Moments in Time

HIV/AIDS Advocacy Stories

POLICY

Moments in Time:
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Contents

Acknowledgments

Abbreviations

ACT UP	AIDS Coalition to Unleash Power, New York
AIDS	Acquired immune deficiency syndrome
ANC	African National Congress
ART	Antiretroviral treatment
ARV	Antiretroviral
AZT	Zidovudine
CA	Cooperating agency
CBO	Community-based organization
CCM	Country Coordinating Mechanism
CDC	Centers for Disease Control and Prevention
COSATU	Coalition of South African Trade Unions
CPSA	Church of the Province of Southern Africa
FAEPTI	Family AIDS Education and Prevention Through Imams Project, Uganda
FBO	Faith-based organization
FDA	U.S. Food and Drug Administration
FEIM	Fundación para Estudio e Investigación de la Mujer (Foundation for Study and Research on Women), Argentina
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater Involvement of People Living with HIV/AIDS
GNP+	Global Network of People Living with HIV/AIDS
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
HST	Health Systems Trust, South Africa
ICPD	International Conference on Population and Development
ICW	International Community of Women Living with HIV/AIDS
IDU	Injecting drug user
IGAD	Intergovernmental Authority on Development
ILO	International Labor Organization
IMAU	Islamic Medical Association of Uganda
INP+	Indian Network of Positive People
KS	Kaposi's sarcoma
LAC	Latin America and the Caribbean
MSF	Médecins sans frontières/Doctors Without Borders
MSM	Males who have sex with males
MTCT	Mother-to-child transmission (of HIV)
NACOSA	National AIDS Convention of South Africa
NACP	National AIDS Control Program(me)
NACWOLA	National Community of Women Living with HIV/AIDS, Uganda
NAP+	Network of African People Living with HIV/AIDS, Kenya
NAPWA	National Association of People Living with HIV/AIDS, South Africa
NEDLAC	National Economic Development and Labour Council, South Africa
NGEN+	National Guidance and Empowerment Network of People Living with HIV/AIDS, Uganda
NGO	Nongovernmental organization
NPC	Wat Norea Peaceful Children, Cambodia

OI	Opportunistic infection
PCP	Pneumocystis carinii pneumonia
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission (of HIV)
SACBC	Southern Africa Catholic Bishops' Conference
SANGRAM	Sampada Grameen Mahila Sanstha, India
SMP	Safety monitoring procedure
STD	Sexually transmitted disease
STI	Sexually transmitted infection
SWAA	Society for Women and AIDS in Africa
SWAK	Society for Women and AIDS in Kenya
TAC	Treatment Action Campaign, South Africa
TASO	The AIDS Support Organization, Uganda
TB	Tuberculosis
TBA	Traditional birth attendant
TNP+	Thai Network of People Living with HIV/AIDS
TRIPS	Trade-Related Intellectual Property Rights
UAC	Uganda AIDS Council
UNAIDS	Joint United Nations Program on HIV/AIDS
UNDCP	United National International Drug Control Program
UNDP	Untied Nations Development Program
UNESCO	United Nations Educational, Scientific, and Cultural Organization
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VAMP	Veshya Ananyay Mukti Parishad, India
VCT	Voluntary counseling and testing
WHO	World Health Organization
W-TAG	Women's Treatment Action Group, Uganda
WTO	World Trade Organization
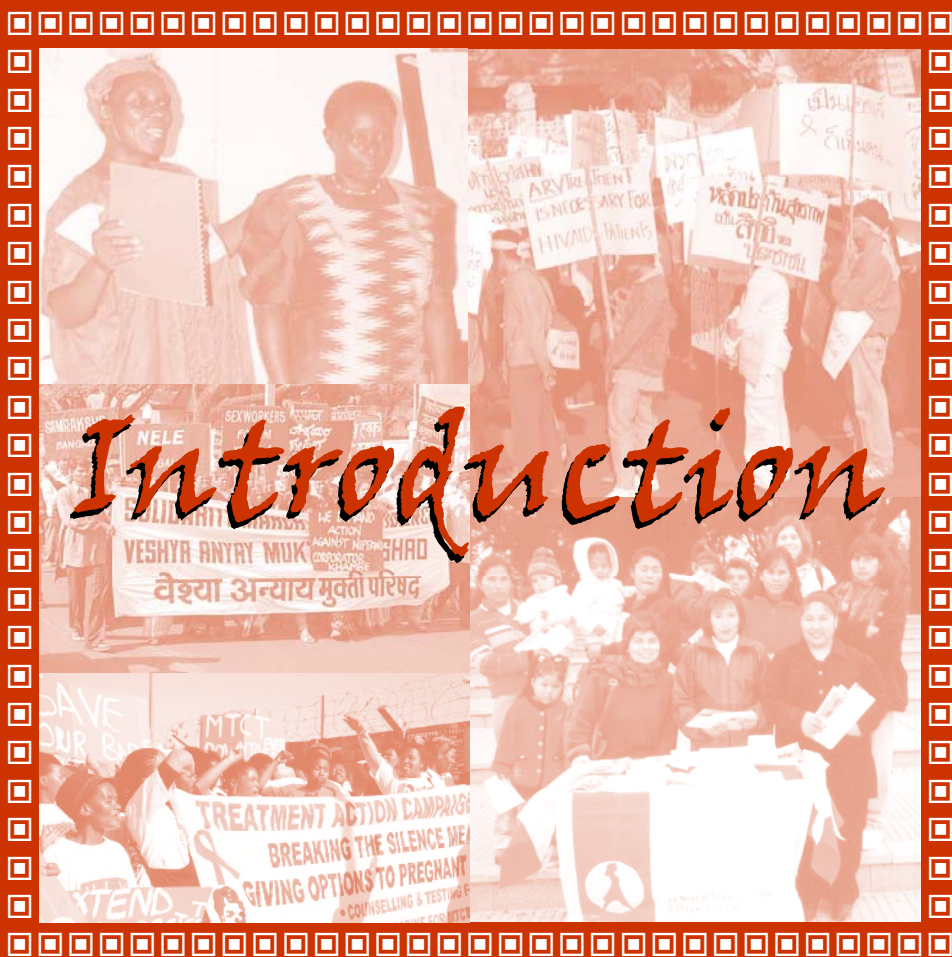
Introduction

SECTION 1

Introduction: Moments in Time

Advocacy strategies have long been part of campaigns to build support for a particular cause or struggle, and the history books are peppered with concrete examples of advocacy initiatives. Even in our own times, we have witnessed policy changes that can occur through the powerful persuasion of advocacy. Each successful advocacy strategy takes place in and represents a specific moment in time. Yet, while advocacy arises from and must respond to a unique context, the advocacy strategies presented in this manual can be adapted and applied in other settings.

With the emergence of HIV/AIDS in the early 1980s and particularly over the last couple of years, the term *advocacy* has increasingly become part of the global language used in discussing health and development initiatives or the development of a national HIV/AIDS policy. While an advocacy process is by no means an unfamiliar one to many of us, the way in which the process has been transformed to meet particular HIV/AIDS advocacy goals is noteworthy. In short, HIV/AIDS advocacy has provided the fertile breeding ground that has brought together a distinct blend of actors—from AIDS activists to clinical researchers; from community workers to heads of large multinational companies; from people living with HIV/AIDS (PLWHA) to health workers. This is truly the unifying nature of the pandemic. With issues extending to prevention, care, and political commitment to drug treatment access, the evolving nature of HIV/AIDS advocacy campaigns has mirrored our collective response to the pandemic. Today's advocacy campaigns afford us the opportunity to reflect on our achievements while acknowledging that a great deal still remains to be done. Distilling practical lessons for future campaigns about how the advocacy process has been transformed to meet the pandemic's demands on all of us will permit us to become more effective advocates.

▣ Why This Manual?

This advocacy manual highlights some of the advocacy moments of our time as told from the unique perspective of those who are engaged in advocacy work in communities around the world. Despite the availability of several excellent guides to advocacy, no group or individual has developed a manual that offers a tapestry of stories as a practical resource for advocacy training, reflective learning, and strategic planning. The manual thus begins a process of documenting HIV/AIDS policy advocacy stories as a means of preserving them and making them available to others as more and more people become involved in HIV/AIDS advocacy issues.

While the manual capitalizes on many of the HIV/AIDS global advocacy efforts that have emerged over the past 20 years, we purposefully selected stories of grassroots advocates who have been working within and among the following constituent groups:

- Women,
- PLWHA, and
- Faith-based organizations (FBOs).

We chose these groups because a central feature of HIV/AIDS advocacy is the need to promote the greater involvement of those most affected by HIV/AIDS at all levels of decision making. We hope that the stories and analysis in the manual provide a tool to help develop the capabilities to think

about, design, and implement a variety of creative advocacy campaigns that meet the challenges of our time.

◾ How Was the Manual Written?

This manual is the result of over 25 in-depth interviews with recognized HIV/AIDS advocates from around the world. We conducted in-person interviews with advocates throughout Africa and the United States and telephone interviews with people from Latin America and Asia. We asked people with an intimate knowledge of a specific advocacy campaign in their country to describe their advocacy experiences and to highlight successes, challenges, and lessons learned. In some cases, we supplemented the stories with factual material from published articles and websites. The stories show how people on the front line define advocacy and underscore the changing styles and strategies used by advocates. In this way, the manual is representative of specific voices and tells a story from several perspectives.

Persons interviewed included advocates from Argentina, Brazil, Cambodia, Costa Rica, Eastern Europe, El Salvador, India, Kenya, South Africa, Thailand, Uganda, and the United States. Many of the "advocacy in action" stories reflect advocacy voices from Africa, but the strategies reported are applicable across continents and cultures.

◾ Who Is the Manual for?

Ideally, the manual is intended for anyone interested in HIV/AIDS advocacy. The stories were written with two major audiences in mind: advocacy trainers and people who are involved in or would like to start an advocacy campaign. For trainers, we see the manual as a resource that can augment already existing capacity-building tools used as part of the advocacy process. For advocates and advocacy organizations, we hope that the stories offer experiences, analysis, and a form of peer-to-peer exchange that will help generate new and innovative ideas.

Although the stories focus on HIV/AIDS, the advocacy models are applicable to other settings and other issues. In fact, we believe that the developments in HIV/AIDS advocacy over the past 20 years can be helpful to other advocacy issues, just as other advocacy issues have been instrumental in the development of HIV/AIDS advocacy.

◾ How Should the Manual Be Used?

The manual is intended to be both interactive and flexible so that trainers and interested readers can use it in ways that best meet their needs. It can be read from cover to cover, but it need not be. Following this introduction, Section 2, Cornerstones and Common Steps of HIV/AIDS Advocacy, provides an analytical context for the advocacy stories that follow. The advocacy stories in Sections 3–6 build on the cornerstones and common advocacy steps outlined in Section 2, but they can also be read independently.

For trainers, it may be most useful to think of the stories as a companion to other advocacy training manuals, especially those that include a "how-to" focus on different steps of the advocacy process. Where appropriate, we have incorporated linkages to the POLICY Project's *Networking for Policy Change: An Advocacy Training Manual*. In particular, the stories provide on-the-ground examples that illustrate cornerstones and common steps of HIV/AIDS advocacy.

For advocates, the case studies are designed to offer experiences and analysis that can be applied to your own work. You may want to read about stories that relate to a particular constituency or issue

that is central to your situation. At the same time, reading about the HIV/AIDS advocacy challenges and successes of different groups and issues may also offer new ways to approach your own advocacy.

For those who do wish to relate the stories to the analytical context provided in Section 2, we have provided several links. Each advocacy story starts with symbols that highlight the cornerstones of HIV/AIDS advocacy most relevant to that advocacy effort.

The advocacy stories are told in Sections 3–6 of the manual. To help readers make productive use of the manual, we have selected six symbols below that match the HIV/AIDS advocacy cornerstones highlighted in Section 2.

Meaningful involvement of people living with HIV/AIDS

Urgency

External and internal advocacy strategies

Organizational structures (self-help groups, conferences, and so forth)

Cultural work and symbols

Challenging stigma and discrimination

In addition, each story contains a set of questions for discussion. For advocates and future advocates, these questions may serve as starting points for discussion and in-depth analysis of the stories. Particularly for those with less experience in advocacy, these questions can assist you to understand the advocacy process as well as the challenges that other advocates have faced. You may find that the discussion of these questions serves as a bridge between analyzing what others have done and applying the knowledge gained to your own efforts. The more you understand and analyze what others have done, the more prepared you will be to begin your own advocacy efforts. Trainers may find that these questions lend themselves well to small group discussions and as a check for understanding of the advocacy process and key issues in planning for an advocacy campaign. Depending on the experience level of those you are working with, you may wish to modify the questions to better meet the needs of the group.

Finally, each section concludes with a list of lessons learned across the stories. Advocates may choose to discuss these lessons learned and carefully consider whether your own advocacy plans

capitalize on the lessons or whether changes may be warranted to address some of the pitfalls others have experienced. Trainers may find that the lessons learned serve as useful summary points and reminders when facilitating advocacy groups' decision-making processes.

Ultimately, though, there are no "right" or "wrong" ways to read and use the stories. The linking symbols, questions, and lessons learned are only a starting point for further conversation, reflection, and planning for action.

◙ What Follows?

Many people regard advocacy as both a science and an art. From a scientific perspective, there is no universal formula for effective advocacy. However, experience suggests that an advocacy campaign is most effective if it is systematically planned and follows a set of concrete "steps."

> ■ **Cornerstones and Common Advocacy Steps** (Section 2). This section of the manual offers an introduction to HIV/AIDS advocacy that includes a framework for understanding the advocacy process and the particular strategies that emerge in the manual's HIV/AIDS advocacy stories. It highlights the challenges faced in HIV/AIDS advocacy and details the different strategies, styles, and structures developed by advocates to meet these challenges. These cornerstones of HIV/AIDS advocacy are linked to a timeline that emphasizes strategic HIV/AIDS advocacy and policy milestones reached since the early 1980s. Section 2 of the manual also focuses on what might be called the common steps of the advocacy process. Each step requires distinct knowledge and skills to ensure effective implementation. A process of thorough training can easily support the development of the required knowledge and advocacy skills, but the true understanding of advocacy comes with the practice of these skills. In this manual, the stories that follow Section 2 offer an opportunity to reflect on how these steps can play out in practice.

