



# Charting a Course





SECTION 2

# Charting a Course: Cornerstones and Common Advocacy Steps

Since the advent of the global HIV/AIDS pandemic, the advocacy efforts of those most affected by the disease and their allies have done much to shape the course of the disease’s spread. The fields of science and medicine have made an enormous contribution toward understanding and treating the disease. But, without the unrelenting and passionate advocacy of our early activists, these advances might have never occurred.

Of course, there are as many definitions of advocacy as there are advocates and causes. Advocacy is a lot like language in the sense that it is partially defined by the context in which it is used. Advocacy is also a concept and a word that is difficult to define in many languages and cultures that look with disfavor on citizen participation. The most important consideration to bear in mind when defining advocacy is that the definition must make sense within the local language and culture and to those organizations and people carrying out the work.

Some definitions of advocacy:

- “Advocacy is a set of targeted actions directed at decision makers in support of a specific policy issue.”  
*Networking for Policy Change: An Advocacy Training Manual.* POLICY Project, 1999.
- “Advocacy means putting across your message to other people to bring about wider public understanding about HIV and other issues, changes in policies, laws and services. Advocacy work can involve action at all levels, locally and through representation [on] national decision-making bodies.”  
*Positive Development: Setting up self-help groups and advocating for change. A manual for people living with HIV.* Global Network of People Living with HIV/AIDS (GNP+), 1998.
- “Advocacy is a process to bring about change in the policies, laws, and practices of influential individuals, groups, and institutions.”  
Adapted from an advocacy skills-building workshop for HIV/AIDS. International HIV/AIDS Alliance, Zimbabwe, July 2001.
- “Advocacy is not just about getting to the table with a new set of interests, it is about changing the size and configuration of the table to accommodate a whole new set of actors. Effective advocacy challenges imbalances of power and changes thinking.”  
*The Action Guide for Advocacy and Citizen Participation.* World Neighbors, 2002.
- “Advocacy is an action directed at changing the policies, positions, and programmes of any type of institution.”  
*An Introduction to Advocacy: Training Guide.* SARA Project, 1997.

These definitions share a common language and common concepts that speak to advocacy as a process and a strategy aimed at influencing policy, law, regulations, programs, or funding. As such, the target of advocacy efforts is decision makers—government officials, religious leaders, and business leaders—who influence and have direct control over such matters.

The following section identifies six cornerstones that characterize HIV/AIDS advocacy, highlights key moments in the history of advocacy for HIV/AIDS issues, and outlines some of the common steps that are essential to successful advocacy efforts. Examples of the unique cornerstones and common steps are explored in the advocacy stories that follow in Sections 3–6.



## 2.1 Cornerstones of HIV/AIDS Advocacy



HIV/AIDS advocacy is, of course, similar in many ways to other types of advocacy carried out by other social movements. In fact, HIV/AIDS advocacy has drawn many of its strategies from earlier social movements throughout the world, such as the civil rights and women's movements in the United States; the anti-apartheid movement in South Africa; the liberation movements in Latin America; and the environmental movement occurring in countries across the globe.

Yet, while HIV/AIDS advocacy shares approaches, concepts, and characteristics with advocacy carried out for other issues, it is also characterized by many elements unique to HIV/AIDS that have added new techniques, strategies, and language to the world of advocacy. Six cornerstones of HIV/AIDS advocacy are described below. Each cornerstone is represented by a symbol that will be used throughout the remainder of the manual when an advocacy cornerstone is illustrated in the advocacy stories.



**Meaningful Involvement of People Living with HIV/AIDS (PLWHA).** As with other movements that recognize the value of empowering the communities most affected by a particular issue, a crucial goal and hallmark of HIV/AIDS advocacy is the meaningful involvement of PLWHA in all aspects of the programmatic and policy responses to the pandemic. The Paris AIDS Summit of 1994 and the 1983 Denver Principles, which evolved when a small group of PLWHA got together at a gay and lesbian medical conference and protested their exclusion from planning workshops related to AIDS, are prime examples of the involvement in advocacy efforts of those most affected by the pandemic. At the Paris Summit, PLWHA formed a working group and prevailed upon the 42 nations present to include the Greater Involvement of People Living with HIV/AIDS Principle, or GIPA, in the final declaration. GIPA asserts the principle that in order to increase the effectiveness of HIV/AIDS policy and programming, PLWHA need to be included at all levels of decision making in political, legal, and social spheres. As a result of these efforts, GIPA is recognized as an essential element and included in all major HIV/AIDS-related international declarations, such as the Declaration of Commitment of the U.N. General Assembly Special Session (UNGASS) on HIV/AIDS in 2001, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), and in many national HIV/AIDS strategic plans. In the United States, GIPA-related efforts led to laws that mandate, as a precondition to the receipt of federal funds, the involvement of PLWHA in the planning councils that distribute funds for HIV/AIDS prevention and care. While many parts of the world are still struggling to achieve the principles asserted in GIPA, those principles have helped shape responses to other diseases, such as breast cancer, and have helped redefine the roles of patient and doctor.



