Chapter 2 showed how WHO and partners are galvanizing treatment scale-up as part of a comprehensive response to the pandemic. Forming close partnerships with communities and civil society groups, particularly people living with HIV/AIDS, will be crucial to achieving the treatment target, to the success of the overall response, and to the wider goal of strengthening health systems. Such community participation will include advocacy, delivery of services and support to patients. Involving communities as full partners will require changes to the way in which public health services are delivered.

Throughout the history of HIV/AIDS, many communities and groups have demonstrated remarkable energy in working to help all those whose lives have been affected. This chapter touches on some of the most inspirational examples of that vigour, which have made important differences to public and political perceptions of the disease and led to major and lasting benefits for the community as a whole. Today, the commitment shown by communities is an invaluable resource that can support the expansion of antiretroviral treatment. Beyond that vital objective, it will powerfully influence progress towards more general improvements in public health and access to care.

This chapter describes the emergence of community participation as a recognized dimension of public health work. It then examines some of the historical milestones of civil society involvement in the fight against HIV/AIDS. It emphasizes the power of a rights-based approach to achieving health goals. Finally, the chapter explores civil society and community participation in treatment expansion, particularly the role of community health workers. Communities are groups of people living near each other, or with various social connections, and often with a shared sense of purpose or need. Within the wider community, specific HIV/AIDS communities exist, made up of people living with HIV/AIDS, their friends, families and advocates. These HIV/AIDS communities may or may not adopt formal organizational structures. Civil society organizations – those that do not fall within government or private industry – include associations of people living with HIV/AIDS and their advocates, faith-based organizations, and other groups such as trade unions or employer associations.
A choir sings farewell to Mzokonah

Mzokonah Malelu was ill for a long time before discovering he was HIV-positive. At first he wanted to tell only his mother, but with the guidance of a counsellor he decided to break the news to everyone in his community. He had a particular message for them about the need for them to protect themselves.

“I hope there will be a purpose in my death, and that my dying will help to educate my family and my community,” said Mzokonah. “I want my funeral to be an HIV/AIDS education funeral, where the message can be spread far and wide.” His wish was granted.

Community participation: advocacy & action

The Society for Women and AIDS in Africa (SWAA) is a pan-African, grass-roots nongovernmental organization established in 1988 in response to the impact of HIV/AIDS on women and children in Africa. It tackles the factors that lead to the unequal impact of the epidemic on women, and seeks gender equity in prevention and care programmes. SWAA works in 40 African countries, focusing on networking, research, advocacy, care and support, human rights and legal issues, orphans and vulnerable children, and prevention options for women. Some examples of its activities are described below.

Achieving the 3 by 5 target will require building partnerships between national governments, international organizations, civil society and communities — and drawing on the specific strengths of each to get the work done on the ground. Government leadership will be indispensable, and civil society cannot replace the public sector. But part of effective government leadership will be forming partnerships with civil society groups and creating mechanisms to harness the skills available within communities. WHO and other international organizations can facilitate and support the process. By working with communities, the 3 by 5 initiative expresses the vision of Health for All affirmed at Alma-Ata (now Almaty, Kazakhstan) in 1978, which unites people’s right to health with their right to participate in the decisions that affect their lives.

Community participation in public health

WHO’s Constitution of 1948 states that “informed opinion and active co-operation on the part of the public are of the utmost importance” in improving health, but it was in the 1980s and early 1990s that the practical benefits of community participation in, and ownership of, health projects began to attract increasing attention. Projects in areas of Guatemala, Niger and the United Republic of Tanzania demonstrated that population health gains could be made as a result of increased community involvement. In these projects, community input helped shape programme priorities and community health workers took on significant responsibilities (1). In 1978, the full participation of the community in the multidimensional work of health improvement became one of the pillars of the Health for All movement. In 1986, the Ottawa Charter, signed at the First International Conference on Health Promotion, identified strengthening community action as one of five key priorities for proactive health creation (2).