Advocacy is also an art. Successful advocates are able to inspire and motivate others to take action, and, when necessary, to transform the issue at hand into an issue that captures the attention of the media or the public. In the ever-changing social climate, advocates need to possess a keen sense of timing and be prepared to act as opportunities present themselves. The art of advocacy lies in the ability of advocates to create an explosion of color in the midst of a dull landscape in order to influence and affect change.

The art and the science of advocacy come together in the advocacy stories in Sections 3–6 of the manual, which focus on the advocacy efforts of grassroots advocates. In particular, Sections 3–6 contain advocacy stories for the following groups and issues:

> ■ **Women's Groups: Leaders by Example** (Section 3). Given that women are disproportionately affected by HIV, bear the burden of care, and often have lower socioeconomic status, it is appropriate that it is the powerful voices of women that rise to the advocacy challenge.

> ■ **PLWHA: People of Courage** (Section 4). Increasingly, decision makers are recognizing the central role of PLWHA in any HIV/AIDS advocacy campaign. In September 1999, UNAIDS stated, "Of equal importance to their role in improving human rights, people with HIV must play an integral role in HIV prevention and care programs in order for them to be truly effective." This section documents the leadership of PLWHA in HIV/AIDS advocacy efforts.

- **FBOs: A Matter of Faith** (Section 5). Owing to their mission of interacting with—and providing services for—people within their own communities, FBOs have organic links to HIV/AIDS care and support. The central role of FBOs working within communities has ensured that, despite some possible ideological differences, these organizations are often pivotal leaders in an advocacy campaign.

- **Access to Treatment: Working Together** (Section 6). The final chapter provides an in-depth look at access to treatment in South Africa. Rather than focusing on a particular constituent group, it instead shows how various organizations work together to create a comprehensive advocacy campaign. In this story, many advocacy constituencies, including PLWHA and FBOs, play a variety of key advocacy roles.

The manual concludes with three annexes that contain useful reference materials for HIV/AIDS advocacy: a Glossary of Terms, Declarations, and Other Resources for HIV/AIDS Advocacy.

Tell Us Your Story

The stories in the manual represent specific moments in time. It is hoped that others will share advocacy efforts that continue to shape a just response by and for the communities, families, friends, and loved ones living with and affected by HIV/AIDS. And it is here that we need **your** guidance. Clearly, the stories reported in this manual represent just a fraction of the many excellent advocacy efforts serving communities throughout the world. We hope that in time we will be able to document the stories of advocacy efforts in other settings and cultures.

In the interactive spirit of advocacy, we ask you to complete the form at the back of the manual and send it to POLICY Project/Moments in Time, c/o Futures Group International, 1050 17th Street, NW, Suite 1000, Washington, DC, 20036. Alternatively, you may send your responses to us at www.policyproject.com/stories. We will document all responses and make a summary available early in 2004. Using the responses, we will begin a process of documenting the experiences shared with us. And in this way, the evolving nature and dynamism that is HIV/AIDS advocacy will provide a source of inspiration and guidance for current and future advocates.

Charting a Course

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					
	👥	🕐	🔄	🏚	🎗	🚫
Women's Groups						
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			✔	✔		✔
PLWHA Groups						
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	✔	✔	✔	✔		✔
Faith-based Organizations						
5.1 Islamic Medical Association of Uganda			✔	✔		
5.2 The Balm In Gilead			✔	✔		✔
5.3 Wat Norea Peaceful Children			✔	✔		✔
Access to Treatment						
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 lymphadenophathy-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. 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).

▣ 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).

▣ 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).

▣ 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).

◪ 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.

◪ 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.
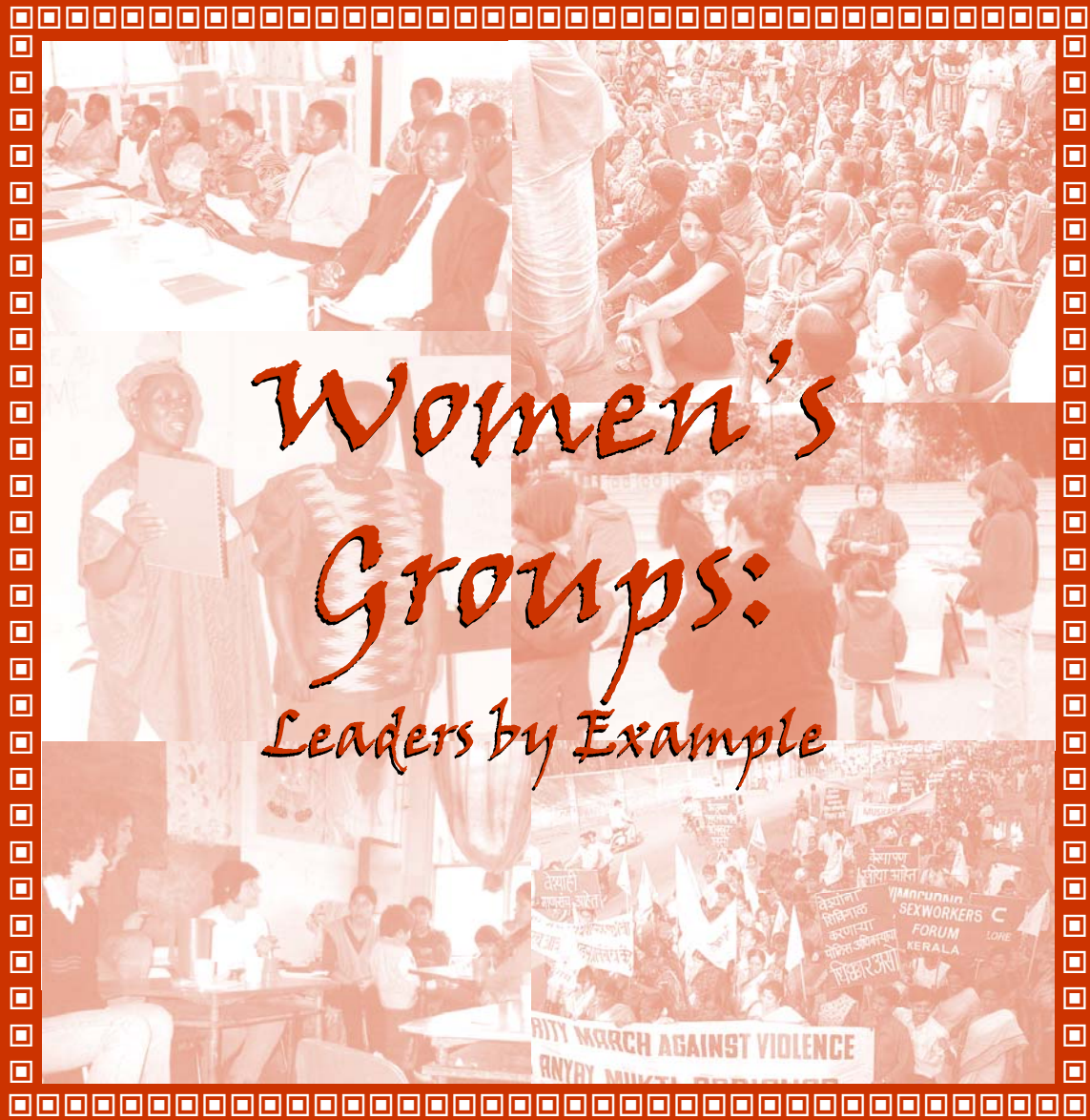
Women's Groups:
Leaders by Example

SECTION 3

Women's Groups:
Leaders by Example

"As we enter the third decade of HIV/AIDS, women, especially the young and the poor, are the most affected. Because gender inequality fuels the HIV/AIDS pandemic, it is imperative that women and girls speak out, set priorities for action, and lead the global response to the crisis."

Women and HIV/AIDS: The Barcelona Bill of Rights,
XIV International AIDS Conference, July 2002

Given women's central role in the HIV/AIDS pandemic, the advocacy stories in this section focus on the experiences of women's organizations. As a consequence of unequal social, economic, and cultural power relations, women are disproportionately affected by HIV/AIDS, bear the burden of care, and find it difficult to make decisions about sexual matters or to live and work in safe and secure situations. Yet, it is also the powerful voices of women that rise to the advocacy challenge.

If programs and policies are to succeed, they must account for the realities of women's lives. For many women, this means addressing their own and their families' material needs, including income generation, food security, the availability of land, planning for children, access to treatment, and inheritance rights. Women's organizations have been vitally important in making these needs visible and advocating for responsive policies, programs, and research. Women's organizations' responses to the HIV/AIDS pandemic have also provided powerful solutions for more effectively addressing women's and communities' needs. The stories showcased here demonstrate how women's organizations have often emerged to meet the immediate needs of community women involved in responding to HIV/AIDS. As women's organizations find solutions to the issues facing them, the solutions themselves often become linked to a broader advocacy focus. In this way, women's organizations often present a proven solution as part of their advocacy message.

At the same time, in most communities and countries, women remain largely excluded from policymaking processes and programs that affect their lives. Women's organizations have, however, played a pivotal role in advocating for reconfiguration of decision-making processes and ensuring women's involvement in those processes. As the stories in this section illustrate, a range of strategies is important to ensure women's successful advocacy and greater participation in decision making. With women often unaware of their rights, many women's groups place special emphasis on consciousness raising and skills building with respect to those rights. In addition, women's self-help organizations have been powerful sources for addressing the stigma and discrimination faced by, in particular, female sex workers and HIV-positive women, providing a foundation from which advocacy can occur. Finally, women have exhibited particular expertise in forming women's caucuses or groups within existing organizations to make sure that their voices, needs, and concerns are heard.

Organizations—such as the **Fundación para Estudio e Investigación de la Mujer** (FEIM) in Argentina, the **National Community of Women Living with HIV/AIDS** (NACWOLA) and

Women's Treatment Action Group (W-TAG) in Uganda, the **Society for Women and AIDS in Kenya** (SWAK), and **Sampada Grameen Mahila Sanstha** (SANGRAM) in India—show how women's groups are at the forefront of responses to HIV/AIDS.

Some of the major advocacy issues and strategies that are evident in the stories of women's organizations include the need to confront stigma and discrimination; the role that evidence plays in winning support for alternative policy solutions; the importance of framing advocacy messages for particular audiences; and the power of developing organizational structures and networks to enable advocacy.

▣ Featured in This Section		
Name of Organization	**Country**	**Advocacy Focus/Strategies**
3.1 Fundación para Estudio e Investigación de la Mujer	Argentina	▪ Reproductive and sexual rights ▪ Youth access to information ▪ Policy reform
3.2 National Community of Women Living with HIV/AIDS	Uganda	▪ Self-help and advocacy network ▪ Stigma and discrimination
3.3 Women's Treatment Action Group	Uganda	▪ Access to treatment for prevention of mother-to-child transmission ▪ Drafting of declaration
3.4 Society for Women and AIDS in Kenya	Kenya	▪ Community mobilization and advocacy network
3.5 Sampada Grameen Mahila Sanstha	India	▪ Sex worker empowerment ▪ Stigma and discrimination ▪ Involvement in policy decision making

3.1 Fundación para Estudio e Investigación de la Mujer
Buenos Aires, Argentina

□ Background

Founded in 1987, Fundación para Estudio e Investigación de la Mujer (FEIM) is a foundation for the study of and research on women. It focuses on reproductive health and sexual health rights for women and youth. It started its work on HIV/AIDS in 1990. Given that most people at the time thought that HIV/AIDS was a disease affecting only gay men and males who have sex with males (MSM), the foundation nonetheless set forth a goal of reaching out to and educating women and young people.

□ Advocacy Environment

Argentina is a Catholic and socially conservative country—two facts that have made it difficult to address issues of sexuality. In 1982, the first cases of HIV in Argentina appeared among MSM; in 1987, the first cases of HIV in women were reported. Women recognized that the convergence of Catholicism, conservatism, and an understanding of the epidemic that identified gay men as the vulnerable population would have an adverse impact on women and HIV prevention. More specifically, women realized that, under these circumstances, an HIV-positive woman would immediately be branded a sex worker, thereby stigmatizing all women and inhibiting awareness-raising and prevention efforts. Women came together to address these issues.

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>
> *"We use HIV/AIDS to talk about sexuality—and to let women speak about sexuality."*
>
> Mabel Bianco,
> FEIM
>
> □□□□□□□□□□□□

At the same time, women in Argentina had been involved in initiating a feminist movement. The movement had succeeded in placing on the social agenda issues relating to (1) sexual and reproductive health and rights and (2) women and development, although the issues failed to capture sufficient public attention. Over the years, women in the medical field and the judiciary had been advocating to bring about changes in the laws and practices that were harmful or unfair to women. Two of issues of particular interest were divorce and reproductive health and rights, which, in view of the influence of the Catholic Church, were major issues for women.

In 1987, Dr. Mabel Bianco, the founder of FEIM, was working in government and took advantage of her position to organize a national meeting of women; the agenda included a slot for HIV/AIDS. Meeting participants recognized and agreed that it was time to create a nongovernmental organization to address the issues of reproductive health and sexual rights. Thus, out of years of

work on the women's movement and with many longstanding relationships in health and the judiciary, the founders of FEIM were able to form an organization dedicated to women's reproductive and sexual rights.

Despite its conservative history, Argentina has developed health and human rights systems that permit the nation to address and advocate for social issues. Argentina's acknowledgment of health and human rights provided a basis for addressing HIV/AIDS from a human rights perspective. Given that the nation's citizenry was well informed regarding human rights, the founders of FEIM recognized that if they were to address issues of reproductive health and sexual rights, they would need to bring together more people than just medical doctors and women; they would need to mobilize all of Argentinean society. To do so, they had to find a common denominator that would bring together all sectors of society; that common denominator was HIV/AIDS, as it touched upon so many rights. With HIV/AIDS as the lead issue, FEIM's founders would be able to mobilize a cross-section of society and move beyond the limitations of their previous advocacy efforts.