**Urgency.** Given that PLWHA themselves are often the main drivers and leaders of HIV/AIDS advocacy efforts worldwide, perhaps the greatest and most poignant distinction between HIV/AIDS advocates and other advocates is the sense of urgency that underlies their mission. Time is a luxury that many HIV/AIDS advocates do not have. The specter of illness and/or death that hangs over the AIDS world leads to actions and strategies that

do not always conform to the rules or expectations of society at large, let alone to the ordered and protocol-driven world of policymakers. It is passion, often driven by anger, fear, and desperation, that has fueled AIDS activism and sets it apart from other causes in which imminent illness and death may not be at stake.



**Creative Use of External/Internal Advocacy Strategies.** The two main styles of citizen-to-institution advocacy are that which originates outside of or external to the institution and that which originates from within or internal to the institution and seeks institutional change. The two styles often operate in combination, such as when citizens from outside the institution “gain a seat at the table” within the institution. The main difference in the two basic advocacy types is the power that each represents—broad, citizen-based power or the power that comes with a particular job location at a particular time and place. While many advocacy efforts use a combination of external and internal advocacy strategies, HIV/AIDS advocates have refined the combined strategy, making it a cornerstone of many successful efforts. For example, in the early days of the AIDS Coalition to Unleash Power (ACT UP) (profiled in Section 4) and today in many parts of the world, it is not unusual to see HIV/AIDS advocates noisily demonstrating outside the “seats of power” one day while a core group of the same advocates dons business attire and meets with senior government officials and policy stakeholders the next day. To be able to carry off the combined approach effectively, HIV/AIDS advocates have maintained flexibility in their approach and, more important, have made sure that they are well informed, often themselves becoming the experts on all aspects of dealing with HIV/AIDS, including scientific research, treatment, epidemiology, law and human rights, and so forth.



**Flexible Organizational Structures to Support Advocacy.** Organizational structures to bring people together are pivotal to advancing the advocacy process. Organizational structure refers to the range of ways in which groups of people come together, form a group or partnership, and plan and implement their activities—whether the simple decision among a group of five HIV-positive people to meet once a week at the same place and same time or the creation of a more complex organization to carry out a multistate letter-writing and media campaign. In almost all advocacy activities, change cannot be achieved without an organization, coalition, network, or partnership. For HIV/AIDS advocacy, several organizational structures have been especially important to developing the base for advocacy as well as for implementing specific advocacy activities. These structures create a space for people to come together, to talk, to educate each other, and to form networks and coalitions. Two structures that have been instrumental in HIV/AIDS advocacy are:

- **Self-help groups and networks.** In HIV/AIDS advocacy, the process of organizing a self-help group is itself a form of advocacy that addresses shifting norms and stigma and discrimination. The formation of a PLWHA support group, especially a group that names itself and is known by the community, communicates the following to the public: *We are people who will no longer remain silent and hidden behind a wall of shame. We will take responsibility for ourselves. We are worth caring about.* As important, we have seen that, in many countries, the formation of a self-help group has been the initial critical step that leads to PLWHA empowerment and the subsequent formation of advocacy groups and networks. Thus, the formation of self-help groups provides a vital foundation for advocacy for policy change.
- **Conferences.** Conferences can be an efficient means of communicating with many different stakeholders at one time—from NGO representatives, to government ministers, to top-level researchers at prestigious institutions, to members of advocates’

own constituency. Conferences often provide the time and space for special interest groups to come together for focused meetings, enabling large numbers of people to engage in demonstrations, dialogue, or debate on the same issues. HIV/AIDS advocates have used national, regional, and international conferences effectively and creatively both to advance their advocacy agenda and to coalesce, plan, and develop organizational structures by which to organize their advocacy efforts after the conference is long over.



