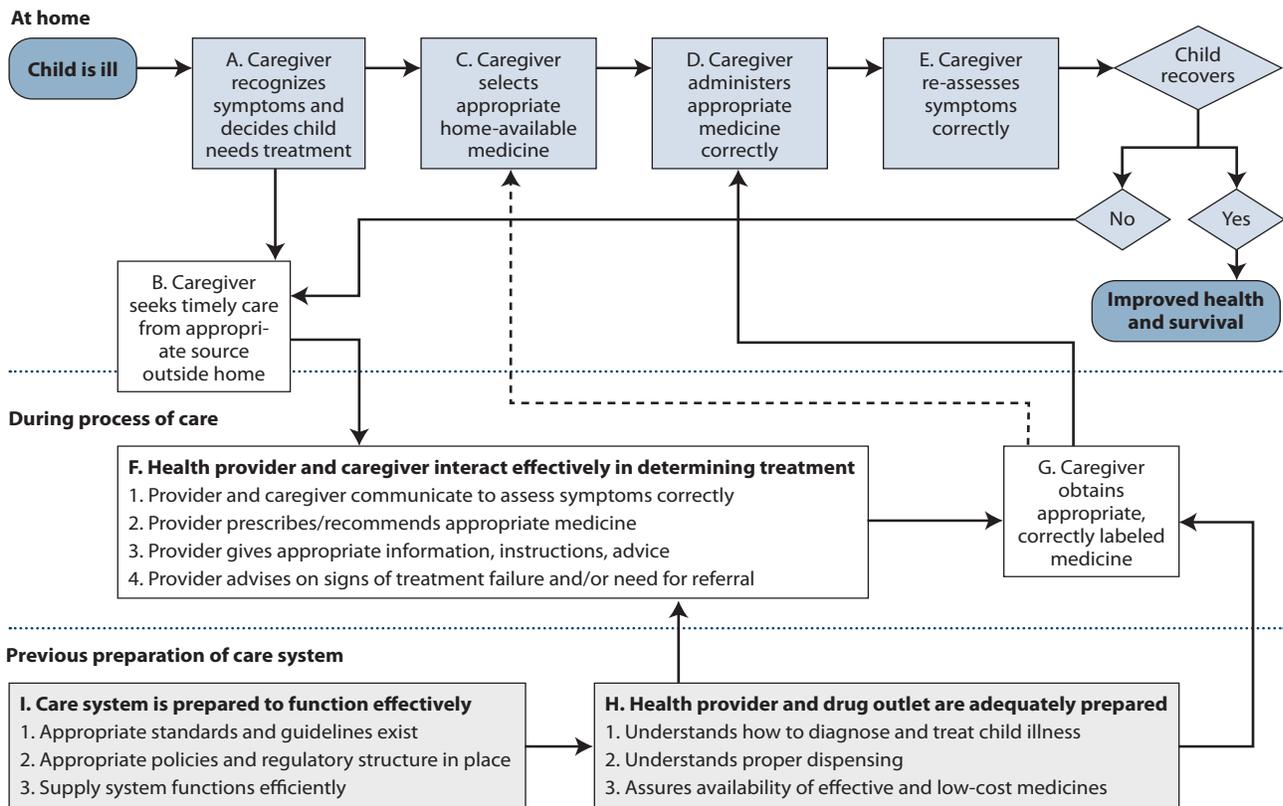
#### Management of outreach services

Over the past thirty years, large numbers of community health workers (CHWs) have been trained in many countries as part of national strategies for primary health care, especially for children. CHWs can be general community health resources, or part of a specialized group, such as community medicine dispensers, traditional birth attendants, or HIV/AIDS communicators. All types of CHWs typically are trained in one or more health care functions, but have no formal professional certification (Haines et al. 2007).

CHWs have been shown to be an effective means of accelerating and extending the delivery of primary health care when they receive adequate training, are regularly supervised, are provided with adequate logistical support, and are linked to established district health systems for technical backup. CHWs can also be valuable in monitoring health in the community and as a referral point between health centers and the community. However, although CHWs are often seen as an extension of the health system, supervision is a challenge to implement and is often not carried out. Supervision should be an important focus of any CHW program in order to ensure the availability and rational use of medicines. Lessons learned about CHW programs (Haines et al. 2007) include—

- *Training and individual support:* Training alone is insufficient; supervision and support increase performance and sustainability.
- *Tasks and roles:* CHWs will probably perform better with clearly defined roles and a limited number of specific tasks to carry out.
- *Incentives:* Targeted incentives, monetary or otherwise, will probably reduce attrition and improve performance.
- *Community and policy support:* Consistent support can help sustain CHW programs; active involvement of communities ensures support is available and promotes the use of community workers by community members.