Since then, there have been both successes and setbacks. The actual capacity of communities to participate in defining and implementing health agendas has been limited by resource constraints, entrenched professional and social hierarchies, and public health models focused on individual behaviours and curative biomedical interventions. Gender, race and class discrimination also play a role. Nevertheless, communities have taken part in many successful public health projects, including sanitation, nutrition, vaccination and disease control programmes (3). Recent reviews of primary health care have continued to find strong support for community participation and there is evidence that such involvement has led to significant health gains (4).

Civil society responds to the AIDS tragedy

The response to the HIV/AIDS pandemic by civil society around the world is one of the most vivid examples of community participation and self-determination. The emphasis in the Declaration of Alma-Ata on community participation “in the spirit of self-reliance and self-determination” fits with the views of early HIV/AIDS activists, expressed in the Denver Principles (5). Drafted in 1983 at a meeting of activists in Denver, USA, they assert the right of people living with HIV/AIDS to dignity in life and death and to representation and power in all decisions concerning their well-being.

In the USA, where the first HIV/AIDS cases had been reported in 1981, then in Europe, Canada and Australia, organizations of gay men and women were the first to respond. The Terrence Higgins Trust was established in the United Kingdom in 1982. Helseutvalget for Homofile (Norwegian gay health association) was created in 1983. These and similar groups built on strategies and social capital developed in the gay rights and feminist movements of the preceding decades.

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Groups such as the AIDS Coalition to Unleash Power (ACT UP), formed in the USA in 1987, combined a successful advocacy strategy with the building of a formidable scientific knowledge base, which enabled members to become informed participants in medical research and the policy-making process. During the 1980s and 1990s, these groups won increased funding for antiretroviral drug research, increased AIDS services budgets at federal, state, and local levels, an accelerated testing process for drugs, and expanded access to experimental drugs for people not accepted into clinical trials.

International civil society organizations, including the International Federation of Red Cross and Red Crescent Societies, have been crucial in the fight against HIV/AIDS. In African countries with struggling health systems, numerous community-based and nongovernmental organizations were on the front lines. In many communities, women assumed key leadership roles. The AIDS Support Organisation (TASO) was founded in Uganda in 1987. TASO’s work has included advocacy and community education, and also a wide variety of services to people living with HIV/AIDS and their families. Working closely with government, other nongovernmental and faith-based organizations, and the private sector, TASO has been a leading contributor to Uganda’s HIV/AIDS control programme. In 1988, a group of African women created the Society for Women and AIDS in Africa (SWAA), to work with and for women and their families affected by the epidemic, based on locally defined concerns and priorities. Today, SWAA has become a continent-wide network, working in 40 countries (see Box 3.1).

Other women-led groups have had a powerful impact at country and local levels. Women Fighting AIDS in Kenya, for example, was founded in 1993 by a group of women in Nairobi, many of whom were HIV-positive. In addition to advocacy for women and children affected by the pandemic, the group offers a wide range of services to women and families, including HIV education, individual counselling and support, home-based care, and training in income-generating activities. From an early stage, faith-based organizations have assumed major responsibilities for activities connected with HIV prevention, community education, care, treatment and support (see Box 3.2).

Faith-based organizations have a crucial role to play in the widespread uptake of HIV/AIDS treatments, because of their influence within communities and their reach in rural and remote areas. Together with religious institutions, faith-based organizations are central to efforts to reduce stigma and discrimination. They account for around 20% of the total number of agencies working to combat HIV/AIDS. They are well positioned to offer psychosocial, moral and spiritual support to people in difficult circumstances, and they now have a growing role in treatment scale-up.

The Saint Stephen’s Anglican Church Widows’ Group in Kisumu, Kenya, for example, helps operate a mobile voluntary counselling and testing clinic that also provides essential medicines for opportunistic infections and runs income-generating activities for women and young people. Although they have not been directly engaged in the provision of antiretroviral drugs so far, their efforts are integral components of a successful scale-up strategy.