**Use of Cultural Work and Symbols.** An important aspect of HIV/AIDS advocacy has been cultural work aimed at changing the broader social environment. Creating and/or changing the environment refers to the broad spectrum of activities that attempt to open up dialogue or advance an agenda at a public level. Efforts to alter the environment can be identified as “cultural or environmental advocacy.” The tactics adopted by advocates to achieve environmental advocacy are familiar to many of us and include the use of public billboards to depict a message, reliance on the media such as television and radio to convey certain ideas, and the development of symbols and slogans that articulate a theme. In some ways, we are talking about clever and creative marketing techniques that convey themes about social justice.



As demonstrated by the work of ACT UP in New York, the creation of cultural symbols was an important part of the group’s advocacy message. Among the best-known symbols was a pink triangle with the words “Silence = Death” beneath it. It came to represent the broad-based voice of activists encouraging the gay community and others most affected by HIV/AIDS to speak out, attempting to educate people about HIV/AIDS, and pressuring the government to acknowledge and respond to the epidemic. In addition, a pervasive and well-known cultural and social message campaign developed by HIV/AIDS advocates is the red ribbon. It is the international symbol of HIV and AIDS awareness and stands for hope, care, and support. The symbol has become so universally accepted that a person in almost any country would recognize the symbol pinned to a lapel or collar or emblazoned on a t-shirt as a show of support for the fight against HIV/AIDS. In South Africa, at the XIII International AIDS Conference in 2000, thousands of people, both HIV positive and negative, wore t-shirts that read, “H.I.V. Positive.” The t-shirt became a part of the culture of the conference and put forward a strong message against stigma and the importance of disclosing one’s positive status. What do these symbols, slogans, and sound bites achieve from an advocacy perspective? Perhaps the most significant effect is the way in which cultural interventions shape a social environment and become an integral part of a society. These interventions can often help create attitudinal shifts that build a supportive policy environment.



**Challenging Stigma and Discrimination.** A final defining characteristic of HIV/AIDS advocacy is the unique role of challenging the stigma and discrimination against PLWHA and those most at risk. In the United States, HIV first surfaced among society’s already marginalized and devalued groups—gay men and injecting drug users (IDUs)—often forced to live in secrecy and shame because of their stigmatized and/or illegal status in society. In many developing countries, even though HIV affects other populations, its pre-existing links to sex, sexuality, and drugs effectively stigmatizes those affected and creates a climate of silence and shame. Accordingly, advocates quickly realized that any efforts to create a more favorable policy environment for prevention and care would be difficult if not impossible without also addressing stigma and discrimination. In other words, a major component of HIV/AIDS advocacy is a set of efforts directed at changing social norms and attitudes.

The unique cornerstones of HIV/AIDS advocacy described above are but a few of the many common themes that have developed over the past 20 years. It is important to recognize that HIV/AIDS advocacy around the world has also been shaped and influenced by specific national and international circumstances set in specific historical moments. Likewise, in the future, PLWHA and HIV/AIDS advocates in individual countries and regions of the world will face different challenges requiring unique advocacy responses. Thus, HIV/AIDS advocacy will continue to evolve and address new challenges.

The table that follows shows which advocacy stories in Sections 3–6 illustrate the HIV/AIDS advocacy cornerstones.

Name of Organization	HIV/AIDS Advocacy Cornerstones					
						
<b>Women's Groups</b>						
3.1 La Fundación para Estudio e Investigación de la Mujer			✓	✓		
3.2 National Community of Women Living With HIV/AIDS	✓	✓		✓		✓
3.3 Women's Treatment Action Group		✓	✓	✓		
3.4 Society for Women and AIDS in Kenya	✓	✓		✓		
3.5 Sampada Grameen Mahila Sanstha			✓	✓		✓
<b>PLWHA Groups</b>						
4.1 AIDS Coalition to Unleash Power	✓	✓	✓		✓	✓
4.2 Network of African People Living with HIV/AIDS	✓	✓		✓		✓
4.3 National Guidance and Empowerment Network of People Living with HIV/AIDS	✓	✓				✓
4.4 Thai Network of People Living with HIV/AIDS	✓	✓	✓	✓		✓
<b>Faith-based Organizations</b>						
5.1 Islamic Medical Association of Uganda			✓	✓		
5.2 The Balm In Gilead			✓	✓		✓
5.3 Wat Norea Peaceful Children			✓	✓		✓
<b>Access to Treatment</b>						
6.3 Treatment Action Campaign	✓	✓	✓	✓	✓	✓
6.4 Health Systems Trust			✓			
6.5 Church of the Province of Southern Africa			✓	✓		✓
6.6 National Health Committee of the African National Congress			✓			



## 2.2 HIV/AIDS Advocacy Timeline



It is important for HIV/AIDS advocates to be familiar with the history of and the unique characteristics and challenges that have set the HIV/AIDS advocacy movement apart from other advocacy efforts. Advocates should also be familiar with the many flexible, creative strategies and mechanisms that have been developed around the world to confront and eliminate these challenges as well as with the lessons learned along the way. The timeline below highlights some of the key developments in HIV/AIDS advocacy since the early 1980s.