▣ Advocacy Focus and Strategy

The church and a conservative society have presented enormous challenges for women advocates. FEIM's strategies have worked to address these challenges.

Using the Media to Build Support

FEIM developed a relationship with the media to mobilize support for its advocacy issues. First, it educated the media on major issues and then used the power of the media as an educator. One of FEIM's earliest advocacy efforts was a day of radio programming in Patagonia, an area of Argentina with five times as many men as women owing to a significant military presence and the dominance of oil production. Not surprisingly, large numbers of sex workers also reside in Patagonia.

Because FEIM had been working with journalists for a number of years, it had already developed good relationships with the radio station, making possible the day of fully sponsored HIV programming. The programming plan called for HIV/AIDS education during the day via interviews with teachers and doctors and then interviews with sex workers during the evening in order to teach women about HIV prevention.

The sex workers informed female listeners that the latter were at higher risk for HIV than the sex workers. Unlike sex workers, they were not in a position to negotiate for safer sex. An unlikely alliance evolved as many women called the radio station to talk with the sex workers, thanking them for their safe sex messages. FEIM realized that the women whose profession put them most at risk could be the best resource for educating women who thought that marriage safeguarded them from HIV transmission. Since then, radio programs have focused on stories of HIV-positive women. As a result, regular media reporting on how HIV/AIDS affects women has contributed to a more informed constituency and supportive policy environment.

Creating a Body of Youth Advocates and Developing a Network

In 1993, FEIM initiated its advocacy work for youth issues. As it started its outreach, an immediate challenge was identifying a group of youth advocates who fully understood issues related to their health and sexuality. The lack of understanding of these issues became clear at one of FEIM's national health days in 1994. During the event, FEIM hosted a creative arts competition for young people to express what they wanted to know about adolescent pregnancy. It became clear that young people had romantic and conservative views on teen pregnancy. It also became clear that young people needed to learn about their health in the context of sexual roles and inequalities. Therefore,

FEIM decided to train peer educators in order to reach out to young people who could become advocates. One of the tasks of the peer educator effort was to expand the peer education curriculum to include discussions of reproductive and sexual health and rights, thereby laying a foundation for advocacy efforts. FEIM continued to build the capacity of youth through its peer educator program over the next five years.

In 1999, based on the network of informed youth established through its peer education program, FEIM was able to establish a network of adolescents specifically dedicated to advocating for sexual and reproductive rights. The adolescent network has since grown to include 16 groups nationwide; it relies on material developed by and for youth on reproductive and sexual health issues.

Carefully Framing Messages Contributes to Policy Success

As they engaged in advocacy, the youth network faced the challenge of gaining support for issues of sexual and reproductive rights—issues that could quickly raise moral concern and controversy in Argentina's conservative policy environment. To advocate for its issues, the youth network thus learned how to choose and frame advocacy issues in ways that could win policymaker support. The youth advocates decided to focus their advocacy efforts on contraception and condom use rather than abortion. In addition, the network turned to public health statistics on teen pregnancy, teen maternal mortality, and rape to educate policymakers and the church about the realities of young people. Reliance on government statistics as an educational tool provided a neutral platform for discussing issues related to youth health and sexuality and thus permitted the policy dialogue to move beyond conservative moral concerns.

Over the past few years, the youth network has lobbied Parliament for a law that would mandate sexual and reproductive health services for adolescents. As one of the health services now provided in about half of Argentina's states per current law, HIV testing is available to young people without parental consent—and in the face of fierce opposition from the Catholic Church and conservatives.

▣ Questions for Dialogue

1. How did FEIM reshape the policy dialogue to focus people's attention on its issue rather than on another issue? How might you apply this to your own advocacy work?

2. What different communication approaches did FEIM use to build support among the different groups it reached—women, youth, policymakers? What are some creative approaches that might be best suited to your various audiences?

3. FEIM found that HIV/AIDS helped to unify different groups in efforts to promote women's rights. In your context, do you think that HIV/AIDS can bring together different groups to promote women's rights? Which groups? What opportunities and what challenges would you anticipate?

4. What has been the role of the media in the context of your advocacy work? What aspects of FEIM's work with the media could relate to your advocacy work?

This story was based on an interview with Mabel Bianco, president of FEIM. For further information about the organization, please visit www.feim.org.ar.

3.2 National Community of Women Living with HIV/AIDS
Kampala, Uganda

▣ Background

The National Community of Women Living with HIV/AIDS (NACWOLA) was founded in 1992 as the only organization in Uganda run by and for women with HIV/AIDS. NACWOLA functions as a membership organization operated primarily by volunteers. It provides support and care to HIV-positive women and their families and enhances access to information, health services, and treatment for opportunistic infections.

▣ Advocacy Environment

Because women are responsible for meeting the needs of their families, they necessarily carry an additional burden when they or a family member are infected with HIV/AIDS. Women have long relied on self-help groups for support in times of need. Self-help groups craft solutions to food security, employment, education, and other problems and permit women to mobilize for action rather than simply "wait" for something to happen. At the same time, self-help groups allow women to gain needed confidence and skills and recognize that there is strength in numbers.

▣ Advocacy Focus and Strategy

Self-Help Origins

Initially, HIV-positive women founded NACWOLA as a self-help effort. Beatrice Were, a founder and former director, recalls, "We were just a group of ordinary women living with HIV/AIDS who wanted to do something for ourselves rather than rely on others. We felt that by working together we could give each other support and reduce self-stigmatization. We really didn't know how to go about formalizing ourselves but, through advice from organizations within the sector, we became established." As with many women's organizing efforts, NACWOLA's founders focused on the immediate needs of the group's members and their families. The "stuff of life" became the locus for action.

NACWOLA's organizational origins also echo the experiences of many women's advocacy groups. In part, the inspiration for NACWOLA came from the experiences of HIV-positive women who attended the VIII International AIDS Conference in Amsterdam in 1992. Frustrated by the lack of relevant gender dialogue and the absence of gender-informed research agendas, women convened meetings to discuss the gender problem and to strategize about ways to address it. The highly charged discussions mobilized people to respond such that three important institutions emerged: the

International AIDS Society Women's Caucus, the International Community of Women Living with HIV/AIDS (ICW), and NACWOLA.

Infrastructure and Capacity for Advocacy

> "We were just a group of ordinary women living with HIV/AIDS who wanted to do something for ourselves rather than rely on others. We felt that by working together we could give each other support and reduce self-stigmatization. We really didn't know how to go about formalizing ourselves but, through advice from organizations within the sector, we became established."
>
> Beatrice Were
> Founder and former director, NACWOLA

What makes NACWOLA an interesting organization from an advocacy perspective is its evolution from a self-help effort to a platform for political action. Prior to the formation of the network, HIV-positive women in Uganda lived in isolation, without ability to access care and support for themselves, much less to advocate for responsive programs and policies that address their needs. Through its dual focus on providing a safe forum for discussion and educating communities about HIV/AIDS, care, and relevant legal issues (e.g., inheritance, will making, property rights, and so forth), NACWOLA has built a strong and informed foundation for successful advocacy work. By maintaining an organizational infrastructure at both the local and national levels, NACWOLA's network also enables HIV-positive women to speak directly to the issues affecting women's day-to-day lives. Out of HIV-positive women coming together to meet basic care and support needs, NACWOLA has built a structure that reaches communities across Uganda—and draws advocacy strength from the power of its numbers.

NACWOLA now has 50,000 members and operates in more than 23 districts in Uganda. In 2001, NACWOLA members presented their views and experiences at more than 30 national and international conferences. NACWOLA's members are frequently asked to sit on commissions or policymaking boards to represent the "women's voice." NACWOLA has created a mobilized and aware constituency of citizens who can identify, articulate, and act on the problems facing them in the fight against HIV/AIDS.

▣ Questions for Dialogue

1. What are some of the organizational strengths of self-help networks that contribute to the advocacy process?

2. How do self-help groups lay a foundation for policy advocacy? What do you see as some of the key capacity-building steps or support needed before self-help groups can engage in advocacy work?

3. Self-help networks have direct access to a wealth of information about the immediate needs and realities of communities. What are the opportunities to use this information for advocacy? How might you gather and document this information?

3.3 Women's Treatment Action Group
Kampala, Uganda

▣ Background

The Women's Treatment Action Group (W-TAG) was established following the Focus on Women satellite meeting, which was convened in concert with the Prevention of Mother to Child Transmission Conference sponsored by Global Strategies in Kampala, Uganda, in September 2001. W-TAG's goal is to show, through actions, that it is possible for women in Uganda to receive ARV treatment not just to prevent mother-to-child-transmission (MTCT) of HIV but also as treatment for HIV/AIDS. It aims to show government how delivery of ARV treatment could be instituted countrywide.

▣ Advocacy Environment

Participants at the Focus on Women satellite voiced particular concerned over the inadequate allocation of resources to Uganda's health sector. Hospitals in each of the country's districts are supposed to provide antiretroviral drugs (including nevirapine) to prevent MTCT, but the nation's infrastructure is poor and of variable quality from district to district. At the same time, few people can afford private treatment. Thus, while the government has been engaged in a limited program to provide this treatment free, hospitals are few and access to these hospitals is, at best, limited.

Participants asked the hard questions: Why must important services be limited to delivery in a hospital setting, especially when nevirapine treatment is straightforward? What are the implications of providing the treatment to mothers who live in resource-poor settings where access to health care or treatment options is largely nonexistent? What can we do about it? These are the questions W-TAG has sought to answer through its formation and work in Uganda.

▣ Advocacy Focus and Strategy

Coming Together at Conferences

W-TAG's history is part of a larger, familiar story of women coming together and recognizing that, with the government's failure to address critical issues, the women themselves need to take action and assume responsibility for life-and-death issues. The Focus on Women satellite meeting brought together women working at the community level with PLWHA, doctors, lawyers, traditional birth attendants (TBAs),[1] and others to explore the important link between MTCT prevention strategies

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[1] TBAs are not licensed professionals but rather an organized group of local community traditionalists providing antenatal care and conducting deliveries for women through the use of traditional practices and local substances, such as herbs. Many pregnant women use the services of TBAs because their services are available within the community at little or no cost.

and women's health in general. The opportunity for women to come together and share their experiences provided a vital forum to identify critical issues and enabled development of a coordinated plan for action and advocacy—with far reaching impact. The satellite meeting led to one of the first African women's declarations about HIV/AIDS. It prompted groups such as W-TAG to form in order to focus in-country advocacy efforts. In fact, the satellite meeting was organized by many of the same women who had organized the Women and HIV Satellite Conference at the XIII International AIDS Conference in Durban, South Africa, in 2000. Clearly, a successful strategy in one setting can be applied to another setting.

Issuing Declarations

W-TAG, along with a group of more than 130 community women who participated in the Focus on Women satellite meeting, helped formulate the declaration, "A Focus on Women." Through their discussions and action planning at the satellite, the community women decided that their needs, priorities, and expertise needed to become a much more visible and powerful presence in deliberations about prevention of MTCT (PMTCT). The community women delivered the declaration in an address on the final morning of the Third International Conference on Global Strategies for Prevention of HIV Transmission from Mothers to Infants in Kampala in September 2001.

This declaration and the Kampala Declaration on Gender and HIV/AIDS issued just two months later inspired women to formulate the Women and HIV/AIDS: The Barcelona Bill of Rights during the satellite conference in Barcelona in 2002 (see Annex B for more information about the declarations). The Kampala Declaration is one of the first women's declarations about HIV/AIDS to come out of Africa while the Barcelona Bill of Rights is the first one on women and HIV/AIDS to come out of international AIDS conferences. Both have been distributed worldwide.

Advocacy by Demonstrating Solutions

W-TAG's advocacy goal grows directly from the "A Focus on Women" Declaration. In particular, W-TAG has worked to expand the reach of government-sponsored PMTCT initiatives by working at the community level with private midwives, TBAs, and communities of PLWHA. With a small grant and donated drugs, W-TAG is training professional midwives and TBAs in basic facts about HIV/AIDS, about MTCT, and about the administration of nevirapine to prevent transmission. W-TAG also works with professional midwives and TBAs to enroll eligible pregnant women; to educate, counsel, and refer them for prevention services; and to follow up with them in the months after delivery.

> *"We see that government is too slow in scaling up PMTCT. We need to move forward and if we take [on this work], maybe government will also be challenged…[to] expand partnerships, or find a way of spreading their programs farther and faster."*
>
> Jane Nabalonzi,
> W-TAG

W-TAG's approach to advocacy has primarily relied on demonstrating a policy solution—and then using that solution as evidence for its advocacy efforts. In asking one of its founders about the decision to establish the group, Jane Nabalonzi responded, "We see that government is too slow in scaling up PMTCT. We need to move forward and if we take [on this work], maybe government will also be challenged…[to] expand partnerships, or find a way of spreading their programs farther and faster." Thus, through direct action, W-TAG is responding to an immense social need as well as demonstrating the viability of a responsive approach.

W-TAG's experience is emblematic of women's advocacy in so far as the group's work responds directly to the needs of women that the organization works with every day. At the same time, W-

TAG is also an organization working toward a long-term advocacy goal of responsive PMTCT programs. It is creating the evidence and advocacy network it needs to push the government to guarantee that PMTCT programs will reach all women at the grassroots level.

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▣ Questions for Dialogue

1. This story features a demonstration project that shows how group actions can lead to a possible policy solution. What is the policy change W-TAG seeks? What next steps could W-TAG take to advocate for official policy change?

2. What data could W-TAG document and collect to show that its policy solution is effective?

3. Why do you think it was important to have drafted the "A Focus on Women" Declaration? How can crafting declarations or consensus statements contribute to advocacy? How have you used or might you use declarations to support your own advocacy work? Which ones?