Figure 31-1 Framework for appropriate Community Drug Management for Childhood Illness



Source: Ross-Degnan et al. 2008.

To be successful, CHWs, who are sometimes volunteers, need to be fully trusted and supported in the community; for example, in Uganda, volunteers selected by community members to distribute ivermectin treatment for river blindness were far more successful than those selected by the local government, who may have been viewed with some suspicion. The annual dropout rate for the community-selected group was less than 2 percent, compared with 95 percent for the others (Katarbarwa and Richards 2001).

A similar trust issue involves remuneration. Although monetary compensation to CHWs results in higher retention rates, it can also cause community members to view the volunteers as government employees rather than as true community advocates. Providing quality services in the community may earn the community health workers recognition and status, and they are often rewarded with payment in kind by community members. Research shows how incentives and disincentives affect the motivation and ultimately the retention of CHWs in the community (Bhattacharyya et al. 2001).

WHO's and UNICEF's Community Integrated Management of Childhood Illness (C-IMCI) initiative initially focused on prevention of childhood illness in the commu-

nity, with CHW responsibilities typically limited to education on sanitation, nutrition, family planning, child health, and immunizations. C-IMCI is evolving, however, and its focus has expanded to include community-based curative services or community case management of common conditions, such as malaria, diarrheal disease, and childhood pneumonia, in line with WHO and UNICEF recommendations in 2004 (WHO/UNICEF 2004). As a result, community case management through adequately trained and supervised community health workers is being increasingly promoted not only as a means of improving quality of care and rational use of medicines but also as a mechanism for increasing availability of medicines (Figure 31-1). Country Study 31-1 illustrates the success of community case management in Afghanistan, the Democratic Republic of Congo, and Nepal.

CHWs receive greater community support when they are empowered to provide curative services and medicines; however, an insufficient pharmaceutical supply can diminish the success of health volunteers. For community case management to succeed, medicines and supplies need to be available, managed appropriately, and used rationally (according to standardized treatment guidelines). Therefore, it is fundamental to pay attention to the supply management

components of any community case management program. (See Country Study 31-2, which describes training community health workers in Senegal about appropriate use of medicines.)

Having informal health service providers in the community is being recognized as a means of enhancing primary health care by providing curative services. For example, in many resource-limited countries, community members often seek advice and medicines first from private drug sellers or medicine vendors; for various reasons they do not choose to seek care in the public sector—especially in rural areas, where public facilities may not be easy to reach. Chapter 32 covers initiatives to improve drug seller services in the community.

### Management of facility-based health services

With the economic crisis of the 1980s, particularly in Africa, infrastructure deteriorated, pharmaceuticals were often unavailable, and civil servants went unpaid for long periods. In response, many governments began to involve communities in the management of public facility-based health services. Now, health care facilities from all sectors—public, nongovernmental, and faith based—benefit from community involvement.

Because essential medicines are necessary for integrated, high-quality, cost-effective basic health services, and because people perceive pharmaceuticals as a quality indicator, medicines have often served as a starting point for community co-financing and co-management of facility-based health services.

Locally elected health committees can participate in the day-to-day tasks of managing health facilities. Such committees can—

- Assist health staff in developing an appropriate payment mechanism or mechanisms (prepayment scheme, flat rate, or fee for service) and in pricing services, including medicines
- Establish procedures for procuring and managing medicines and other supplies
- Determine criteria and develop an administrative system for those who cannot afford to pay or who should be exempt from paying for other reasons
- Establish a system of internal control of receipts and expenditures that ensures financial viability, accountability, and transparency in managing the system
- Participate in the day-to-day financial management and bookkeeping and prepare the health center's budget

#### Country Study 31-1

##### Community case management successes

**Afghanistan.** After decades of war, Afghanistan's child survival rates were close to the world's worst. Geographic isolation, cultural strictures, and poor security blocked many women and children from accessing care at public health facilities, so the Afghan government trained 20,000 community health workers—half of them women and most nonliterate. Their jobs include providing Integrated Management of Childhood Illness and advice to mothers on child care and family planning. About half of all sick children are now seen by CHWs, and increased access has contributed to the 25 percent decline in child mortality seen over five years (Aitken et al. 2009).