### 1981

- ✓ The Centers for Disease Control and Prevention (CDC) reports five cases of pneumocystis carini pneumonia (PCP) among gay men in Los Angeles in its *Morbidity and Mortality Weekly Report*. Many consider the report as marking the beginning of the HIV/AIDS pandemic, initially referred to as gay-related immune deficiency.

### 1982

- ✓ The CDC formally names the disease acquired immune deficiency syndrome (AIDS) after the disease is reported not just in gay men but also in women, male heterosexual IDUs, hemophiliacs, blood transfusion recipients, and babies. Fourteen nations report confirmed cases of AIDS.

### 1983

- ✓ Researchers under Dr. Luc Montagnier at the Pasteur Institute in France isolate a retrovirus they call lymphadenopathy-associated virus, which subsequently will be identified as the cause of AIDS. AIDS is reported in 33 countries.
- ✓ A small group of PLWHA gather at the Fifth National Lesbian/Gay Health Conference in Denver, Colorado, and draft the Denver Principles, considered by many the first act of PLWHA advocacy and self-empowerment.
- ✓ A heterosexual AIDS pandemic is reported in Africa.

### 1985

- ✓ In the United States, a 13-year old boy named Ryan White is barred from attending school because he has AIDS. Ryan becomes an unlikely HIV/AIDS advocate. He fights his local school board and wins the right to attend school. His courageous stand later leads to the Ryan White CARE Act Program, a \$2 billion annual federal assistance grant program for the care and treatment of PLWHA.

- ✓ AIDS claims its first known celebrity with the death of American movie star Rock Hudson.
- ✓ The U.S. Food and Drug Administration (FDA) approves the first HIV antibody test.

## 1987

- ✓ The Global Network of People Living with HIV/AIDS (GNP+) is founded. Today, GNP+ operates six regional secretariats and is a major force in PLWHA advocacy around the world.
- ✓ The AIDS Support Organization (TASO) is founded in Uganda and considered by many to be the first nongovernmental organization (NGO) in Africa to address HIV/AIDS.
- ✓ The FDA approves AZT (zidovudine), the first antiretroviral agent to treat AIDS. At \$12,000 a year, it is one of history's most expensive drug therapies.

## 1991

- ✓ Visual AIDS and Broadway Cares/Equity Fight AIDS, two New York City-based organizations founded by members of Broadway's acting community, introduce the red ribbon as a symbol of HIV/AIDS awareness.

## 1992

- ✓ The International Community of Women Living with HIV/AIDS (ICW) is founded by a group of HIV-positive women from many different countries in attendance at the VIII International AIDS Conference, held in Amsterdam.

## 1994

- ✓ Representatives of 42 nations sign a declaration at the Paris AIDS Summit, declaring AIDS a crisis. Initially excluded from the process, PLWHA form a working group. In the end, the working group prevails upon the summit to include the Greater Involvement of People Living with HIV/AIDS Principle, or GIPA, in the final declaration.
- ✓ The Network of African People Living with HIV/AIDS (NAP+), the National Association of People Living with HIV/AIDS in South Africa, and other PLWHA groups are founded throughout Africa to represent the interests and aspirations of people infected and affected by HIV/AIDS.

## 1995

- ✓ The Joint United Nations Program on HIV/AIDS (UNAIDS) is created to lead, strengthen, and support a global response to the pandemic.

## 1996

- ✓ As a result of intense advocacy efforts by PLWHA and their allies, Brazil becomes the first developing country to provide antiretroviral treatment (ART) through its public health system.

- ☑ Worldwide, 22 million people are estimated to be living with HIV/AIDS.

## 1997

- ☑ The Indian Network of Positive People (INP+) is founded in February 1997 by 12 PLWHA. Today, it has chapters in six states throughout India.