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This story was based on an interview with Jane Nabalonzi, a founding member of the Women's Treatment Action Group (W-TAG).

3.4 Society for Women and AIDS in Kenya
Nairobi, Kenya

▣ Background

The Society for Women and AIDS in Kenya (SWAK), established in 1996, mobilizes women and girls to fight HIV/AIDS. SWAK is an affiliate of the larger, continent-wide network Society of Women and AIDS in Africa, or SWAA.

▣ Advocacy Environment

When SWAK was established in 1996, Kenya had not yet started to address HIV/AIDS, let alone focus on gender and HIV/AIDS. SWAK was created to bring the dialogue home and to provide a vehicle for engaging women and girls as the major change agents in the struggle against AIDS.

▣ Advocacy Focus and Strategy

Coming Together as a Network

The creation of SWAK highlights the value of networks as forums for fostering peer learning, promoting opportunities for growth, and creating the infrastructure for a powerful advocacy network. SWAK's efforts focused on community mobilization through local coordinating committees that commit to recruiting women, organizing local education workshops structured around creative communication methods, and coordinating basic care and support mechanisms such as home visits. Through these different women-initiated and led activities, SWAK provides the power of a network through which community women can advocate for the resources, programs, and policies necessary to support needed responses to HIV/AIDS.

Creating an Organizational Structure to Allow Bottom-Up and Cross-Sector Involvement in Policy

Like NACWOLA, SWAK's organizational structure enables the information flow critical to maintaining effective advocacy networks. SWAK's communications flow from the grassroots to the national level and back again, thereby ensuring that feedback is readily accessible and that national policy initiatives are more responsive to citizen's concerns. SWAK's collaboration with other actors in the fight against HIV/AIDS also has laid the groundwork for multisectoral partnerships. For instance, SWAK addresses the legal needs of HIV-positive women and their families by forging links with legal professionals who, in turn, train local paralegals to identify important issues and make informed referrals. In 2002, SWAK was funded to bring legal professionals and community advocates together in the creation of a legal referral network.

Engaging in Direct Action for Change

When asked about SWAK's advocacy workshops in different communities, Ludfine Opudo, SWAK's national coordinator and a woman living with HIV, describes the group's approach as informal. "We look at what people are already doing, we share those experiences and learn from each other…. We ask people, 'what skills do you already have, and are already using, to send a message or effect change in your communities'?" Ms. Opudo then tells the story of how women in one village generated change through action.

After her husband died of an HIV-related complication, one woman defied the traditional practice of wife inheritance and was not inherited by her husband's family. She lost her land and access to other property rights. When the woman died, she had no family to prepare her for burial. Did people in the community prevail upon the husband's family to fulfill an obligation to his wife? Did a local advocate try to persuade the church or community elders to ensure that the woman's death was recognized with dignity? No. No words were used, just *action*. The local SWAK support group simply dug a grave in order to give the woman a proper burial. One of the SWAK organizers recalls that as the women began digging, the men in the community were put to shame and, in response, took up their shovels and trowels and finished digging the grave, as is customary in Kenya.

> *"We look at what people are already doing, we share those experiences and learn from each other…. We ask people, 'what skills do you already have, and are already using, to send a message or effect change in your communities'?"*
>
> Ludfine Opudo, SWAK

This small episode demonstrates the power of direct and immediate action. In advocacy efforts, actions many times speak louder than words. People who might otherwise remain silent may be able to show their support for change through action. In the case of SWAK, the women, already mobilized into a group, used existing skills to influence their community. In their own way, the women made a statement—any woman, any individual, whether HIV positive or not, deserves dignity in life and in death. The women's action also underscores a basic tenet of their approach to advocacy: anyone can be an advocate.

◉ Questions for Dialogue

1. Why was direct action a powerful advocacy strategy? Can one person's direct action lead to policy change? How? What other steps might a community take to ensure that change becomes widespread?

2. Are you involved in any networks? If so, what are the strengths of the structure(s), and how can you use the network(s) to advance your advocacy work?

3. Imagine yourself in a community where no formal organization structures exist to address your constituency's issue. What steps would you take to organize into a body that could advocate on its own behalf? Where would you start? To whom would you talk?

This story was based on an interview with Ludfine Opudo, national coordinator of SWAK. For further information about the organization, please visit www.famafrique.org/swaainter/anglais/sommairea.html.

3.5 Sampada Grameen Mahila Sanstha
Maharashtra, India

▣ Background

Sampada Grameen Mahila Sanstha (SANGRAM) began its work in India in 1992. Its peer education and condom distribution programs offer female sex workers tools specifically for responding to the HIV/AIDS epidemic and generally for improving their own health. SANGRAM's approach envisions the sex worker as a woman who can be empowered to change her circumstances and become an agent of change for herself and her community.

▣ Advocacy Environment

In the Sangli District of India's Maharashtra State, the HIV/AIDS epidemic had been growing at a disproportionate rate relative to the rest of the country. The incidence of HIV/AIDS in the sugarcane-rich district is second only to Mumbai. Since the early 1990s, women in sex work have borne the brunt of India's HIV/AIDS epidemic. Moreover, in the words of Meena Seshu, founder and general secretary of SANGRAM, "With AIDS, the stigma faced by sex workers has increased tenfold. Manuals on AIDS control refer to them as 'vectors in the spread of AIDS' or 'the bridge population.' This thinking diverts attention from coming up with holistic strategies, and involving all sections of society, to combat HIV/AIDS and instead criminalizes these women further." Those who formulate health interventions typically regard women in sex work as *victims* with little capacity to change anything, let alone their health status.

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>
> *"With AIDS, the stigma faced by sex workers has increased tenfold."*
>
> Meena Seshu,
> SANGRAM
>
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One of the greatest obstacles faced by SANGRAM in responding to the health needs of sex workers was resistance from brothel owners and the sex workers themselves, who were wary of the SANGRAM organizers. They had had enough of mainstream messages that held them responsible for the spread of the virus, says Ms. Seshu. "They could not understand why we were taking so much interest in them," she recalls. In some areas, brothel owners and criminals tried to block the program, even killing a peer educator in one instance. Many women in sex work shunned identification while irregular working hours and a high turnover of sex workers made it difficult to maintain constant contact with others. SANGRAM's philosophy also clashed with the approaches of other NGOs, creating tensions among organizations.

The breakthrough came when a powerful brothel owner realized that SANGRAM was talking sense. The owner recognized that SANGRAM was concerned not only about how sex workers could protect others from infection but also about how the women could protect *themselves* from infection. SANGRAM'S message made economic sense to the brothel owner. With support,

SANGRAM laid the foundations of a peer education program in Gokulnagar. Its main focus is to educate women in sex work about HIV/AIDS, to distribute condoms to them, and to train and counsel women who are unable to enforce condom use.

▣ Advocacy Focus and Strategy

Focusing the Peer Education Program on Empowerment

To promote its focus on the empowerment of sex workers, SANGRAM's peer education program is organized around two underlying premises: first, insiders are more effective than outsiders in reaching the community; second, women in sex work are the only ones who can enforce condom use for their own protection. SANGRAM identified 16 peer educators and, with them, decided that every seventh house on a street would be the home of a peer educator and that peer educators would tell their neighbors about HIV/AIDS and distribute condoms.

From this small beginning in 1992, the peer education program has grown to span six districts in Maharashtra and the border areas of North Karnataka. About 120 peer educators drop off 350,000 condoms to 5,000 women in these communities every month. The peer education program delivers condoms to communities characterized by dwellings as modest as small huts as well as to communities with sturdy homes in industrial centers such as Karad, where some household women turn to sex work on market days. The program covers a wide array of sites where women are engaged in sex work.

The impact of the condom distribution program is evident in many ways. Several peer educators report an increase in condom use in their areas. Areas that previously asked for 6,000 condoms now ask for 8,000. If condom supplies are depleted in one area on the highway, the sex workers walk over to the next area for more.

The condom distribution program has been successful for a number of reasons. First, the peer educators own and shape the process and rely on a shared sense of identity. The "educators" and the "educated" live in similar circumstances and can understand each others' experiences. Second, as the women experienced a drop in sexually transmitted infections (STIs) through condom use, they suddenly saw their own health improving.

Third, not only has the peer education program successfully reduced the spread of HIV but a strong sense of program ownership has also forged a rare solidarity among the educators and the educated. That sense of ownership is partly a function of conscious strategies adopted by SANGRAM's staff. The organization often plays a facilitating role to build leadership and encourage solutions from within the community.

Finally, the program has spread from one district to another, not at SANGRAM's behest, but as the peer educators suggest new areas for expansion based on informal contacts. In an informal process that speaks volume for the program's utility, educators typically suggest areas where their friends, cousins, or relatives live.

Expanding to a Collective to Include Constituencies of Youth, Rural Women, and MSM

Collective developed. Given SANGRAM's emphasis on processes and strengthening the community from within, a natural next step was the formation of a collective to emphasize sex workers' self-determination through a sex worker-run organization. In 1996, the peer education program broadened into VAMP, the Veshya Ananyay Mukti Parishad, a collective of women in sex work. VAMP aims to consolidate a common identity among the women and empower them to find

their own solutions. Although the relationship between SANGRAM and VAMP is like mother and daughter, VAMP has developed its own mission. It is separately registered as a collective and has its own board of members drawn from women in sex work. While it is still guided by SANGRAM, VAMP is intended to function independently in the future.

As part of its responsibilities, VAMP—with the help of SANGRAM—now runs the peer program in the eight districts where it began. In 2000, VAMP initiated an integrated program on STI/HIV/AIDS interventions among truckers. Using the collective of women in sex work and a peer educator model as a best practice for the STI/HIV/AIDS intervention program, the trucker program promotes safe sex behavior that is enforced through techniques developed by women in sex work.

Youth and rural women reached. In 1997, SANGRAM built on its own work with the collective and started a District Campaign. The campaign focuses mainly on three constituencies: rural women who often contract HIV from their husbands and lovers without knowing it but have the least access to knowledge or information; young adults who need information, education, and counseling on issues of sexual health and sexual rights; and adolescents, who constitute a significant proportion of the clientele of the sex workers. The project is spread over 700 villages of Sangli District, which embodies eight *tehsils* (an administrative unit dealing with taxes and land records). In addition, within each tehsil, VAMP also has an HIV/AIDS prevention and care center run by a trained social worker. Women organizers also run 38 subcenters in the eight tehsils.

MSM organized. In 2000, a small group of men approached SANGRAM with the idea of starting a program for MSM. A study by Blackstone Market Facts for Family Health International mapped MSM and revealed that MSM in Sangli District are significant in number; a behavioral surveillance study revealed that most such men are married and do not practice safe sex. In response, SANGRAM enlisted help from the Naz Foundation to hold a training session on MSM and HIV/AIDS; 20 men attended. The training session gave rise to an intervention that resulted in the formation of a support group called MUSKAN. The group works in the cities of Miraj, Kolhapur, Ichalkaranji, and Belgaum in the neighboring state of Karnataka.

Taking a Seat at the Table

Six years after SANGRAM started working with women in sex work, the state government finally started "hearing" their voices. In late 1998, the government announced plans to work with women in sex work in Maharashtra, the state in which SANGRAM carries out its work. The change in attitude on the state government's part was a response to the increased visibility achieved by SANGRAM though the self-awareness, empowerment, and collectivization of sex workers and indicated that women had started to make their mark. In the districts where SANGRAM is active, women in sex work are not prepared to remain passive recipients of government aid. They are in a position to initiate dialogue with the government and demand their rights.

The District Campaign is following SANGRAM's lead by creating a collective consciousness among household women, empowering them to develop the ability to negotiate independently and assert their rights. The MSM group, too, is laying the groundwork to develop the consciousness and confidence to assert its rights.

1. What processes did SANGRAM follow in working with sex workers? How did these processes contribute to developing a powerful network among a stigmatized and socially marginalized group? How might you apply these strategies to your own advocacy work?

2. How did SANGRAM's focus on the empowerment of sex workers as agents of change in a peer education program prepare SANGRAM to have a seat at the table as an advocate? What other capacity building might be needed to ensure that SANGRAM is a full participant at the table?

3. What do full involvement and representation mean in the decision-making process? Are there decision-making processes in which you would like to increase the representation of marginalized groups? What advocacy process would be needed to bring about this change?

This story was based on an interview with Meena Seshu, SANGRAM's founder and general secretary.

Lessons Learned

- **Organizing women to address their immediate needs is often a critical first step to initiating advocacy.** The process of responding to concrete needs is itself a strong organizing tool. By meeting sex workers' immediate needs, SANGRAM was able to educate the workers about the need for condoms and how to advocate successfully for their use. From this foundation, sex workers could transfer the skills acquired through advocating with clients and the community to advocating in government decision-making processes. Similarly, in NACWOLA, women recognized the need to come together to support themselves and their families before engaging in broader advocacy related to policy change.

- **Creating an organization that responds to women's needs in the context of HIV/AIDS provides a strong infrastructure for advocacy efforts.** The formation of an organization draws attention to a set of issues and creates an infrastructure for responding to and resolving those issues. It can build the capacity of leaders needed as advocates, especially with regard to vulnerable or otherwise marginalized populations. It also provides the government with a way to connect with and receive input from those affected by a particular issue.

- **Building powerful advocacy networks can start with existing relationships.** In Argentina, FEIM benefited from its existing reproductive rights networks. In East Africa, the relationships forged through self-help groups laid the groundwork for a powerful advocacy structure. And, in India, relationships fostered through outreach provided an organized constituency base from which to launch advocacy.

- **Creating forums for the voices of women within existing institutions advances women's advocacy.** Satellite sessions at conferences that focus on women's needs have provided unique opportunities for women to exchange information and develop advocacy strategies, including the issuance of declarations. Gaining access and power to participate in policy- and decision-making processes is essential if women are to be able to represent and advocate for their and their communities' needs.