**Democratic Republic of Congo (DRC).** Since 2005, the community case management (CCM) program in DRC has trained hundreds of CHWs to manage uncomplicated childhood conditions. A key component of the CCM strategy was managing medicines, and training included how to track inventory and calculate medicine needs. Initial program results showed that 90 percent of twenty randomly sampled CHWs dispensed the correct quantity of medicine; all said the medicine name and formulation and how to administer it; 90 percent asked

the caregiver to repeat the instructions to assure understanding; and stockouts were rare (Bukasa et al. 2008). Investing in pharmaceutical management from program initiation has encouraged positive results, including minimized stockouts and appropriate dispensing practices.

**Nepal.** The Ministry of Health in Nepal trains female community health volunteers (FCHVs) to provide some health services in their community. When FCHVs were given responsibility for managing childhood pneumonia using co-trimoxazole, some observers questioned the cadre's ability to correctly diagnose and treat pneumonia, especially those who were semiliterate. These concerns were addressed by using pictorial training materials to facilitate understanding. The intervention also includes regular refresher training for the FCHVs and community orientation to the concept. In the program's first decade, districts with FCHVs doubled the number of children who receive treatment—saving an estimated 6,000 lives a year. The intervention now covers about 80 percent of children, with plans for universal coverage in the next two years (Dawson et al. 2008; Global Health Council 2009).

Source: Embrey et al. 2010.

### Country Study 31-2

#### Community health workers appropriately treat pneumonia in Senegal

The government of Senegal increased population access to health services by developing a network of health huts run by trained birth attendants (matrons) and community health workers. The Ministry of Health had used CHWs to treat malaria, diarrhea, and other minor ailments but had opposed their dispensing antibiotics because of fear of inappropriate use, which could contribute to drug resistance. Nevertheless, antibiotics were widely available in the market and were also inappropriately used in some health huts. In part on the basis of this information, the Ministry of Health agreed to operational research to test the feasibility of using CHWs to manage acute respiratory infection (ARI).

The research design was a nonrandomized controlled study with four intervention districts. Literate CHWs were trained for three days using a World Health Organization ARI algorithm in case management, followed by periodic one-day refreshers and ongoing supervision. Work tools included stopwatches, weighing scales, information materials, calculators, patient registers, and pharmaceutical stock cards. Co-trimoxazole was available in the health system through the national system's cost recovery, and its availability at the health hut was facilitated through store management training and supervision. Related educational activities and com-

munity mobilization were initially carried out by CHWs, who were joined by health promotion volunteers.

The training included 113 literate CHWs in ninety health huts. Postintervention tests showed marked improvement in CHW knowledge of ARI, unrelated to level of formal schooling. Under direct observation, nearly 90 percent of CHWs correctly evaluated, classified, and treated ARI cases, and more than 90 percent knew general danger signs. A record review showed that 95 percent of pneumonia cases were correctly classified, 97 percent were correctly treated, and 69 percent of severe cases were appropriately referred (an additional 22 percent received co-trimoxazole). Nearly twice as many pneumonia cases were treated in intervention areas than in control districts. The percentage of mothers knowing at least two danger signs increased from 33 percent in August 2003 to 65 percent in April 2004. Two CHWs inappropriately dispensed 552 tablets to older patients (of 36,800 tablets total), for a misuse rate of 1.5 percent. No stockouts of co-trimoxazole occurred during the study period. The study concluded that literate CHWs who are adequately trained and supported can correctly classify ARI, appropriately treat pneumonia with co-trimoxazole, and refer severe cases.

Sources: BASICS II 2004; Briggs et al. 2003.

- Carry out stock inventories of pharmaceuticals and other supplies and equipment
- Recruit and manage the support personnel hired with community funds (community pharmacy salespersons, guards, drivers, and so forth)

In some countries, health committees have a clear mandate to carry out evaluations of the performance of health staff and, if necessary, file complaints and propose disciplinary measures to district health offices.

Country Study 31-3 describes experiences with community participation within the Bamako Initiative framework in three different countries.

#### Promotion of appropriate medicine use

The inefficient and even unsafe treatment of illnesses through inappropriate medicine use is a problem in many settings (see Chapter 27). These problems are caused by irrational medicine prescribing practices on the part of providers (which may include non-health care professionals, such as informal drug vendors or caregivers). Other

causes include popular misconceptions and nonadherence to treatment on the part of patients. Advocacy by organized consumer groups and efforts to improve public access to information are effective ways to address these problems (see Chapter 34).

Consumer education helps improve adherence to recommended medicine therapies. As part of this process, consumers are able to provide feedback to prescribers on the effectiveness of medicines, undesirable side effects, and so on. Such a process is reinforced when personal links have been established between consumers and providers at the community level and when community members are organized and vocal in demanding quality health services, such as in some social-marketing programs discussed in Chapter 33.