## 2001

- ☑ In April, U.N. Secretary General Kofi Annan issues a call to action for the creation of a global fund to fight HIV/AIDS. A few months later the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) is created.
- ☑ In June, the United Nations holds a historic General Assembly Special Session on HIV/AIDS and produces the Declaration of Commitment on HIV/AIDS.
- ☑ In November, the International Muslim Leaders' Consultation on HIV/AIDS marks the first time Muslim leaders convene in an international forum to collaborate on combating HIV/AIDS.

## 2002

- ☑ Primates of the Anglican Church gather in April in Canterbury, England, to issue the Primates' Statement on HIV/AIDS, which delineates the church's response to the global crisis in human suffering caused by HIV/AIDS.
- ☑ In July, during the XIV International AIDS Conference, held in Barcelona, Spain, women living with HIV/AIDS and other women advocates remind the world that women now account for nearly half of PLWHA and produce Women and HIV/AIDS: The Barcelona Bill of Rights, demanding a more visible role for women in setting the priorities and leading the response to the global pandemic.

## 2003

- ☑ In March, representatives from civil society organizations meet in Paris to devise strategies to advocate for increased funding to the GFATM. The "Fund the Fund" campaign is launched as a call to action for civil society organizations to advocate their governments for increased investment in the Global Fund.

The HIV/AIDS pandemic is not static. PLWHA and HIV/AIDS advocates in individual countries and regions of the world face different challenges that require an advocacy response at different times. Thus, HIV/AIDS advocacy continues to redefine itself, evolve, and develop new strategies to address emerging challenges. Yet, common steps can be identified in all advocacy campaigns, as described below.



## 2.3 Common Steps in the Advocacy Process



Although HIV/AIDS advocacy is characterized by cornerstones that distinguish it from other types of advocacy, effective HIV/AIDS advocates pay attention to many common steps shared with advocates from other fields. This section provides a brief description of these common steps, which are listed below as a logical guide to the advocacy process. Even so, experienced advocates recognize that the art of advocacy requires the ability to adapt to changes in the environment, to be creative in applying the steps in a way that fits the context, and to juggle several steps at the same time. The POLICY Project’s *Networking for Policy Change: An Advocacy Training Manual* provides more detail.

### Common Advocacy Steps

1. Know who you are
2. Know the policy environment
3. Define the issue
4. Set advocacy goals and objectives
5. Identify target audiences
6. Build support
7. Develop the message
8. Select channels of communication
9. Raise funds
10. Develop an implementation plan
11. Collect data at each step along the way
12. Monitor the process and evaluate the outcome

The stories included in Sections 3–6 of this manual offer many vivid examples of how HIV/AIDS advocates have applied common steps in the advocacy process. Where appropriate, we have specified links between the common steps described in *Networking for Policy Change* and the stories included in this manual.



*Networking for Policy Change: An Advocacy Training Manual* is a manual for trainers in reproductive health advocacy. It is written as a guide for facilitators and includes tools and suggested activities for building skills to implement the steps in the advocacy process. The manual is available in Adobe format or can be ordered at no charge at [www.policyproject.com](http://www.policyproject.com). See Section III, Unit 1, of *Networking for Policy Change*, which focuses on the basic steps in the advocacy process and how advocacy differs from other related concepts.



## ▣ Know Who You Are

To be most effective in advocacy, whether as an individual, an informal group, an established organization, or a network, it is critical to be clear about the values and the mission that sustain you or your group. Clarity of purpose anchors the other steps in the advocacy process by providing a reliable measure for decision making along the way. It is also important to identify your relative strengths and weaknesses so that you can capitalize on your assets and determine the means to complement your weaknesses. What additional knowledge and skills does your group need? How can you build your internal capacity to advocate effectively? Of course, it is necessary to organize yourself to take action—whether on your own, within an organization, or as part of a network. The more people involved in advocacy, the more complicated is the effort. Thus, particularly with networks, which are often characterized by shared leadership, volunteerism, and diverse organizations, it is valuable to reach early consensus on identity issues.

In the HIV/AIDS arena, advocacy networks often emerge from what begin as PLWHA self-help groups. As individuals come together and seek supportive environments for understanding, for open discussion, and for meeting basic care and support needs, groups can coalesce into organizations for capacity building and mobilizing communities to address stigma and discrimination; in fact, many groups become strong voices for policy change. The story of the National Community of Women Living with HIV/AIDS (NACWOLA) in Uganda describes the evolution and empowering capacity of self-help groups (see Section 3.2).

More information and tools for building and organizing networks is included in Section I of *Networking for Policy Change*. Topics discussed include the impact of networking, defining advocacy networks, effective communication skills, team-building, negotiation, and forming mission statements.