- **Developing women's capacity to assert their rights can build the confidence and advocacy skills women need to shape changes in the policies, practices, and programs that affect them and their communities.** Given the importance of women's rights, it is essential that women engage in consciousness raising and skills building with respect to their rights. Women's groups often provide a forum or organization through which women, especially women who face increased stigma and discrimination such as female sex workers and HIV-positive women, can learn about and assert their rights.
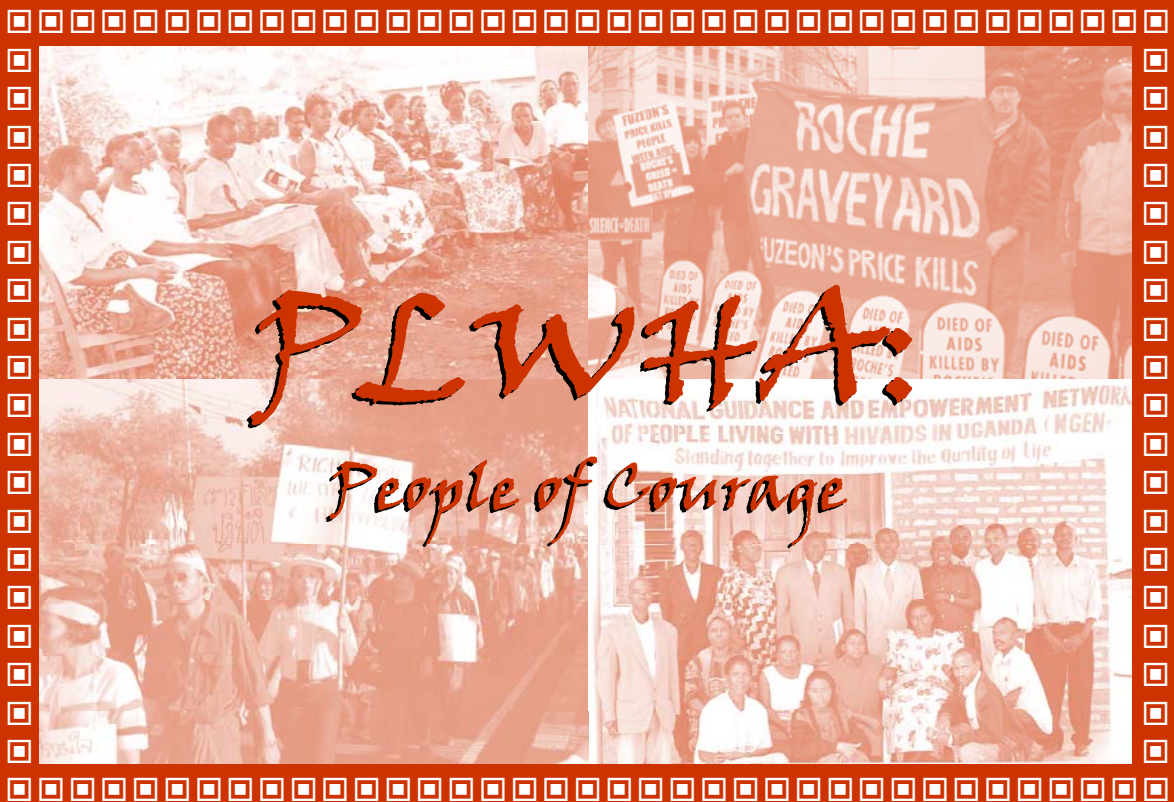
PLWHA:
People of Courage

SECTION 4

PLWHA: People of Courage

> *"We condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others. We are People with AIDS."*

Denver Principles, 1983

People living with HIV/AIDS (PLWHA) throughout the world have demonstrated their courage and tenacity not only in the ways they have learned to live with a potentially life-threatening illness but also in the countless ways they have organized themselves to challenge ignorance, apathy, fear, stigma, and discrimination. Many have taught themselves and their peers the "science" of advocacy and community organizing. Some, as demonstrated in this section, have raised advocacy and organizing to high art. They have used their newfound knowledge and skills to create strong and visible grassroots organizations and national networks that are at the forefront of the global response to the pandemic. In the process, they have gone on to become recognized leaders in their local communities, their home countries, and internationally.

From the **AIDS Coalition to Unleash Power (ACT UP)** in the United States—a pioneer in HIV/AIDS advocacy—to the **Network of African People Living with HIV/AIDS (NAP+)** in Kenya, the **National Guidance and Empowerment Network of People Living with HIV/AIDS (NGEN+)** in Uganda, and the **Thai Network of People Living with HIV/AIDS (TNP+)**, this section highlights the contributions made by groups representing PLWHA. Individually and collectively, the stories underscore the critical importance of the Greater Involvement of People Living with HIV/AIDS (GIPA) principle in all aspects of local, national, and global responses to HIV/AIDS. Despite great strides in achieving GIPA in many parts of the world, much remains to be done. In too many places, PLWHA are left out of the decision-making processes that directly affect their lives. The stories told here should help decision makers and PLWHA better understand the importance of GIPA and ensure that PLWHA are truly and meaningfully involved in all aspects of our collective response to the HIV/AIDS pandemic.

Some of the major advocacy issues and strategies that are evident in the stories of PLWHA associations include access to life-saving treatments, respect for human rights, and an end to the silence and discrimination that too many PLWHA still face. The stories also highlight the creative use of internal and external advocacy strategies, the powerful role of self-help groups and networks in supporting advocacy efforts, and the importance of defining winnable advocacy objectives and goals.

▣ **Featured in This Section**		
Name of Organization	**Country**	**Advocacy Focus/Strategies**
4.1 AIDS Coalition to Unleash Power	United States of America	- Theatrical and confrontational style of advocacy - Use of media to deliver the message - Internal/external approach
4.2 Network of African People Living with HIV/AIDS	Kenya	- Reducing stigma through leadership development - Use of networks
4.3 National Guidance and Empowerment Network of People Living with HIV/AIDS	Uganda	- Reducing stigma through personal disclosure - Greater involvement of PLWHA
4.4 Thai Network of People Living with HIV/AIDS	Thailand	- Defining the issue - Building alliances

4.1 AIDS Coalition to Unleash Power
New York City, USA
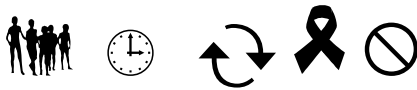
▣ Background

The AIDS Coalition to Unleash Power (ACT UP) was established in 1987 in New York City. Its mission is to advocate for the rights of PLWHA and for supportive government policies. ACT UP New York was one of the first HIV/AIDS advocacy organizations in the world.

▣ Advocacy Environment

As HIV began to spread primarily in the gay communities of the United States in the late 1970s and early 1980s, the basic facts about the disease were not known. Scientists could not tell us if it was transmissible and, if so, by what means. Moreover, they were unable to advise people how to protect themselves. At the same time, there were no advocates for HIV/AIDS and no HIV/AIDS organizations.

Most Americans were not prepared to stand up and work to combat an unknown illness infecting primarily the gay community. In the early days of the HIV/AIDS epidemic, the challenge was to create an advocacy environment in which people could learn about the disease, advocate for supportive services, and pressure government to not waste time in undertaking research initiatives.

The enormity of the problem and the resistance on the part of the government to respond to it demanded new and unusual measures. What was needed was an organization that was not afraid to do whatever had to be done to break through the denial and silence that characterized the first few years of the HIV/AIDS epidemic in the United States.

This is the environment that gave birth to ACT UP. Initially, ACT UP New York was composed mainly of gay men and women. Over time, it has played a significant role in shaping the direction of HIV/AIDS advocacy around the world.

▣ Advocacy Focus and Strategy

One of the founders of ACT UP New York is Eric Sawyer, who has been an HIV/AIDS activist since the early 1980s, when the first statistics were publicized about a strange illness afflicting gay men. During the mid-1980s, as people who became sick often lost their housing, Sawyer began to develop his skills in creating housing for and advocating for the housing needs of PLWHA. He partnered with a housing developer in Harlem and began talking to the New York City Department of Housing Preservation and Development about establishing a skilled-nursing facility. At this point,

he decided to focus his advocacy on addressing the housing needs of PLWHA and pressuring the U.S. government to invest in more research on HIV/AIDS. In a telephone conversation, Larry Kramer, ACT UP's founding father, shared with Sawyer his idea of starting an advocacy group that would draw attention to the lack of funding, research, and support services for PLWHA. Kramer invited Sawyer to attend a meeting to discuss formation of such a group. At the meeting, Sawyer was asked to help stage the first of many civil disobedience demonstrations against HIV/AIDS. It was 1987, and ACT UP was born.

Theatrics Generates Media Coverage

ACT UP held its first demonstration on March 24, 1987, on New York City's Wall Street, the financial capital of the world. The demonstration highlighted the fact that, even though the government had allocated funds to HIV/AIDS research, a hiring freeze at the National Institutes of Health meant that none of the money was finding its way to research. The demonstration also demanded that pharmaceutical companies invest more in clinical trials to investigate and develop effective drugs against the disease.

ACT UP demonstrations were decidedly theatrical. For the organization's first demonstration, Joseph Papp, one of New York City's leading theater directors, directed his theater staff to develop life-size puppets of the director of the U.S. Food and Drug Administration, which hung in effigy from a lamppost. In time, as the government and public health community considered measures to institute mandatory testing and quarantining of PLWHA, ACT UP seized on another opportunity to develop further and refine its advocacy style. At the Gay Pride Parade, a group of activists created a stage on the back of a flatbed truck. They depicted a scene of a concentration camp, with Sawyer wearing a mask of Ronald Reagan (the U.S. president at the time) and laughing at the people in the "camp" who were covered with Kaposi's sarcoma lesions. A sign read, "Test drugs, not people." As the truck drove the parade route, thousands of onlookers and television viewers became aware of the fight to fund HIV/AIDS research and protect the rights of people against mandatory HIV testing.

> "It is time for the legal, medical, public health, and activist communities to join together to pursue a principled fight for the human right to health. Working independently we have won many battles. By uniting, I believe, we can win a universal right to health."
>
> Eric Sawyer
> ACT UP Founding Member,
> 2001

The gay movement brought to HIV/AIDS advocacy the recognition that highly staged, theatrical antics could attract the attention of the media and thus the general public. Drawing from lessons on how the media covered the civil rights, antiwar, and gay rights movements of the 1960s and 1970s, ACT UP believed that the only way to get noticed and reach the public was to stage provocative, media-friendly events. It also learned that newspapers often misrepresent events, making it especially important for demonstrators to carry a banner bearing the group's message. The banner in the photograph would tell the story even if the news coverage did not.

Timing and Press Releases Boost Coverage

ACT UP's advocacy style also involved the staging of a "scene/demonstration," again in New York City's financial district but in front of the New York City Department of Housing Preservation and Development. To ensure coverage on the 5:00 and 7:00 p.m. news broadcasts, ACT UP scheduled the demonstration for 4:00 p.m. It notified and briefed the media via a press release accompanied by a list of issues and demands. Citing the number of PLWHA probably living in the subway system or city shelters and the potential public health disaster if PLWHA were housed with people with untreated tuberculosis, the press materials demanded government funding of medically appropriate

housing for PLWHA. As for the "scene/demonstration," ACT UP set up a stage representing a squatter's camp of homeless PLWHA while 20 activists chained themselves to old, beaten furniture that they scattered in the middle of the street as part of the camp. The demonstration caused major traffic delays. In response, the city brought in garbage trucks as police and fire department personnel tried to cut the activists from the furniture in an attempt to end the demonstration. By this time, however, the demonstration, the issues, and the demands had been broadcast on the news for hours. Shortly after the demonstration, officials in the New York City Department of Housing and the New York State Homeless and Housing Assistance Program announced the formation of a $50 million capital fund to build medically appropriate housing for PLWHA. The advocacy had been a success. Such theatrical demonstrations came to be a driving force and characteristic style of ACT UP's advocacy.

A Combination of Internal/External Advocacy Relations and Actions Increases Advocacy Power

Through a network of friends from the gay community—people who worked in government, social services, health care, unions, and as advocates for low-income families—ACT UP brought together activists and professionals to create a critical alliance of those affected, those infected, and professionals working on their behalf. Many gay men and lesbians trained and working as doctors, lawyers, and social workers entered their respective professions with a sense of social responsibility to their community. Clearly, ACT UP harnessed the social responsibility of various professionals to create a wide-ranging network.

Through its alliance of committed individuals, ACT UP developed an "internal/external" strategy, in which lobbying from the inside was supported by advocacy on the outside. Often, the same representatives from the medical professions, social services, and government who met civilly with public officials and decision makers during business hours would exchange their business attire for activist street clothes later in the day and loudly engage in eye-grabbing demonstrations. This dual approach enabled ACT UP to reach people they never would otherwise have been able to reach. Over time, ACT UP developed several important alliances within government and vice versa. Each gained from the relationship, which had started as adversarial but ended up as collaborative.

Along with lobbying public officials from behind the scenes, ACT UP carried out demonstrations that targeted individual people, thereby attempting to hold specific individuals accountable for policy decisions that affected people's lives. The organization developed ways of publicly shaming people for their indifference or counterproductive policy initiatives. By acquiring inside information, ACT UP learned who was holding up funding or drug approvals and then targeted the appropriate people for "actions."

In addition, both "insiders" and "outsiders" wrote articles for supportive newspapers and magazines and invited editorials demanding expedited eligibility for social services. The same individuals also called for the creation of a "coordinating" agency for PLWHA that would allow PLWHA to rely on one government agency for all their needs. The insider-outsider alliance led to the creation of what is now called the Division of AIDS Services.

Expertise in Information and Lived Experiences Underpins Advocacy

The ACT UP strategy combined activism with expertise. Accordingly, ACT UP evolved into an organization well versed in the day's issues and with the personnel and know-how to develop solutions. As decision makers lobbied by ACT UP came to realize that the organization commanded solid expertise and was not just a group of "radical rabble-rousers," they recognized the wisdom of working with rather than against ACT UP.