An involved and informed community can also promote appropriate medicine use by helping to reduce disease stigma, such as for HIV/AIDS and tuberculosis, thereby encouraging early case detection and treatment adherence. For example, clinics can alert the community support group to trace a patient who has missed an appointment. Community members can also play a successful role in the treatment delivery process; for example, volunteers from the

### Country Study 31-3 The Bamako Initiative in Benin, Guinea, and Mali

Since the late 1980s, the Bamako Initiative has been implemented to some degree in half the countries of sub-Saharan Africa. More than ten years later, experiences in Benin, Guinea, and Mali showed that communities were able to strengthen delivery of health services and ensure supply of essential medicines by forging a partnership between the state and organized community groups.

Before reforms were put in place, the vast majority of poor families in the three countries did not have access to affordable, quality health services or medicines, and the public health sector was in shambles. Immunization coverage was under 15 percent, and less than 10 percent of families made at least one visit per year to public health facilities. Although services were supposed to be free, patients often had to pay, and pharmaceuticals were often unavailable in the health unit. The only reliable source of medicines and care was usually in the informal private sector—mainly drug peddlers—where rural families typically spent 5 U.S. dollars per capita out of pocket per year.

In all three countries, the priority of the Bamako Initiative-related activities was to establish accountability and empower communities to take ownership of their health centers and services. A contractual arrangement between the state and communities promised delivery of basic professional health services by decentralizing decision making and management and instituting community cost sharing and co-management of health services. Communities were also involved in managing pharmaceuticals and revenue: The community pharmacies had double locks, requiring both the health center's chief nurse and a community representative to open; bank accounts required double signatures. Members of committees participated twice a year in the monitoring of health services—analyzing problems and helping to design new actions—and budgeting the use of these revenues, within clear national standard guidelines.

During the more than ten years of the Bamako Initiative in these three countries, access to community-based

health services was restored for more than 20 million people, use of services increased among children and women in the poorest segment of the population, and a sharper decline of mortality in rural areas compared to urban areas occurred in Guinea and Mali. Immunization levels increased in all three countries, with Benin averaging close to 80 percent, which is one of the highest levels of immunization among the poor in Africa (see figure below). Much of the success can be linked to ensuring the supply of affordable essential pharmaceuticals and commodities in health centers under the scrutiny of the committees and the involvement of communities in the planning and management of services, particularly immunization and maternal child health interventions.

The implementation of these initiatives were not without challenges. Top-down organization of health committees in the community tends to uphold elitism, and the rest of the population can feel marginalized. However, over time, the representation on committees improved, following guidelines from the policy makers. A remaining problem is the weak “voice” of the poorest citizens who have the least time to participate in meetings or other voluntary community support activities.

#### Steady improvements in immunization coverage in Benin, Guinea, and Mali



Source: Knippenberg et al. 2003.

community have been used as supporters for patients undergoing tuberculosis treatment in Cambodia and Peru (Thim et al. 2004; Shin et al. 2004), and worldwide, community-based groups have been established to support people living with HIV/AIDS.

When unregulated private markets offer pharmaceuticals of dubious quality, without prescription, and at exorbitant

prices, consumers must be sensitized to the health risks and costs involved. Community health workers, health committees, and networks at the grassroots level can, with increased access to information and technical support from health staff, serve as advocates to consumers for the promotion of reliable sources of local pharmaceutical procurement and the rational and correct use of medicines.

### 31.6 Health professionals' contribution to the process

Formal-sector health professionals play a key role in facilitating the process of community participation in health, and particularly in the supply and use of medicines. They serve as—

- Motivators who draw out people's untapped skills, experiences, and leadership potential
- Supporters who help the community establish strong and appropriate organizations for the planning, implementation, and management of community-based health activities
- Resource persons who establish links between the community, government agencies working in health and health-related areas, and other relevant organizations and services
- Trainers of community leaders, members of health committees, and community health workers who build on the knowledge and experiences that exist in the community
- Supervisors of community health workers who ensure delivery of quality health services

To fulfill these roles effectively and to create productive partnerships at the community level, health professionals must be able to—

- Communicate with the community and establish relationships with people, including community health workers and others who provide medicines
- Listen well and learn from the community
- Share skills and experiences with the community
- Respect people's ideas, skills, and wisdom
- Promote equity in male-female representation and in representation of the various social, economic, and age groups in local decision-making bodies
- Be aware of and respect the social practices, traditions, and culture of the community
- Foster collaboration with other projects, organizations, and services
- Promote a holistic or integrated approach to health development

### 31.7 Facilitating community participation in health programming

The participatory process for health programming includes community needs assessment, local decision making and participatory planning, community organization and leadership, and participatory monitoring. In the following sections, practical suggestions are given for each of these phases.