Some faith-based organizations have designed systems for tackling inequity and gender issues in relation to access to antiretroviral drugs. They have worked to ensure that certain individuals or groups do not have privileged access to treatment, but rather that communities develop their own criteria for access. Other organizations are involved in the direct provision of drugs. For example, the Mission for Essential Drugs and Supplies, a joint collaboration between the Christian Health Association of Kenya and the Kenya Episcopal Conference-Catholic Secretariat, is providing affordable essential medicines including antiretroviral drugs. They are importing generic drugs for the Mission and for other nongovernmental organizations at a reduced cost. The Mission’s health facilities also have a home-based care component that supports monitoring of adherence to antiretroviral therapy and tuberculosis medications, and contributes to nutritional and other socioeconomic support to households and communities.

Faith-based organizations could be brought into treatment scale-up in order to combine their comparative advantages (in, for example, community mobilization, care activities, bringing about adherence and promoting confidence to seek treatment) with the training of their non-medical personnel in relevant medical skills.

The POWER OF A HUMAN RIGHTS APPROACH

Advocacy arguments have increasingly been grounded in a human rights framework. This draws on both fundamental moral principles and the legal obligations of states to respect, protect and fulfil human rights, including the right to health. These obligations derive from international law, regional human rights agreements and national laws (6). A rights-based approach to HIV/AIDS has propelled social mobilization by civil society groups in a growing number of countries.

In Brazil, the Brazilian Interdisciplinary AIDS Association, founded in 1986, works to defend the rights of people with HIV/AIDS through research, education and policy analysis. In Bolivia, Venezuela and other Latin American countries, civil society organizations have successfully used legal action based on human rights conventions to obtain access to treatment through national health systems (7).

The Treatment Action Campaign in South Africa uses community education and mobilization, mass civil protest, media campaigns, legal mechanisms, and alliances with other nongovernmental organizations and labour groups to defend the rights of people infected with and affected by HIV. Its national fight for access to HIV/AIDS therapy led to the Pan-African Treatment Action Movement, launched in August 2002.

Human rights standards and principles should also guide the planning and implementation of treatment policies and programmes. The human rights approach recognizes that rights are universal and respects the value of full participation of all members of society. Such an approach also requires increased accountability of decision-makers and greater equity in health care policies.

Countries have increasingly acknowledged these imperatives. At the 1994 World AIDS Summit in Paris, 42 governments declared that the enhanced involvement of people living with or affected by HIV/AIDS was critical to ethical and effective national responses to the epidemic. This principle of greater involvement is fundamental to the fairness of any policies and programmes concerning HIV/AIDS (6). In 1998, the Office of the United Nations High Commissioner for Human Rights and UNAIDS jointly developed international guidelines on HIV/AIDS and human rights, a tool that applies human rights law and norms to the specific context of HIV/AIDS and identifies what states can and should do in the light of their human rights obligations (6). Commitment to these principles was reinforced in the Declaration of Commitment on HIV/AIDS, adopted at the United Nations General Assembly Special Session on HIV/AIDS in 2001 (10).

Nongovernmental organizations and civil society groups have the application of human rights standards to the problem of access to medicines for the poor (see Box 3.3). Efforts such as the Access to Essential Medicines Campaign and the Drugs for Neglected Diseases Initiative of Medicines Sans Frontières have focused global attention on the medicines crisis in the developing world and helped drive public debate on the effects of trade and intellectual property rights regulations on poor people’s access to treatments for a wide variety of health problems (11–13).