Given that ACT UP members were individuals with established relationships with PLWHA and, more often than not, PLWHA themselves, the organization was able to provide practical solutions to government as it was formulating its response to the epidemic. A prime example is the development of the Division of AIDS Services and publicly funded housing programs for PLWHA.

▣ Ongoing Challenges

Attempts to Build Bridges Beyond the Gay Community Falter

ACT UP's brand of HIV/AIDS advocacy caught fire within the U.S. gay communities; in the span of a couple of years, ACT UP chapters took root in many major U.S. cities and later in cities around the world. Yet, one of the challenges faced by ACT UP—despite efforts to expand advocacy to the broader HIV/AIDS-affected communities—was the public's perception of the organization as a "gay group." Even though ACT UP posted meeting notices throughout the city and not just in gay enclaves, conducted meetings in "non-gay" community venues, and forged alliances with other groups, the organization was unable to develop a broader base. As the 1980s ended and the epidemic moved beyond gay men to other hard-hit communities—African Americans and Latinos, IDUs, the homeless—ACT UP's inability to attract and retain individuals from these communities proved to be a critical blow. It was and still is a lesson on how stigma and homophobia can undercut HIV/AIDS advocacy efforts.

Building Bridges Internationally Remains a Challenge

Another challenge faced by ACT UP has been how to develop relationships with HIV/AIDS activists across the globe. Since the 1987 International AIDS Conference in Washington, DC, ACT UP has been involved in HIV/AIDS work at the international level. While many of the factors that create vulnerability in the United States cut across cultures, what may work in New York may not necessarily work in Bangkok, Nairobi, or Quito. Yet, despite substantial differences, there are many similarities. Discrimination, stigma, denial, sexuality, fear, and hatred are global issues that create a highly complex and challenging advocacy environment.

▣ Questions for Dialogue

1. What led ACT UP to develop its signature media style of provocative demonstrations and street theater? What were its benefits? What were its limitations?

2. How did ACT UP develop and use "expertise"? How did this strategy complement the organization's more public, rabble-rousing style?

3. Consider the policy and political environment in which your organization works. Which aspects of ACT UP's strategy could work? Which ones would not? Why? How could you modify ACT UP's strategy to work in your environment?

This story was based on an interview with Eric Sawyer, a founding member of ACT UP and the Health GAP Coalition. For further information about the organization, please visit www.actupny.org.

4.2 Network of African People Living with HIV/AIDS
Nairobi, Kenya

▣ Background

Founded in 1994, the Network of African People Living with HIV/AIDS (NAP+) is based in Kenya and operates under an active secretariat in Nairobi. Its mission/goal is to create a network that can provide support to PLWHA and PLWHA organizations in Africa. It builds the capacity of empowerment groups and develops the leadership skills of individuals in the network.

▣ Advocacy Environment

In many ways, the HIV/AIDS policy environment in Africa in the early 1990s resembled that in the United States in the 1980s. There was an urgent need to establish networks that would lend support to PLWHA, challenge stigma, and develop channels for advocacy. Yet, the governments of most African countries were neither paying attention to the growing pandemic in their midst nor investing in HIV/AIDS education, prevention, or treatment. In addition, few people who were living with HIV/AIDS were willing to disclose their health status.

Unlike the United States, however, the political environment in many African nations was not only indifferent to HIV/AIDS and any attempts at organized advocacy, but it was also actively hostile to any such efforts. Kenya, under the government of President Moi, who had been in power for over 20 years, had a history of violent government responses to demonstrations, effectively discouraging the development of PLWHA networks that would have organized and advocated on behalf of PLWHA.

Nevertheless, some efforts by PLWHA to organize and advocate on their own behalf did flourish. The story of NAP+ and one of its founders, Michael Angaga, is a case in point.

In 1993, Michael Angaga, currently NAP+'s regional coordinator, received an invitation from the United Nations Development Program (UNDP) to travel to Senegal to review HIV/AIDS research protocols to be implemented in four African countries. As Angaga was exiting from the plane, he met a colleague from Zambia who had disclosed his HIV-positive status. Although Angaga had known of his colleague's status for three years, he had never before met someone who was openly living with HIV/AIDS. The experience left Angaga with an indescribable feeling of hope and possibility. The knowledge that people could "come out" as HIV positive and function from a position of strength and leadership opened a new path for Angaga. It was this recognition and sense of hope that Angaga sought to share and foster in other PLWHA.

> *"The knowledge that other people could 'come out' as HIV positive and function from a position of strength and leadership opened a new path."*
>
> From statements made by Michael Angaga
> NAP+

With a new vision, Angaga and a pioneer group of activists set out to create a support network for PLWHA. In inquiring about the major advocacy issues facing HIV-positive people, Angaga and his colleagues saw that, for each individual or group, simply working in isolation was a barrier to action. In isolation, groups cannot gain access to critical information or gauge the relevance of their work. Most important, isolated groups miss out on the positive reinforcement that comes from working together. Positive reinforcement is one of the most important—but often most frequently neglected—strategies in advocacy planning.

With respect to the political context, Angaga also realized that the freedom to disclose one's status without repercussions was a critical precondition to reducing stigma and discrimination. Yet, a sense of isolation is a major barrier to disclosure. To address isolation, bolster individual efforts, and create safety in numbers, NAP+ developed a regional network of PLWHA to help foster an environment conducive to advocacy. NAP+ recognized the importance of making it possible for PLWHA to be open with and learn from each other. It also understood that PWLHA must counsel and support each other in order to lay the foundation for advocacy.

▣ Advocacy Focus and Strategy

Prioritizing Stigma

Building on relationships developed during the research protocol seminar in Zambia, a small secretariat emerged to support the initiation and development of PLWHA empowerment groups in different regions of Africa. The formation of the secretariat was one of the first steps in creating the support needed to carry out advocacy. In 1994, at one of the early AIDS conferences in Mombasa, Kenya, PLWHA came together, explored pathways for action, and formally declared themselves an organization. Other participants at the conference reported experiences similar to Angaga's earlier experience—a sense of elation that HIV-positive people could openly talk to and support each other. As participants at the 1994 conference discussed the formation of an organization, they asked, "What are our priorities?"

Given that stigma was and continues to be one of the greatest obstacles in the fight against HIV/AIDS, Angaga and the core founding group of NAP+ decided that addressing stigma through PLWHA empowerment was a critical first step. Angaga recalls that even the core group of individuals who had gathered in Mombasa to explore these issues had to struggle to be honest and open with each other—despite the knowledge that they were all HIV positive. Unless stigma was addressed, they wondered, how would PLWHA be able to demand equal treatment in employment, health care, and civic leadership. Thus, NAP+'s advocacy goal called for decreased stigma.

Recognizing Empowerment Groups and Safe Environments as Essential to Addressing Internal Stigma, Rights, and Leadership Development

To challenge and overcome stigma, NAP+ decided that its principal advocacy methods would focus on establishing empowerment groups and developing PLWHA leadership through IEC efforts. NAP+ produced quarterly publications, periodic reports, and manuals, such as *Food for the People Living with HIV/AIDS*, to enable local PLWHA empowerment groups to assist their constituents.

One of NAP+'s signature programs is the Ambassadors of Hope program. PLWHA from around Africa travel as "ambassadors" to other countries to talk about and raise awareness about HIV/AIDS

and to lead and create support groups for PLWHA, particularly in countries where such groups do not yet exist. The program takes the first steps to reduce isolation and stigma, especially internalized stigma, and helps to foster an environment that will support the development of an advocacy network.

The Ambassador of Hope program is based on the concept of peer learning. It develops visible leaders who can in turn promote public awareness and education. A striking and innovative feature of the program is that PLWHA, often reluctant to reveal their health status in their home country, can take advantage of the opportunity to travel to other places and provide leadership in open and public ways. This strategy yields several benefits. First, it gives PLWHA the powerful experience of functioning as a leader in a safe environment; second, it provides a role model for PLWHA in the host country and demonstrates that a person can live with HIV/AIDS; and, third, it builds capacity and leadership in both the host country and the ambassador's country of origin. The opportunity to be "freer" in other countries gives people a way to "practice being out" as they develop their leadership skills, which they eventually use back home.

Promoting Visibility and Exchange of Information Through Networks and Conferences

NAP+ continues to expand its reach in Africa, ensuring the wide visibility of PLWHA. It is an important vehicle for the promotion of increased information, education, and networking among PLWHA and the wider HIV/AIDS community. NAP+ sponsored its first conference for PLWHA in Kenya in 2000. A second conference was held in Pretoria, South Africa, in December 2002 with over 150 delegates in attendance.

▣ Questions for Dialogue

1. What were the necessary conditions for PLWHA advocacy that NAP+ identified in the context of Africa in the early 1990s?

2. What are some of the benefits and risks to using personal disclosure as an advocacy strategy? How has NAP+ addressed them?

3. What are some of the important processes and structures that NAP+ has put in place to build and sustain its network?

4. How do stigma and discrimination affect the advocacy efforts of your group? Can you apply any of the lessons learned by NAP+?

This story was based on an interview with Michael Angaga, founder and regional coordinator of NAP+. For further information about the organization, please visit www.naprap.org.

4.3 National Guidance and Empowerment Network of People Living with HIV/AIDS
Kampala, Uganda

▣ Background

Founded in 1995, the goal of Uganda's National Guidance and Empowerment Network of People Living with HIV/AIDS (NGEN+) is to empower HIV-positive people to better their lives in powerful ways. It provides counseling and support groups for PLWHA.

▣ Advocacy Environment

In Central and East Africa in the late 1980s, little information was available about HIV/AIDS. At the same time, with virtually no government-sponsored prevention programs in existence on the African continent, tremendous community-wide denial, resistance, and a lack of awareness about HIV/AIDS were the norm. The one exception was Uganda. Under the leadership of President Museveni, Uganda had developed an HIV/AIDS education and awareness approach extending from the highest levels of government to all sectors of society. Uganda demonstrates what is possible when political will at the top provides the basis for action. The formation of NGEN+ with the support of President Museveni is a story of action on the ground meeting political support from "above."

▣ Advocacy Focus and Strategy

Major Rubaramira Ruranga returned from the war in rural Uganda in 1986. In 1989, after hearing from a friend about HIV and how it is transmitted, the major decided to undergo testing. At the time, the only facility offering HIV testing was a research institute, which performed the testing without providing information or counseling about the disease. When Ruranga's test results came back positive a month later, the major was more afraid than "when I fought my enemies hand to hand in the bush." He knew that this enemy had no cure, and he was sure that it meant a death sentence. On hearing that he was HIV positive, the major had only one question: How long would he live?

Years of fear and loneliness in facing his HIV-positive status eventually motivated Ruranga to serve as a spokesperson and advocate for the rights, needs, and concerns of PLWHA in Uganda and worldwide. The experience also led him to become involved in the creation of NGEN+.

Using Disclosure as an Advocacy Strategy to Address Stigma and Discrimination

Throughout his years of working in HIV/AIDS, Ruranga has observed several barriers to the battle against HIV/AIDS. For example, the general public assumed that PLWHA were all sick and/or about to die. That impression stemmed from the fact that many of the public images and stories of PLWHA focused on individuals near death.

Ruranga believed that such a misconception deserved to be challenged. After all, it not only lulled people into believing that they were neither HIV positive nor at risk of the disease if they "looked" healthy, but it also suggested that HIV-positive people were unable to work or otherwise contribute to society. He knew that both impressions were wrong. He also observed that many public reactions to PLWHA were stigmatizing and dehumanizing.

Accordingly, Ruranga decided that he needed to disclose his HIV-positive status; on World AIDS Day in 1993, he revealed his condition at a national event. Coming from an able-bodied military man in uniform, the mere disclosure of the major's HIV status challenged many misconceptions about HIV/AIDS. Ruranga therefore helped undermine the popular assumption that an HIV-positive individual looked sick or was about to die.

Organizing PLWHA to Become Centrally Involved in Mainstream Institutions

Another issue that concerned Ruranga was the creation of separate HIV/AIDS institutions such as HIV/AIDS-specific health centers, especially as they were isolated from the rest of the health care sector. He felt that disease-specific institutions marginalized and further stigmatized PLWHA. Indeed, the fact that HIV/AIDS care was not integrated into Uganda's basic medical and public health approach to diseases was leading to the creation of a separate health care infrastructure that the country could not well afford. In opposing a separate system of care, Ruranga stressed that the response to HIV/AIDS should address the cofactors of poverty, gender relations, and violence. He also recognized that HIV-positive people needed to speak for themselves if HIV/AIDS care was to come into the mainstream health care system and address more than just the health aspects of the disease. This recognition led Ruranga to become a strong and ardent supporter for the involvement of PLWHA in all aspects of the response to HIV/AIDS.

> *"There are still problems of a bureaucracy that does not seem to see where HIV/AIDS is going. We still find problems getting funds to improve the empowerment of PLWHA, and to use their newly gained experience to the maximum."*
>
> Major Rubaramira Ruranga, Founder of NGEN+

For these reasons and because he wanted to help other men in the military, Ruranga went to Uganda's president—whom he had met through his military service—to ask for his support to start an organization. With financial support from the president, Ruranga created NGEN+. The group's vision was to provide education, foster PLWHA self-empowerment, and promote capacity development among PLWHA—with the goal of full involvement in Ugandan society.

To achieve its goals, NGEN+ has helped organize PLWHA into local networks throughout Uganda, thus creating a common voice to advocate and lobby for an improved quality of life. NGEN+ has served as an important vehicle that brings together PLWHA to share experiences and skills, promote "positive living" among themselves, and encourage HIV prevention within their networks and in the community at large. Through empowerment, the PLWHA community is able to work effectively with and mobilize government departments, other NGOs, and the private sector to become more involved in HIV prevention and care and support for PLWHA and their families.

Operating in 18 districts of Uganda, PLWHA networks have provided training on issues of positive living; communication skills, networking, lobbying, and advocacy; and information on HIV transmission, prevention, and management of the disease. NGEN+ has trained members of the Ugandan Armed Forces, the Uganda Police, and the Prison Service. It also lobbied the Ministry of Health for improved access to highly active antiretroviral therapy (HAART).