#### Community needs assessment

Conducting a needs assessment is the first step in initiating a community-based participatory health project. The purpose is to involve the project beneficiaries in determining their health problems, the causes of those problems, and their primary needs as the basis for planning community activities and for establishing baseline data against which progress can be measured in the future. Areas to be covered, the choice of method, and data analysis issues all need to be considered when planning such an assessment.

**Key areas to be covered.** Community participation in the needs assessment phase is fundamental. When undertaken as a joint exercise, a needs assessment can encourage dialogue between health professionals and community members, so that accurate and complete information is available to both parties when deciding on appropriate actions.

*Basic community health needs:* Assessing basic health needs begins with identifying and ranking problems, causes, cost of health care, health-seeking behavior, access to health services and medicines—including affordability of medicines and health care and use of medicines by the consumers and providers in the community. Specific needs in relation to problems identified, what the community would like to do to improve its health situation, and community resources that could be mobilized can then be considered.

*Community decision-making process and power structures:* How does the community work? What are the rules of the group? Who makes them? Who enforces them? How does power depend on sex, age, tribe, kinship, knowledge, money, education? Who makes decisions, and who controls resources at the household and community levels? What are the power relations between women and men, between basic service delivery systems and the community, between community and local authorities, between various socioeconomic and political groups? How do people feel about the decisions that affect their lives and the way these decisions are made?

*Education and socialization:* How do schooling and traditional education influence people's knowledge, attitudes, and behavior in dealing with health issues, in particular their choice of health care provider and their use of medicines?

*Beliefs and values:* How do beliefs, ideology, or religion affect people's understanding of health and development?

*Basic population data:* These data include population, number of households in the community, number of inhabitants living within five kilometers of the nearest health facility, and age and sex distribution.

*Facilities and infrastructure:* What community facilities (schools, churches, temples, markets), clinics, health posts, pharmacies, shops, drug shops, water supplies,

street lighting, communications, and transport (such as roads or paths) exist?

*Past and ongoing health and health-related projects:* Are any past, ongoing, or planned projects or programs relevant? Achievements, approaches, constraints, resources, organization, and management of activities; services involved; and potential for coordinating efforts all need to be considered.

**Methods.** A community needs assessment is not necessarily a formal investigation. Common sense, creativity, and ingenuity can be used to determine the most appropriate methods, modify existing methods, or suggest new methods.

It is important to start by establishing contacts in the community and by identifying key informants who could be useful in providing information and in organizing and facilitating community meetings and group discussions. This information can be gathered in the following ways—

*Door-to-door visits (household surveys):* Conducting structured or informal interviews at a sample of households.

*Group discussions:* Holding casual, focused, or deliberately structured discussions at various levels of the community or neighborhood.

*Individual discussions:* Interviewing private providers and shopkeepers, for example.

*Participatory mapping and modeling:* Involving community members in making maps (social, demographic, health, water resources), using the ground, floor, or paper. (Box 31-1 provides some tips for participatory mapping. These tips can also be used in other interactions with the community.)

*Role-playing:* Helping community members describe their situation and needs by taking different roles.

*Seasonal diagramming:* Determining through discussion with community members, seasonal variation in illnesses, health care costs, access to health services, food availability or shortage, economic difficulties and impact effect on health, and coping mechanisms.

*Secondary sources:* Reviewing data from files, maps, project reports, population census reports, health center records, or articles.

*Transect walks:* Systematically walking with informants through an area and observing, asking, listening, discussing; identifying different zones, local technologies, introduced technologies, health-seeking behavior, average distance to nearest health facility, community-felt needs, perceived solutions, opportunities; and mapping and diagramming.

Many tools exist for situational analysis or needs assessment in the community. One example related to availability and use of medicines at the community level is

### Box 31-1 Tips for helping in participatory mapping

- Help people get started by letting them do it themselves.
- Be patient. It's their map.
- Look, listen, and learn.
- Facilitate. Don't dominate.
- When community members are mapping, modeling, or diagramming, don't interfere.
- Sit back and watch. Or go away!
- Keep a permanent (paper) record, including mappers' names, to give them credit for their contributions.
- If necessary, suggest that sometimes a succession of maps works better.