An international coalition of activists and civil society groups worked with representatives of developing countries before and during the World Trade Organization (WTO) Ministerial Conference in Doha, Qatar, in November 2001. Civil society engagement gave impetus to the Doha Declaration, which formally clarified that the WTO Agreement on Trade-Related Aspects of Intellectual Property Rights “can and should be interpreted and implemented in a manner supportive of WTO members’ right to protect public health and, in particular, to promote access to medicines for all” (14) (see Box 2.5). In April 2002, the United Nations High Commissioner for Human Rights welcomed the Doha Declaration and urged the international community quickly to define ways of enabling all countries to benefit from its provisions (15).
CIVIL SOCIETY AND TREATMENT EXPANSION

Civil society advocacy helped open the way for the 3 by 5 initiative. UNAIDS and WHO calculated in 2001 that it should be possible to provide 3 million people in developing countries with antiretroviral therapy by the end of 2005, but international commitment, funding and patient enrolment lagged. Energetic advocacy by activist groups in forums such as the 2002 Barcelona International AIDS Conference helped to turn the idea of expanded access to antiretroviral drugs into a definite policy commitment engaging national governments, the United Nations and other major international institutions.

Following the declaration of the global AIDS treatment emergency, representatives of people living with HIV/AIDS from Africa, Asia, the Caribbean, Europe, Latin America and North America were among the key partners consulted in the design of WHO’s 3 by 5 strategy. Ongoing collaboration is vital. Catalysing innovative partnerships is one method of changing ways of thinking and working in global health. The treatment initiative is making community participation a measurable element of programme processes and outputs: an intermediate target has been set of 3000 partnerships established worldwide between formal antiretroviral therapy outlets and community-based groups by December 2004 (16).

From advocacy to service implementation

Advocacy, community education and promotion of rights will be crucial to the success of scaling up treatment. The vital role of communities in prevention and long-term care has been widely acknowledged (17). In many countries aiming to expand coverage with antiretroviral therapy despite severe health workforce shortages, members of local communities will also participate directly in service provision and support (18). Growing evidence from innovative treatment programmes shows that community members and their organizations are also capable of performing a broad range of essential tasks in the provision of antiretroviral treatment services.

Rapid assessments of treatment sites in a number of high-burden countries, together with a few documented programmes, suggest that the core function of communities and families lies in adherence support. In some treatment programmes, community organizations have transferred to their own settings tasks traditionally performed by facility-based formal health workers. For example, trained community members monitor side-effects and supervise pill intake in Haiti and Rwanda (18, 19).

Some associations of people living with HIV/AIDS in settings with limited treatment access have, purely as a survival strategy, initiated their own services with support from organizations in richer countries. They rely on the formal health care delivery system only for essential medical tasks. Many treatment-related tasks, such as the administration of laboratory monitoring, are performed by community members (20). Another example of moving tasks out of formal medical facilities and into the community comes from Uganda, where TASO’s Masaka branch takes responsibility for the initial selection and counselling of patients for antiretroviral treatment, then refers them to a treatment programme located in the district hospital (see Box 3.4).

In some cases, community members have worked within formal health centres. For example, in Thailand, day care centres have been set up within public health facilities, where people living with HIV/AIDS can meet and participate in various activities. Community organizations are an integral part of the care and treatment system. In Khayelitsha, South Africa, lay people have moved into the primary health care centre as counsellors, helping patients to make treatment plans in order to enhance adherence (21).

Experiences in several existing antiretroviral treatment sites suggest that the relationship between health facility and community can and should be structured as a genuine partnership. A partnership model allows for regular dialogue, assigns tasks to those best suited regardless of professional status, and supports mutual feedback. Considerable investments are necessary in terms of training, staff time for supportive supervision, and additional support. A critical issue is sharing ownership of the treatment programme: health workers who are usually accustomed to maintaining control over service provision, specifically with regard to treatment, may be reluctant to share ownership of the treatment programme with communities or even accept community members’ input in responding to clients’ needs.

Employing people living with HIV/AIDS as paid staff members is another strategy that may allow facilities to benefit from their unique skills and knowledge and help to break down barriers between health services, communities and clients. Different disease programmes have reported that health professionals often initially resist the involvement of community members in care and treatment, but later accept this involvement when they see the positive results obtained (24, 29).