Mentoring to Build Leadership

Ruranga has made it a point to mentor and develop the capabilities of the PLWHA he has counseled. When people have come to him for help, he has not only sought to help them, but he has also gone on to support them further in developing their own leadership skills. Some of these people have taken their place among the nation's leading advocates for HIV/AIDS. They include the Reverend Canon Gideon Byamugisha, who is one of the few Anglican leaders to disclose his HIV-positive status and to challenge the church on how it deals with HIV/AIDS; Milly Katana, now a representative on the Global Fund to Fight AIDS, Tuberculosis and Malaria; and Beatrice Were, the director of the International Community of Women Living with HIV/AIDS. Ruranga saw that supporting the development of PLWHA leadership was inseparable from the advancement of issues and, therefore, an integral component of HIV/AIDS advocacy.

Spurring Greater Involvement of PLWHA

Ruranga has been active in pushing for PLWHA representation on the Uganda AIDS Council (UAC). Until recently, no PLWHA had a voice on the UAC. In addition, three PLWHA now sit on a partnership forum with civil society. This seemingly small step took years of education and much persuasion until the UAC understood the vital importance of PLWHA participation.

▣ Questions for Dialogue

1. How did Ruranga's personal story and social position (i.e., his class, profession, or family's or friends' status) advance his advocacy? What were the risks or limitations, and how did he minimize them?

2. How did NGEN+ promote the greater involvement of PLWHA in decision-making bodies?

3. Is there a leader or someone of stature in your community who has connections and resources similar to those of Ruranga? How could your organization work or partner with that person?

4. Why is it important to develop the leadership capabilities of PLWHA? What avenues exist for your group to gain and practice leadership skills? Does your group have an opportunity to assist in developing the skills of other groups?

This story was based on an interview with Major Rubaramira Ruranga, founder and coordinator of NGEN+. For further information about the organization, please visit www.enda.sn/africaso.org/ngen.html.

4.4 Thai Network of People Living with HIV/AIDS
Bangkok, Thailand

▣ Background

The Thai Network of People Living with HIV/AIDS (TNP+) was formed in 1997. It provides broad national representation to the issues and concerns of PLWHA and functions as a national support network to Thailand's many small PLWHA groups.

▣ Advocacy Environment

Paisan Tan-Ud, the former chair and one of the founders of TNP+, helped create the organization at a time when most people in Thailand had little information about HIV/AIDS. In addition, as was the case in many developing countries, most doctors were both uneducated about HIV/AIDS and unable to care adequately for persons with the disease. Seeing too many friends living under duress and others dying from AIDS without care and support, Paisan and other PLWHA friends and colleagues decided that the delivery of care and speaking out on HIV/AIDS was not enough. They wanted—and needed—to do more. With this sense of passion, they set out to establish a PLWHA network.

When the organizers of the Asia Pacific Islands AIDS Conference in Chiang Mai, Thailand, in the mid-1990s provided Paisan and his friends with the opportunity to meet at their conference, Paisan realized that they had a unique opportunity to bring people together. They seized the moment to gather PLWHA from all over Thailand in one room—the first time that PLWHA from Thailand had ever assembled—and used the opportunity to push for greater organization and networking among themselves. From this one chance to network and strategize, a national group emerged. A year later, a national network was formed, with Paisan elected as chairperson.

▣ Advocacy Focus and Strategy

TNP+'s mission is to improve the quality of life for PLWHA and all those affected by HIV/AIDS. The organization adopted the following objectives:

- Support and strengthen PLWHA groups;
- Campaign for human rights and social welfare for all PLWHA and those affected with HIV/AIDS; and
- Cooperate with NGOs and government entities to respond to the epidemic.

At the outset, TNP+ identified two critical tasks for itself: (1) challenge and push the government to support PLWHA and their concerns as a way to confront the epidemic; and (2) support the government in its efforts to eliminate barriers created by other international bodies as it tries to support PLWHA.

In the five years since its formation, TNP+ has grown from 100 groups based mostly in northern Thailand to 495 groups located in every region of the country. Financial support from the government has been central to TNP+'s growth. TNP+'s advocacy and pressure from community groups has led to the creation of an HIV/AIDS budget within the national government budget. TNP+ also successfully convinced government officials to allocate a percentage of the HIV/AIDS national budget to PLWHA groups. Financial support from AIDSNet, a large NGO in Chiang Mai, has also been pivotal to TNP+'s growth.

Identifying Allies

From the outset, TNP+ recognized the importance of identifying and forming partnerships with allies. Thus, TNP+ members built and strengthened their relationships with other NGOs that were similarly dedicated to both guaranteeing the right to health care for all and making treatment available to PLWHA. These relationships proved critical. It was through Médecins sans frontières (MSF)/Doctors Without Borders and the AIDS Access Foundation that TNP+ discovered that treatment was available to prevent certain opportunistic infections (OIs). This piece of crucial information led TNP+ to identify and select the 100% Bactrim Campaign as its first advocacy effort.

Choosing a Winnable Issue

During its first year, TNP+ devoted itself to identifying its strengths and advocacy focus along with the strategies the organization would adopt to pursue its goals. It used the opportunity of a subsequent national AIDS conference and the gathering of PLWHA to determine its first advocacy focus and long-term plan. It identified access to preventive treatment for pneumocystis carinni pneumonia (PCP) as its priority banner issue. Commitment to the issue led, in 2000, to the creation of the 100% Bactrim Campaign, which informed the group's later campaigns and activities.

Two factors led TNP+ to decide on the Bactrim campaign as opposed to another campaign. First, given that PCP is a major killer of PLWHA and that Bactrim can prevent and/or treat the disease at a relatively low cost, TNP+ recognized that the government could make the drug available. Second, with only two tablets a day needed, the Bactrim regimen is simple to follow. The careful choice of an advocacy objective—*a winnable issue*—permitted TNP+ to realize a success around which it could structure other campaigns and achieve future successes, particularly the strengthening of the basic infrastructure of the health care system. In addition, the campaign managed to save hundreds, perhaps thousands, of lives. Since its beginnings, the campaign has made it possible for 80 percent of TNP+ members to receive Bactrim prophylaxis.

Laying the Groundwork: Advocacy for Access to ARV

About the same time that TNP+ initiated the Bactrim campaign, members began to hear about antiretroviral (ARV) therapy from friends and researchers who had attended the 1996 International AIDS Conference in Vancouver, Canada. Realizing that the high costs of ARVs would make treatment inaccessible to most PLWHA, TNP+ decided to run a campaign in parallel with the Bactrim campaign aimed at reducing the price of ARVs. In many ways, the Bactrim campaign served as a pilot project for the ARV campaign by strengthening the group's capability and the infrastructure for developing and implementing an ARV treatment program.

To reduce the price of ARVs, TNP+ saw that it would have to develop relationships with a new set of partners. In addition to the relationships already formed, TNP+ forged alliances with, among others, university professors, the Consumer Protection Foundation, and the Center for AIDS Rights. Nonetheless, TNP+ had to overcome several obstacles to ensure that ARVs would become more accessible. One of the most daunting obstacles revolved around compulsory licensing and safety monitoring procedures (SMPs) for the production of drugs. Even though Thailand commanded the expertise and ability to produce several of the needed new drugs, international trade law prohibited the country from producing generic drugs. The production issue became one of the major advocacy issues that TNP+ had to address in fulfilling its commitment to make ARV treatment available to PLWHA. The organization recognized that it had to learn about the issue and teach others about it.

Advancing Advocacy by Raising Visibility of Issues Inside Thailand and Internationally

In 2000, TNP+ held its first PLWHA public demonstration in front of the Ministry of Public Health, with about 200 people in attendance. The demonstration was intended to pressure the government to invoke its legal right to use compulsory licensing to ensure access to affordable medicines, in this case, to produce the pill form of ddI (didanosine), an ARV drug used in combination therapy. Vowing not to leave until the government issued a response, the demonstrators continued their action for three days and two nights. The government finally responded by requesting more time. TNP+ agreed to end the demonstration but put the government on notice and vowed to return if its issues were not addressed. In addition to pushing the government to use its right to produce generic drugs, the demonstration increased awareness of HIV/AIDS, particularly the need for treatment, and raised the profile of TNP+.

To gain national and international support for its issues, TNP+ wrote letters to world leaders, met with representatives from the government Office of Intellectual Property, and lobbied the government's Generic Production Office. In addition, TNP+ met with treatment activists from the Treatment Action Campaign in South Africa and partnered with international organizations, such as MSF, Health GAP, and ACT UP.

Although TNP+'s activities, as of this writing, have not led the Thai government to produce the pill form of ddI, its campaign can boast of several other successes. The pressure that TNP+ brought to bear on the government has brought TNP+ into the public's consciousness, thus raising its stature in the eyes of both the citizenry and the government. TNP+'s work, along with other treatment advocacy organizations' efforts, contributed to the decision on the part of the World Health Organization (WHO) and UNAIDS to review issues related to drug pricing. TNP+ also initiated a review of the SMPs, which led to the government's undertaking a similar review. As a result, the Thai government changed the law governing drug pricing so that certain drug prices would be more equitable and affordable.

Knowing the Issues

Like ACT UP before it, TNP+ recognized the importance of becoming well informed on the issues. As part of its advocacy work, TNP+ leaned about and became an expert on a range of issues previously foreign to the group—government structure and how it operates, national and

international law, drug production, and international relations. Its enhanced knowledge increased TNP+'s credibility with decision makers and won allies both nationally and internationally.

Recognizing Access to Health Care as a Human Rights Issue

Another accomplishment of TNP+ is its ability to integrate HIV/AIDS into the broader issues of health care in Thailand, forming coalitions with groups that address issues related to the elderly, children, and other consumer groups. TNP+'s response to a government health plan provides an example. In 2001, the Thai government initiated a type of universal health care program called the "30 baht plan,"[2] launching the program with the following slogan: "30 baht cures all diseases." The program covered all diseases except chronic liver failure and HIV/AIDS.

In 2002, a year after the 30 baht plan took effect and just before World AIDS Day, TNP+ decided the time was right to push for access to ARV treatment for PLWHA and that the "30 baht plan" was the ideal vehicle for its advocacy campaign. Accordingly, TNP+ set a goal of securing ARV treatment coverage under the "30 baht plan." TNP+ again organized a demonstration in front of the government house and, within a week, drew 1,000 participants who demanded that the "30 baht plan" cover ARV treatment.

At a press conference, TNP+ deftly made the case that the main barrier to access to treatment for PLWHA was the lack of political will, not the lack of financial resources as the government claimed. It identified government corruption and military spending as problems that, if addressed, would free up resources for HIV/AIDS care. TNP+ pointed out that, while HIV/AIDS was the number one killer in Thailand, the government still maintained that treatment was too expensive and not cost-effective. To refute that argument, TNP+ noted that, even though a study on the cost-effectiveness of treatment for HIV-positive individuals had never been performed, such studies had been performed with other diseases.

As part of an overall plan of action, TNP+ joined with other networks, including a law society, to bring an alternative health care plan before Parliament. The plan was structured around two considerations: (1) the constitutional principle of nondiscrimination in access to health care; and (2) the premise that people pay taxes equally such that everyone deserves equal coverage for health care. In order for the bill to be introduced into Parliament, the partnership needed to collect 50,000 signatures. In a short time, TNP+ succeeded in collecting over 30,000 of the required signatures.

In response, the Minister of Public Health said that the government would eventually cover ARV treatment in the plan but that the "right process" had to be followed. Not content with waiting for the "right process," TNP+ formed a committee to assist the government in developing the capacity to include ARV treatment in the universal health care plan. The committee is composed of 10 people from government and 10 people from NGOs, six of whom are PLWHA, including Paisan.

◘ Challenges as TNP+ Moves Forward

Reaching Rural Constituents

An important issue facing TNP+ is the need to address the gap between what is available to people in urban versus rural areas. In rural areas, many people, including doctors, are not fully educated on basic treatment options for OIs while, in Bangkok, PLWHA are able to access ARVs as well as treatment for OIs, even if only in clinical trials. Not surprisingly, many PLWHA in rural areas are

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[2] Baht is the basic unit of currency in Thailand.

dying more quickly. While the move to challenge the government to produce its own drugs will go a long way toward addressing urban-rural differences, much more needs to be done.

Developing Leadership

TNP+ recognizes that it must address capacity building and leadership development as priority issues. Many TNP+ members are poor and sense that their government has never valued them. Now, as HIV/AIDS advocates, they are challenging and fighting their government. Their success depends on the expenditure of time, energy, and resources to develop their leadership abilities. In addition, many network members do not have access to computers and the Internet. Given that communication is essential in coalition work and that TNP+ members must resolve complex issues, access to information is critical.

Overcoming Stigma and Discrimination

TNP+ is working on the development of a training curriculum and other educational materials on sexuality, drugs, and HIV/AIDS. The effort grows out of the recognition that much of the public—PLWHA included—lacks information or misunderstands these issues and that few programs exist to prevent or treat HIV and other diseases among IDUs. Stigma and discrimination against drug users in Thailand is particularly high. TNP+ hopes to contribute toward a national climate and policy environment centered more on human rights and away from stereotypes and moralistic judgments.

▣ Questions for Dialogue

1. What were some of the criteria that led to TNP+'s focus on the 100% Bactrim Campaign as its first advocacy objective? What were the benefits of choosing the campaign as a first advocacy objective?

2. In the "30 Baht Campaign," what were some of the strategies used by TNP+ to move coverage of ARVs onto the policy agenda?

3. In selecting its issues, designing its campaigns, and reaching its target audiences, TNP+ was keenly aware of the importance of information. What are the risks of moving forward without understanding your information needs? What types of information would help your group and your advocacy efforts? How can you obtain the needed information?

This story was based on an interview with Paisan Tan-Ud, founder and first chairperson of TNP+. Paisan has since founded and now works with the Thai AIDS Treatment Action Group.