## ▣ Know the Policy Environment

In addition to looking inward, advocates need to assess the policy and political environment. They must understand the history of how the issue has been addressed over time, the legal and policy documents that support or undermine the issue, the current political situation, and the many actors who influence the policy process. Studying the policy environment is a fundamental step for all advocates, but particularly for those with limited knowledge of or experience in interacting with the power structures in their country, region, or community. Without filling the knowledge gaps about the policy environment, advocates run the risk of misdirecting their efforts and making avoidable mistakes.

An aspect of the policy environment that advocates need to consider in designing their advocacy approach is the degree to which the citizenry is familiar with and experienced in political or policy change. In environments where citizens in general have less awareness of their rights and limited experience in advocating for those rights, advocates must devote time to informing citizens of their rights and guiding them in the exercise of such rights. For example, in South Africa, citizens had experience in promoting their rights and therefore were prepared to advocate for them in the access-to-treatment campaign (see Section 6).

Several ideas for increasing knowledge of and building skills in assessing the policy environment are included in Section II of *Networking for Policy Change*, which focuses on how to assess the policy environment, including how to identify key policy actors, issues, and opportunities. Topics discussed include the role of government and civil society in policy formulation, rules and procedures by which policy decisions are made, and mapping the policy process.

## ▣ Define the Issue

An advocacy campaign essentially begins when a group agrees to address an issue or problem in order to promote a policy change. In turn, it is important that the issue supports the group's mission and meets the test of certain criteria. Criteria can include, for example, the group's strong commitment to the issue, the perception that the issue can be satisfactorily resolved, and a clear focus on the issue.

The experiences of FBOs active in HIV/AIDS advocacy show that focusing on issues related to spiritual guidance and care often match the core strengths of their missions. Thus, FBOs can craft messages consistent with their faith and mobilize support for the issue within their own power structure (see Sections 5 and 6).

For PLWHA groups, the issue of stigma is a common advocacy focus. The stories of the Network of African People Living with HIV/AIDS (NAP+) in Kenya and the National Guidance and Empowerment Network of People Living with HIV/AIDS (NGEN+) in Uganda show how making the issue of stigma a priority matches the groups' very essence and paves the way for addressing related advocacy issues (see Sections 4.2 and 4.3).

More information and suggested group activities for reaching consensus on an advocacy issue are included in Section III, Unit 2 of *Networking for Policy Change*. This section lays the foundation for identifying advocacy goals and objectives, from explaining the elements of an advocacy objective to teaching participants how to determine priority issues.

## ▣ Set Advocacy Goal and Objectives

An advocacy goal is a general statement of the change a group hopes to achieve in the long term (e.g., three to five years) as related to its chosen issue. Advocacy objectives describe the short-term, specific, measurable achievements that contribute to realization of the advocacy goal. For instance, an advocacy group may decide that its short-term advocacy objective is to gain the government's commitment to form a multisectoral task force to study access to treatment as a step toward a larger advocacy goal of a national policy on HIV/AIDS treatment issues.

In deliberating over which treatment issue to focus on, the Thai Network of People Living with HIV/AIDS (TNP+) showed the value of choosing and advocating for a winnable, short-term objective (see Section 4.4).

More information and tools for groups to use in determining advocacy goals and objectives are included in Section III, Unit 2, of *Networking for Policy Change*.

## ▣ Identify Target Audiences

The primary target audience includes the decision makers who have the authority to bring about the desired policy change. The secondary target audience includes persons who have access to and are able to influence the primary audience, including other policymakers, friends or relatives, the media, religious leaders, and the like. Identification of both the primary and secondary target audiences is an essential ingredient in successful advocacy. To succeed in its advocacy, a group must identify individuals in the target audience, learn about their positions and relative power base, and determine whether the various individuals support, oppose, or are neutral about the advocacy issue.

As described in the story of the ACT UP campaign, the coalition was creative in, first, identifying a broad range of critical target audiences, from the media to major policymakers, and, second, choosing appropriate and divergent strategies to reach them (see Section 4.1).

More information and suggested skills-building activities for identifying and understanding target audiences are included in Section III, Unit 3, of *Networking for Policy Change*. You will learn to use a “power map” to identify support and opposition around a particular advocacy issue, identify target audiences, and analyze their interest in an advocacy issue.