Front-line facilities – health centres – are in direct contact with families and clients on a daily basis, and therefore in a position to maintain a functional partnership with communities. Evidence suggests, however, that this unique opportunity is often missed. Community organizations are frequently overlooked by health professionals, and their potential to contribute to health is often not appreciated by the health care system (26).

Shared ownership – increasing the control of communities and clients over health services – is not only desirable from a human rights point of view, it is a requirement for reaching the poor with antiretroviral treatment and other health services. Many success stories exist. In Zambia, the Chikankata faith-based district hospital generated a community process that resulted in excellent joint work for HIV/AIDS prevention and care (27). In one of the poorest communities in Haiti, clients and their fellow community members have become active contributors to antiretroviral treatment services (28). The network of AIDS Communities in South Africa mobilized external support and built a broad partnership to set up and run a treatment clinic in KwaZulu-Natal (28). The success of the partnership model is clear at the level of small programmes, so the challenge is to scale up these models. As countries move to expand delivery of treatment, existing health service structures may be used to facilitate community partnerships. The most relevant in many settings may be those front-line structures connected with primary health care.

To establish community involvement as normal practice in existing health facilities targeted for scale-up of antiretroviral therapy, efforts are needed to change the relationships between communities and health providers. This implies fostering appropri-
Recent experiences show that, with supervision, HIV/AIDS treatment programmes can be introduced for the poor by communities using community health workers. In the Masaka district of Uganda, antiretroviral treatment programmes are available in small-scale community and faith-based settings integrated into the local public health system. The Masaka district office of The AIDS Support Organisation (TASO) which is the national non-governmental non-profit health care organization, is also located on the hospital premises. TASO fulfills various critical roles related to treatment, including: initial selection (based on agreed criteria), counseling and referral of candidates for treatment from the members enrolled in its community and faith-based care programme. This maximizes the treatment readiness of patients before they first visit the facility for counseling and clinical review. The Kitovu mobile service (a faith-based community and home care organization) is a similar referral partner. TASO helps to maintain quality care. If community health workers are not involved in this area, people are less interested in and supportive of their activities. Experiences from Nepal, for example, show that when policies were established that allowed community health workers to dispense medication, community workers’ motivation and their acceptance by the wider community increased. Poor performance of community health worker programmes is also frequently associated with an insufficient supply of drugs.

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In the Masaka district hospital as an outpatient service, the following areas are vital for achieving success:

1. **Inclusion of curative activities**: Community health workers have functioned successfully in small-scale non-governmental programmes as well as in largescale national programmes integrated into the public health system. In many countries in sub-Saharan Africa, for example, faith-based organizations have provided quality care for 20 years. Many faith-based health care facilities have large staffs of outreach workers, home and community health workers, who function in unique networks. These networks have also played important roles in HIV/AIDS prevention and care. The 3 by 5 initiative will partly be run through these infrastructures, using the capacities and networks already in place.

2. **Community health workers**: Community health workers are a prime area for the practical approach to increasing treatment coverage. Although current knowledge is far from exhaustive, the existing evidence provides enough information to enable planners and implementers to move immediately to build programmes in a step-by-step, problem-solving manner, tackling obstacles as they arise. Operational research will be vital in providing quick feedback on lessons learnt from community health worker participation, as programmes scale up. This research must be planned and budgeted for.

3. **Motivation and acceptance**: Community health workers should not be viewed simply as local helpers who can temporarily take on tasks the formal health care delivery system lacks the resources to perform. They are not primarily a cheap way to deal with human resource constraints.