Management Sciences for Health's Community Drug Management Assessment tool, which uses household surveys and individual interviewing techniques to study availability of medicines and their use by clients, drug sellers, or providers. This assessment manual is accompanied by an intervention guide to orient decision makers at a variety of levels on the best interventions to improve the availability and use of medicines in the community. Box 31-2 tells how the *Community Drug Management for Childhood Illness: Assessment Manual* can assess the practices of household caregivers or patients and their medicine providers.

**Data analysis.** When analyzing the data, bear in mind these key points—

*Ranking of health problems and health-seeking behavior:*

Identify and rank the most important health problems and health-seeking behaviors for each of the major health problems identified and for vulnerable groups, such as children and pregnant women; the health care provider (traditional healer, health center, hospital, community health workers, drug sellers, self); and availability of medicines and average cost of treatment.

*Wealth ranking:* Identify clusters of households according to wealth, including those considered poorest and unable to pay for health care. Identify mechanisms to help the poor.

*Analysis of differences:* Seek opinions of all groups within the community and analyze differences in opinion by gender, age, social group, economic group, and occupation.

*Trend analysis:* Compare people's accounts of the past and the present; their reports of how things have changed (how health status has improved or worsened; changes in the size of families, the status of women, level of education, income, food, and nutrition); and the causes of these changes and trends.

**Box 31-2****Assessing management of medicines for childhood illnesses and adult malaria in the community**

The availability, appropriate management, and rational use of medicines are critical to the successful implementation of health programs. Child survival and malaria control programs have shown that identifying and treating patients early and appropriately in the community help prevent illnesses from worsening and reduce mortality. However, activities targeting only the public sector have limited impact because they may not reach households or private-sector providers, where most childhood illnesses and malaria cases are treated.

The Community Drug Management for Childhood Illness (C-DMCI) tool (Nachbar et al. 2003) has been developed to study the practices of household caregivers or patients and their medicine providers for childhood illnesses and adult malaria. This tool helps district health managers, program planners, and regional and national policy makers identify problems in pharmaceutical management in the community at the household and provider levels through a household survey and individual interviews with different providers of medicines in the community. The tool's survey questionnaires are designed to be administered by local community members such as schoolteachers, staff of nongovernmental organizations (NGOs), or others who are not health professionals. Data from the survey responses can then be analyzed by district health teams, national program staff, or NGO staff.

The C-DMCI uses an indicator-based approach to identify strengths and weaknesses of community pharmaceutical management, as well as to provide a systematic method of monitoring the effect of interventions targeting health providers, caregivers, and patients. The data collection instrument for assessing the products and services of drug sellers and health providers focuses on pharmaceutical availability, provider knowledge, and appropriate dispensing in both the private and public sectors. The instrument for assessing the practices of household caregivers and patients provides data on their behaviors and practices when choosing, purchasing, and administering medicines. An accompanying guide

(Ross-Degnan et al. 2008) can help decision makers prioritize problems and design appropriately targeted interventions to improve pharmaceutical management for childhood illnesses and adult malaria in the community.

In Senegal, the Ministry of Health, in collaboration with the Rational Pharmaceutical Management (RPM) Plus Program and the BASICS project, conducted an assessment using the newly developed C-DMCI assessment tool. The survey took place in 2002 in two districts.

Some key findings included—

- Oral rehydration solution (ORS), which is recommended as the first-line treatment for diarrhea, was not available in private pharmacies and was insufficiently available in the public sector.
- Only 56 percent of children with fever took the first-line antimalarial medicine, and fewer than 20 percent of children with pneumonia or diarrhea took the appropriate first-line treatment (co-trimoxazole and ORS, respectively).
- In general, the medicines were not correctly administered in the home, even when instructions were given to caregivers at the time of purchase; only about 60 percent of patients took chloroquine for three days.
- Only about 30 percent of caregivers took children with symptoms of pneumonia for care on the same day symptoms started.

Based on evidence showing wide misuse of antibiotics, the Ministry of Health introduced a policy permitting CHWs, with special training and close supervision, to treat cases of childhood pneumonia with co-trimoxazole. Evaluation showed that nearly 90 percent of workers correctly evaluated, classified, and treated acute respiratory illnesses, and there were no co-trimoxazole stockouts. In addition, nearly twice as many pneumonia cases were treated in intervention areas than in control districts. As a result, the Ministry of Health extended the community-based pneumonia treatment project nationwide.

Sources: Ross-Degnan et al. 2008; Senauer et al. 2008; Briggs et al. 2003; Nachbar et al. 2003.

## Local decision making and participatory planning

Using the information collected in the needs assessment, community members, health professionals, and decision makers collaboratively decide what actions need to be taken, how, when, and with what means. The planning process should take place in a climate that fosters two-way communication and mutual learning, so that all stakeholders feel equally involved. The steps in participatory planning are shown in Box 31-3.