## ▣ Build Support

Building a constituency to support a group’s advocacy issue is critical for success. The larger the support base, the greater are the chances of success. Group members must reach out to create alliances with other NGOs, networks, donors, technical experts, coalitions, civic groups, professional associations, grassroots groups, activists, and individuals who support the issue and will work to achieve the group’s advocacy goals. Potential collaborators can be identified in many ways—by reaching out to acquaintances, attending conferences and seminars, enlisting the support of the media, holding public meetings, reviewing publications, and searching the Internet, to name a few.

Part of any advocacy campaign includes elements of information, education, and communication (IEC) and community mobilization. Because of the fear, misinformation, and discrimination associated with HIV/AIDS, advocacy campaigns organized around HIV/AIDS policy issues often include a strong focus on awareness raising and community mobilization. Efforts can range from large-scale activities that target specific messages to different population groups or more subtle activities such as drawing attention to the valuable work that an AIDS support organization performs on a daily basis. In these ways, the public begins to learn about the impact of HIV/AIDS as individuals and organizations emerge to address the issue in myriad ways. The Society for Women and AIDS in Kenya (SWAK) is an example of an advocacy group that places a premium on community mobilization and has organized itself to be able to do such work effectively (see Section 3.4).

For HIV/AIDS advocates in many countries, generating a broad base of support has proved difficult because of the often negative and stereotypical views that people hold about the disease and those associated with it. Despite the great strides of the last 20 years, people often remain cautious and even fearful about associating themselves with HIV/AIDS or related causes. The stigma of HIV/AIDS continues to create hardships for inexperienced groups as they attempt to form powerful and influential constituencies and coalitions. Most of the groups whose stories are told in this manual have used a range of strategies to address stigma in order to build support for their advocacy efforts; an example of a successful strategy is NAP+’s Ambassadors of Hope program (see Section 4.2).

More information on building support is included in Section III, Unit 3, of *Networking for Policy Change*. Topics discussed include how to identify support and opposition for your advocacy issue and how to analyze your target audience.

## ▣ Develop the Message

Advocacy messages need to be developed and tailored to specific target audiences in order to frame the issue and persuade an audience to support the advocacy group's position. Three important questions can guide the preparation of advocacy messages: Who are you trying to reach with the message? What do you want to achieve with the message? What do you want the recipients of the message to do in response to the message (the action you want taken)?

The story of how The Balm In Gilead was able to develop and deliver messages to leaders within Black churches underscores the importance of understanding the language and perspectives of the target audience (see Section 5.2). In addition, the Islamic Medical Association of Uganda (IMAU) built support among Islamic leaders to conduct HIV/AIDS education by framing its prevention messages within the context of the Muslim faith and its valued traditions (see Section 5.1).

In addition to addressing policymakers and advocating for specific policy action, a significant portion of the messages in an HIV/AIDS advocacy campaign should be directed at the general public in an effort to address the denial, stigma, and fear associated with HIV/AIDS. Messages aimed at addressing denial may focus on the realities of HIV/AIDS prevalence; messages crafted to counter stigma may point to the leadership roles played by PLWHA in stemming the pandemic; and messages designed for turning fear into hope may highlight how communities can make a difference by engaging in small acts of compassion.

More information and suggested skill-building activities for crafting and practicing the delivery of advocacy messages are included in Section III, Unit 4 of *Networking for Policy Change*. Topics discussed include message development, formats, and moving your target audience to action.

## ▣ Select Channels of Communication

Selecting the most appropriate medium for advocacy messages depends on the audience. The choice of medium varies if the aim is to reach the general public, influence decision makers, educate the media, or generate support for the issue among like-minded organizations/networks. Common channels of communication for advocacy are interpersonal communication and mass media. Channels for effective interpersonal communication are myriad and can include one-on-one meetings, conferences for policymakers, public debates, and participation on policy task forces. Advocates often present their written messages in succinct fact sheets, letters, and presentations. In working with the mass media, advocates prepare press kits, write press releases, hold press conferences, and invite media coverage of public demonstrations.

Selecting the appropriate messenger is important. Particularly because of the stigma and discrimination associated with HIV/AIDS and the shift in social mores that is needed to support long-term and sustainable policy change, advocates have found that community leaders, religious leaders, or other publicly recognized and trusted persons are especially influential messengers. The members of IMAU recognized the value of involving religious leaders in a coordinated response to HIV/AIDS (see Section 5.1). Likewise, Buddhist monks in the Wat Norea Peaceful Children project

in Cambodia have integrated HIV/AIDS prevention and care issues into their traditional role as teachers as they work within their communities (see Section 5.3).