4. **Community ownership**: One approach to strengthening the active engagement of communities in health development is to train and deploy people as community health workers. Antiretroviral treatment programmes in resource-limited settings have so far not often built on existing community worker programmes, but it is important that countries assess their experiences in this area and look for chances to work with community health worker cadres and recruit people living with HIV/AIDS (see Box 3.5). Community health workers have functioned successfully in small-scale non-governmental programmes, as well as in large-scale national programmes integrated into the public health system. In many countries in sub-Saharan Africa, for example, faith-based organizations have provided quality care for 20 years. Many faith-based health care facilities have large staffs of outreach workers, home and community health workers, who function in unique networks. These networks have also played important roles in HIV/AIDS prevention and care. The 3 by 5 initiative will partly be run through these infrastructures, using the capacities and networks already in place.

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6. **Specific arrangements for greater community ownership**: Community health worker programmes can and should be seen as part of a broader strategy to empower communities, enable them to achieve greater control over their health and improve the health of their members.

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that supervision is effectively provided by regular meetings, simple forms that facilitate reporting and feedback, and willingness of health professionals to engage with communities (19, 20). A community health workers’ programme should be integrated into a referral system that includes more advanced care centres able to respond to problems that cannot be solved at lower levels.

Remuneration: where financial compensation is provided to community health workers, both benefits (retention of workers) and negative effects (being viewed by communities as government employees) have been found (28). Community health workers who volunteer can usually contribute only a limited time each week. Innovative ways to compensate volunteers for their time have been introduced. For example, community volunteers involved in the onchocerciasis control programme in Kabarole district, Uganda, combined the distribution of drugs to control onchocerciasis with the retail of condoms which became an effective income-generating activity (28).

In several countries, volunteers receive no payment, but do receive incentives with monetary value, for example a bicycle that can be used for other purposes. Payment is needed to sustain the required level of commitment in the long run whenever community health workers are contributing an amount of time comparable to that given by professionally trained health workers. No community health workers’ programme, whether relying on volunteers or paid workers, is without costs, and every such programme will need a budget to be effective and sustainable.

Relationship with the community: support and recognition from community organizations and leaders, and appreciation from members of the community, are identified as critical incentives for community health workers (28). Fostering such relationships will mean involving associations of people living with HIV/AIDS and other community-based organizations and leaders whose support will be vital. Through their networks, community organizations may complement community health workers by tackling needs such as nutrition and income generation. Efforts to keep community health workers strongly attached to community organizations are therefore important. This can be accomplished by working through existing community-based organizations in setting up and monitoring the community health workers’ programme. It will be critical to put in place arrangements that guarantee accountability. One way to achieve this is to give the community organizations, rather than the formal health care system, control over monetary or other compensation for community workers.

COMMUNITY EMPOWERMENT AND PUBLIC HEALTH: SHAPING THE FUTURE

Community involvement is essential to all aspects of a comprehensive approach to HIV/AIDS: prevention, treatment, care, support – and research (see Chapter 5). In

Box 3.5 Applying the expertise of people living with HIV/AIDS: Hellen’s story

Hellen is the administrative clerk at an HIV/AIDS clinic in rural Uganda. As a person living with HIV who started antiretroviral treatment nine months ago, Hellen has considerable insight into the ups and downs of treatment. With this expertise, she is able to respond to many of the concerns that patients bring to the clinic. Innovative ways to compensate volunteers for their time have been introduced. For example, community volunteers involved in the onchocerciasis control programme in Kabarole district, Uganda, combined the distribution of drugs to control onchocerciasis with the retail of condoms which became an effective income-generating activity (28).

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the process of strengthening health systems. Success in accelerating this process could be a lasting contribution of the 3 by 5 initiative to global health improvement.

This chapter has demonstrated the vital role that communities and civil society organizations play in the fight against HIV/AIDS and the success of the 3 by 5 initiative. Governments and international organizations, including WHO and its partners, will catalyse this process. The next chapter shows how the comprehensive response, with the close involvement of all these allies, aims to strengthen health systems and hence bring long-term improvements in health services for all.

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