## Community organization and leadership

Certain actions require collective efforts beyond the capacity of individuals, households, and even health committees and community health workers. The creation or strengthening of community organizational capacity is important for empowerment objectives. Creating organizational capacity can be laborious and time-consuming, but it is vital for ensuring the sustainability of community-based projects. The following tips for health professionals and community leaders can facilitate the process of community organization or group formation—

- Identify charismatic community leaders and strengthen their leadership skills.
- Ensure that the people involved are those who are genuinely concerned with community health.
- Clearly define the specific tasks to be performed by each community representative and health-service representative.
- Build on existing formal and informal functional grassroots structures that have credibility in the

community, to the extent possible. These may include women's groups, youth groups, or religious groups.

- Ensure an equitable representation of women and various socioeconomic groups on village committees.

## Participatory monitoring

Information is an essential tool for local decision making, and participatory monitoring offers ways to share information. Increasing beneficiaries' capacity to collect information and use it for action is important: information confers power. By having increased access to information, communities increase their ability to make decisions and gain greater control over their own development.

Participatory monitoring can serve as an educational process, a management tool, and a surveillance system. As an educational process, it increases participants' awareness and understanding of the various factors that affect their health and development in general. As a management tool, it helps measure progress, identify problems, and inform decisions aimed at improving efficiency in the delivery of essential health services, including medicines. Finally, as a surveillance system, participatory monitoring provides community members, health services, and other related services with vital quantitative and qualitative data on the status of community health and nutrition and on consumer behavior. For pharmaceutical management and use, this information might include data on household expenditures for medicines, sources and availability of medicines in the community, and consumer medicine use practices. If the purpose of monitoring is to assess the effectiveness of a particular intervention, then the indicator measured would relate to the intervention's objectives.

### Box 31-3

#### Steps in participatory planning

1. Encourage community members to reflect on problems identified through the needs assessment.
2. Facilitate dialogue on possible solutions, including pros and cons for each solution.
3. Decide on priority areas that need community action.
4. Set clear and measurable objectives.
5. Establish qualitative and quantitative indicators.
6. Determine resources needed to achieve objectives.
7. Determine the ability and willingness of the community to contribute time, money, and labor; what forms of contribution are needed; and what cost-sharing mechanisms will be put in place.
8. Determine the division of responsibility between the community and health professionals (who will do what).
9. Determine mechanisms for monitoring progress, supervision, and technical backup.
10. Identify training needs for community members and health professionals.
11. Determine mechanisms for ensuring transparency in project management and accountability of health services and community-elected bodies to the public they serve.
12. Determine the frequency of community meetings and the most effective channels for reporting to the community on project activities, including the amount of revenue generated and expenditures.

Some of the methods listed for community needs assessment can also be used for monitoring; for example, the door-to-door survey is essential. The main difference between the two processes is that whereas community needs assessment is usually conducted at the beginning of a project, participatory monitoring is continuous.

When developing a community-based monitoring system, the following key components of participatory monitoring should be addressed—

- Organize community members around specific tasks: data collection and analysis, presentation of information for community and health-service feedback, communication of results, facilitation of the interaction about data issues, and coordination of the participatory planning exercise.
  - Provide staff of health and health-related services continuous technical and methodological backup for the process. Use feedback sessions as platforms for maintaining a regular dialogue between service users and providers.
  - Simplify the methodology for gathering and analyzing information, so that those with little formal education can actively participate.
  - Develop a consensus as to what is the most essential information for action at the community and facility levels and what information is needed for monitoring.
  - Focus on information as a powerful tool for local decision making and action and not simply on the generation of data.
- Link community-based planning and monitoring to facility-level planning and monitoring. Information at the community level and the dialogue between health staff and users often generate quantitative and qualitative information that can be vital to improving the performance of health facilities.

### 31.8 Creating an enabling environment

Community participation rarely emerges on its own without some external influence. It succeeds best within an enabling environment and with the support of appropriate mechanisms at all levels. Conditions that favor the development of community participation include the following (Oakley 1989)—

- Political commitment to community participation in health development and to the general notion of people's participation
- Interest in the decentralization of health services and the corresponding strengthening of district health systems that will serve as the basic health unit for community participation
- Existence of a minimum health structure that can serve as the basis for community participation in health care
- Development of people's managerial capabilities to take responsibility for a process of participatory health development

#### Country Study 31-4

#### Creating an enabling environment in the community to encourage tuberculosis treatment compliance

The Cambodian Health Committee, a nongovernmental organization, developed a community-based approach to TB case detection and treatment compliance in Svay Rieng, one of the poorest provinces in Cambodia. Barriers to TB treatment had included a lack of access to health facilities in rural areas and the economic burdens of time spent at and in travel to health centers. The program consisted of two components—one health center based and one home based. Both components relied on a set of interventions that included pretreatment patient education, patient supporters to supervise treatment, a treatment contract, food incentives, surprise home visits, and a microfinance project that established a network of village banks. The banks' low-cost loans to families involved in treatment and the food supplements provided to patients as an incentive to take their medication were special ways of reducing poverty in the

community and raising the public visibility of the TB treatment program.