More information about effective advocacy communication is included in Section III, Unit 4, of *Networking for Policy Change*. Topics discussed in this section include the techniques of persuasion, how to develop advocacy messages, elements and characteristics of a message, and how to deliver advocacy messages to various audiences.

## ▣ **Raise Funds**

Advocacy campaigns can always benefit from outside funds and other resources. Resources can help support the development and dissemination of materials, cover travel expenses to meet with decision makers and generate support, underwrite meetings or seminars, and absorb communication expenses.

The story about TNP+ illustrates how raising funds from both the Thai government and nongovernmental sources is vital for capacity building and ensuring future viability (see Section 4.4).

More information and suggested group activities for identifying fundraising possibilities are included in Section III, Unit 6, of *Networking for Policy Change*. Among the topics included are sources of financial support, developing a fundraising strategy, and mobilizing resources.

## ▣ **Develop an Implementation Plan**

An advocacy group should develop an implementation plan to guide its advocacy campaign. The plan should identify activities and tasks, responsible persons/committees, the desired time frame for action, and needed resources. Playing to the respective strengths and assets of the participating individuals and organizations is important when determining roles and responsibilities in the campaign. Should an organization take the lead in developing the press releases because it has a journalist or storyteller in its ranks? Should another group organize and manage the logistics of an event because it brings experience from running a food pantry or managing a small shop?

The Wat Norea Peaceful Children project (see Section 5.3) and the Church of the Province of Southern Africa (see Section 6.5) are both examples of organizations that have used participatory strategic planning processes to develop a clear understanding of local needs, strengthen advocacy efforts, build partnerships, and foster community-wide commitment to address HIV/AIDS.

More information and suggested tools for developing an implementation plan are included in Section III, Unit 7, of *Networking for Policy Change*. You will find recommendations for setting specific advocacy objectives that will contribute to the achievement of stated goals, reviews of data collection and analysis techniques, and suggestions for establishing benchmarks that will help you recognize if, when, and how well desired results are achieved.

## ▣ **Collect Data at Each Step along the Way**

Accurate information is crucial at *all steps* of the advocacy process. Gathering evidence and promoting fact-based advocacy is essential in gaining credibility and a seat at the decision-making

table. Advocates should collect and analyze data to help identify and select their issue as well as to develop advocacy objectives, craft messages, expand their base of support, and influence decision makers.

The Balm In Gilead's effort to convince local ministers to address HIV/AIDS within their congregations was organized around the provision of convincing statistics on prevalence rates in the ministers' own communities. The information was crucial in overcoming the denial within the church leadership and persuading the ministers that HIV/AIDS was affecting their congregations (see Section 5.2).

In its access-to-treatment campaign, TNP+ realized that it needed to reach out to a new and unfamiliar set of target audiences, educate itself about its new counterparts, and collect information in order to communicate effectively (see Section 4.4).

More information and suggested skill-building activities for data collection and its use in advocacy are included in Section III, Unit 5, of *Networking for Policy Change*. Topics covered include data collection scenarios, comparing qualitative and quantitative methods, focus group discussions, secondary data analysis, baseline studies, and interviews.

## ■ Monitor the Process and Evaluate the Outcome

Monitoring and evaluation occur throughout the advocacy process. Before undertaking an advocacy campaign, the group should decide how it will measure progress and evaluate results. How does it know it is making progress toward its goal? How will lessons learned from one activity affect the next activity? What will be different following the completion of the advocacy campaign? How will the group know that the situation has changed?

The story of IMAU's work in Uganda demonstrates the impact of gathering baseline and follow-up information as a means of monitoring, evaluating, and documenting successful advocacy efforts (see Section 5.1).

More information on how to monitor and evaluate advocacy efforts is included in Section III, Unit 8, of *Networking for Policy Change*. Topics discussed include the difference between monitoring and evaluation, how to develop a monitoring and evaluation framework, and how to use a framework once it has been constructed.

## ■ Conclusion

Advocates responding to the urgent and ever-changing HIV/AIDS pandemic can draw from and build on the time-honored and fundamental advocacy steps as well as from the lessons learned by advocates who have gone before them. However, the very nature of the issue demands and will continue to demand novel approaches.

In reading the following stories of the individuals, groups, and networks that have been on the forefront of HIV/AIDS advocacy, the reader will recognize the fundamental steps described above as well as the unique twists and turns and interpretations that are central to the process of HIV/AIDS advocacy.