The program resulted in some of the highest TB case-detection rates in the world; case-notification rates in the home-based program were over four times higher than the national rate of 144 per 100,000 people, and cure rates in new patients were over 90 percent for both health center- and home-based components. Both loan repayment and TB cure rates were close to 100 percent for the 590 families that participated in the village bank loans. The interest charged on the loans was used to train ninety-six village health agents to conduct community education and help with patient detection and follow-up. The use of food gifts as an incentive for treatment compliance was adopted nationwide as part of the Cambodian National TB Program.

Source: Thim et al. 2004.

An enabling approach requires training sessions for community representatives and leaders so that they can acquire basic managerial and organizational skills (group formation, leadership), basic financial management skills (budgeting and accounting), communication skills, and methodologies and skills for local information management (data collection, analysis, presentation of information, and feedback).

Health staff and other development agents can promote participation by providing technical support to—

- Develop local, community-based structures through which people can participate and hold health services accountable
- Maintain a continuous dialogue between service providers and community groups—consultation with communities should take place at all stages of the process, and health committees should work with other community leaders to find feasible mechanisms for regular interaction
- Improve local-level coordination among sectors so that the underlying basis of poor health can be understood
- Gain support from nongovernmental organizations, which can provide additional resources for health as well as play an important role in promoting community participation
- Supervise activities and provide feedback to the district level
- Create enablers and incentives to encourage community involvement in health care

An *enabler* is defined as a stimulus provided to a patient, caregiver, or health care provider to facilitate adherence to treatment; for example, a voucher to cover transportation expenses to attend clinics or to visit patients. An *incentive* is an added stimulus to encourage participation in treatment, such as monthly food baskets for patients if they adhere to treatment norms and make clinic visits, or food or other rewards to community treatment supervisors who properly supervise patients. Country Study 31-4 shows how a province in Cambodia created an enabling environment for a community-based tuberculosis program.

Finally, community initiatives and participation in health must be seen as part of the broader network of community participation in development and in all social services. ■

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## ASSESSMENT GUIDE

### Enabling factors

- Is there political commitment to community participation in health development?
- Is there interest in the decentralization of health services and the corresponding strengthening of district health systems?
- Does a health structure exist?
- Is there a commitment to developing people's managerial capabilities to enable them to take responsibility?

### Community participation indicators

- Do communities contribute money, labor, or materials to health projects or support community health workers?
- Are community members asked for their views and informed of project plans?
- Do community members actively participate in decisions and in the control of resources?
- What mechanisms exist to increase people's access to information, knowledge, and skills and to help them make their goals and priorities known?
- What organizational structures exist at the community level to facilitate participation?
- What community members provide health services or medicines or preventive health messages?

### Community participation and pharmaceutical management

- Are community health workers used to help extend health care services to peripheral levels?
- Are they seen as part of the health care system? Are they volunteers?
- Who monitors them?
- What are the main sources of medicines and care in the community?

- What are the availability and use practices of key medicines in the community?
- Do mechanisms exist for consumers to provide feedback to prescribers on the effectiveness of medicines, undesirable side effects, and so on?
- Does community cost sharing exist to help cover the costs of health services and pharmaceutical supply?
- Are communities involved in the management of facility-based health services?

### Involvement of health professionals

To what extent do health professionals—

- Establish relationships within the community?
- Share skills and experiences with and learn from the community?
- Ensure service quality through monitoring and supervising community health services?
- Respect people's ideas, skills, and wisdom?
- Promote equity in male-female representation and in the representation of various social, economic, and age groups in local decision-making bodies?
- Respect the social practices, traditions, and culture of the community?
- Foster collaboration with other projects, organizations, and services on behalf of the community?

### Community participation in program planning

- Do communities participate in needs assessments?
- Do communities participate in the dissemination of the results?
- Do community members and health professionals plan together what actions need to be taken, how, when, and with what means?
- Are community members involved in monitoring project activities and results?

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