Lessons Learned

- **Transforming language and images to represent PLWHA as partners in any response to HIV/AIDS is crucial to advocacy efforts.** The language used to describe PLWHA remains a vital part of the effort to challenge stigma and discrimination. Representations that affirm the role of PLWHA as active partners in all levels of decision making are key to helping policymakers fully enact GIPA.

- **Creating PLWHA networks provides a foundation for advocacy efforts by reducing isolation and promoting sharing of information, peer learning, attainment of rights, and visibility.** In networks, individuals are a part of something that can speak louder than each individual on his or her own. Membership in a network provides people with a social identity and sense of belonging from which they can advocate and live within their community and country. Especially for PLWHA groups engaged in advocacy, a positive group identity as an advocate rather than as a "victim" is essential.

- **Building on their direct relationship with their constituents provides PLWHA organizations with a powerful structure for representation.** PLWHA groups serve as a vital link between PLWHA and their communities and governments. They are often the major vehicle for nurturing and developing individuals committed to serving in local and national planning and policymaking bodies, thus helping ensure achievement of GIPA.

- **Developing capacity and leadership of PLWHA requires commitment and long-term investment.** Viable, effective organizations need capable members and leaders who know how to run advocacy programs, get things done, and represent the issues and their constituency. As government and donors increase the volume of resources dedicated to HIV/AIDS, adequate funding must be made available to PLWHA groups for training and capacity development. PWLHA groups also need to invest in capacity building and leadership development, including developing strategies to address the still present reality that members will be lost to the disease.

- **Recognizing that governments are not monolithic is key to advancing advocacy initiatives.** As part of this, it is essential to recognize that members of government can be allies or opponents depending on the issue. Developing effective strategies for both of these scenarios is necessary for advancing the HIV/AIDS agenda.

- **Ensuring that PLWHA networks fully represent the changing face of the pandemic is an ongoing challenge.** PLWHA organizations must work toward the inclusion and representation of all relevant constituencies. Stigma and discrimination, homophobia, and gender inequities may prevent the participation of the most vulnerable groups. A continuing challenge for PLWHA groups is to continue to build a unified constituency across race, gender, class, and sexual orientation.
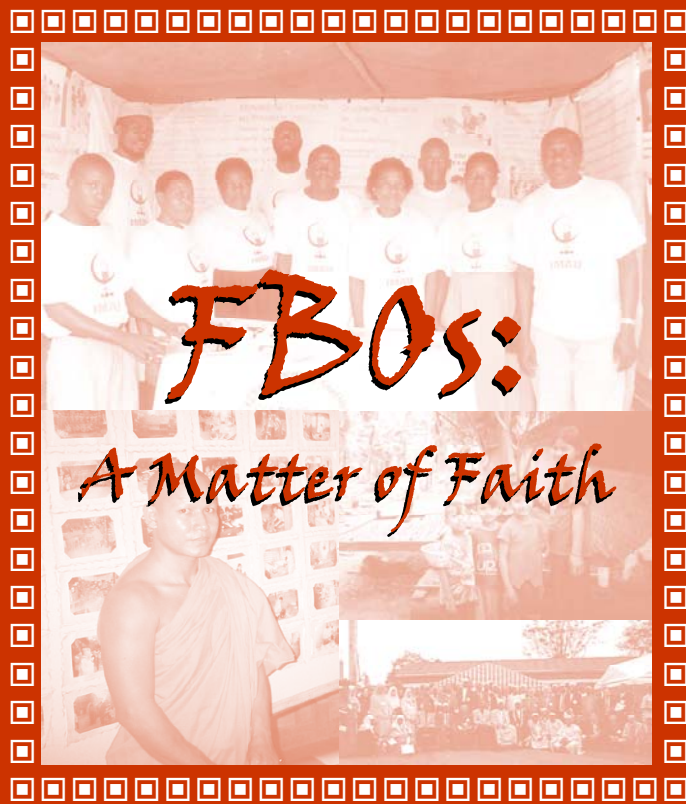
FBOs:
A Matter of Faith

SECTION 5

FBOs: A Matter of Faith

> *"Right from the beginning of the HIV/AIDS crisis, local communities have been at the very forefront of caring for those affected by HIV/AIDS. Faith-based organizations are rooted in local structures and are therefore in an excellent position to mobilize communities to respond to the HIV/AIDS crisis. In many cases, religious organizations and people of faith have been among the first to respond to the basic needs of people affected by the disease, and indeed have pioneered much of the community-based work."*

Statement by FBOs attending UNGASS in 2001

This collection of stories and experiences features faith-based organizations (FBOs), which are vitally important to the response to HIV/AIDS at the community level. FBOs are sometimes the most respected and stable organizations operating in resource-constrained settings, and they often provide a range of essential health and social services in addition to attending to the spiritual needs of their communities. Given that FBOs and leaders are esteemed and trusted by the communities they serve, they are also in a unique position to confront and speak out against the stigma and discrimination surrounding HIV/AIDS and to appeal to values of care and compassion.

At the same time, the nature of HIV/AIDS has posed a major challenge for communities of faith. The HIV/AIDS pandemic touches on several issues that are central to religion and faith, including sexuality; the family; death, dying, and the afterlife; caring and compassion; morality; and the meaning of life and faith itself. The ways in which FBOs approach these sensitive issues can serve as examples for other advocacy groups.

As with the advocacy approaches that originate from women's groups and PLWHA associations, advocacy within the faith-based sector begins with the experiences, values, and institutions of a particular community of faith. Accordingly, faith-based approaches to HIV/AIDS issues can be extremely diverse and range, for example, from improving life skills and HIV prevention awareness among youth to strengthening home-based care efforts to denouncing attitudes that stigmatize or condemn those affected by HIV/AIDS.

Organizations—such as the **Islamic Medical Association of Uganda** (IMAU), **The Balm In Gilead** of New York City, and **Wat Norea Peaceful Children** (NPC) based in Cambodia—are demonstrating how FBOs are playing a leading role in addressing the HIV/AIDS pandemic across the globe. Representing Muslim, Christian, and Buddhist faiths, they have found a way to ground their work in the values and tenets of the communities they serve; and they have used the strength of faith-based institutions and networks to develop strong advocacy campaigns.

Some of the significant advocacy issues and strategies that are evident in the stories of FBOs are the importance of knowing oneself and demonstrating a clear understanding of your organization's goals and values; the need to confront stigma and discrimination; the importance of framing advocacy messages for particular audiences; and the benefits of building on existing organizational structures and networks.

▣ Featured in This Section		
Name of Organization	**Country**	**Advocacy Focus/Strategies**
5.1 Islamic Medical Association of Uganda	Uganda	- Awareness raising - Networking across the faith-based and public health sectors - Capacity building for Islamic leaders
5.2 The Balm In Gilead	United States of America	- Awareness raising - Stigma and discrimination - Developing a network of Black churches - Policy development and leveraging resources
5.3 Wat Norea Peaceful Children	Cambodia	- Stigma and discrimination - Care and support for children affected by HIV/AIDS - Women's empowerment - Establishing a Buddhist leadership network

5.1 Islamic Medical Association of Uganda
Kampala, Uganda

▣ Background

The Islamic Medical Association of Uganda (IMAU) was founded in 1988 to establish a community of peers for Islamic health professionals. Drawing on its expertise in both Islamic principles and medical science, IMAU also seeks to promote healthy and enlightened communities. The organization has established branches in 12 districts across Uganda and has worked to increase collaboration with national, regional, and international groups. IMAU first began to address HIV/AIDS issues in 1989.

▣ Advocacy Environment

Uganda is often noted as an HIV/AIDS success story. Multisectoral collaboration, strong political will, broad-based community involvement, and open dialogue are integral aspects of a comprehensive response that has helped to slow the spread of the country's HIV/AIDS epidemic. Beginning in the mid-1980s, Ugandan President Yoweri Museveni became an early, proactive HIV/AIDS policy champion and has continued to provide charismatic leadership on HIV/AIDS issues to this day. Uganda was the first country in sub–Saharan Africa to offer anonymous voluntary counseling and testing for HIV. The AIDS Service Organization (TASO) was an early model for providing comprehensive, compassionate care and support for PLWHA and their families. Influenced by a "complex set of epidemiological, socio-cultural, political, and other elements," Uganda has witnessed significant declines in both HIV prevalence and the number of new infections, including among younger age groups.[3]

It is within this enabling context that IMAU's unique approach to HIV/AIDS advocacy emerged. Religion plays an important role in the lives of Ugandans, and a majority considers itself to be "religious." Uganda is home to a variety of communities of faith, with Muslims comprising 20 to 25 percent of the general population. The Muslim community historically has had less access to resources, and it was not until the 1970s and early 1980s that a significant number of Muslim health practitioners began to appear. IMAU was able to occupy a distinct niche by serving as a network for these new professionals and combining Islamic principles and medical knowledge to promote the health of local communities.

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[3] U.S. Agency for International Development (USAID). 2002. *What Happened in Uganda? Declining HIV Prevalence, Behavior Change, and the National Response.* Washington, DC: USAID and the Synergy Project.

▣ Advocacy Focus and Strategy

IMAU began addressing HIV/AIDS issues early in its history. Given that its members were familiar with Islamic teachings, equipped with medical knowledge, and enjoyed access to the existing health care infrastructure, IMAU was well positioned to catalyze a Muslim response to HIV/AIDS. It was able to facilitate discussions within Muslim communities on several issues. Its first major effort was to help enable faith-based leaders to talk about HIV/AIDS in their communities. Dr. Magid Kagimu, the director of IMAU, recalls that the imams, spiritual leaders who head local mosques, and other religious leaders were grateful to receive information on HIV/AIDS. The imams recognized a growing problem in their communities and realized that they were unable to respond adequately; consequently, they welcomed the involvement of IMAU. Important moments in IMAU's advocacy work are highlighted below.

Linking Faith-based and Public Health Responses to HIV/AIDS

IMAU immediately understood the value of involving faith-based leaders in a coordinated response to HIV/AIDS and therefore quickly reached out to Islamic leaders. In September 1989, IMAU convened a National HIV/AIDS Education Workshop that brought together Islamic leaders from all over Uganda to explore HIV/AIDS issues and share experiences. Participants included every Ugandan district khadi, Muslim health professionals, and representatives from the Ministry of Health and the World Health Organization.

One of the primary insights resulting from the conference was the realization that Islamic teachings provide an existing and highly relevant framework for HIV/AIDS prevention activities. For example, the emphasis on control of sexual behavior as the primary means for preventing HIV transmission could be easily integrated into prevailing teachings regarding self-control, obedience to God, fidelity, and the importance of chastity in Islamic life. Prompted by the experiences shared at the conference, His Eminence the Chief Khadi declared a jihad on AIDS, a pronouncement that has set the stage for a vigorous response within Uganda's Muslim communities.

Building on Core Values and Using Trusted Leaders

IMAU's HIV/AIDS education and communication efforts are based on the understanding that interventions in Muslim communities are more likely to be effective if they reflect the core values of the community and the community's faith. To some degree, the public education campaigns crafted by the government in the early 1990s did not resonate with members of the Muslim community. For instance, religious Muslims did not respond to an emphasis on condom promotion. Similarly, a singular focus on monogamy did not acknowledge the role of polygamy in Muslim communities. Accordingly, IMAU looked to Islamic teachings and cultural traditions, such as mutual fidelity and moral responsibility not to endanger others, to frame culturally appropriate and relevant HIV/AIDS awareness campaigns for its constituents. IMAU also recognized that, in order for its campaign to have maximum impact, the "message bearers" should be trusted members of the community—hence the importance of involving faith-based leaders. In addition, IMAU underscored the importance of working at the

> *"We all knew about the preventive measures needed to stop one from getting AIDS, but the support given by the top leaders allowed others to accept them and bring discussion on HIV/AIDS in the open and started the process on how to actually prevent the problem within the Muslim community."*
>
> Dr. Magid Kagimu
> Interview with Inter Press Service
> June 9, 1999

community level to design and carry out programs that would be as responsive as possible to local needs, assets, and concerns.

Extending the Reach of Advocacy Messages

With the support of the most prominent members in the Muslim community, IMAU designed its HIV/AIDS education projects to reach Muslim families through imams, other religious leaders, and educators who had trained with and were endorsed by imams. One of the organization's main programs is the Family AIDS Education and Prevention Through Imams (FAEPTI) Project, which began in 1992. The FAEPTI Project strives to build the capacity of imams to reach out to their community members through mosques and home visits. The project trains imams to integrate relevant HIV/AIDS information into their spiritual teachings and provide basic care and spiritual counseling to individuals through home visits. Together with the imams, the FAEPTI Project also trains Family AIDS Workers to use the opportunity of home visits to provide education, basic counseling, and motivation for behavioral change. District khadis and county sheiks also attend the training workshops. In addition, FAEPTI gives bicycles to all leaders (including imams, county sheiks, and district khadis) and provides resources for income-generating activities in the form of hens and goats, or the financial equivalent, in order to promote sustainability and to provide incentives to volunteers. As of November 2001, the FAEPTI Project covered 15 districts and had involved over 1,000 mosques and trained over 7,000 community volunteers.

Other IMAU programs use similar methods to reach people at the grassroots level. The Community Action for AIDS Prevention Project operates in urban areas and is designed to train representatives from a variety of faiths to reach out to communities through mosques, churches, and other local gatherings. The project also develops the capacity of bicycle transporters ("boda boda boys") and market vendors to raise HIV/AIDS awareness during the course of their typical interactions with customers. Another IMAU project seeks to reach Muslim youth through informal schools, called Madarasa schools, associated with mosques. Through the Madarasa AIDS Education and Prevention Project, imams and youth assistants are trained to integrate an HIV/AIDS education curriculum into their regular teachings on Islamic faith and culture.

Demonstrating Results, Achieving Visibility, and Moving Forward

IMAU has been able to demonstrate the positive impact of its programs, thereby increasing its credibility and influence. For example, before initiating the FAEPTI Project, IMAU conducted a baseline survey in its pilot districts to measure HIV/AIDS awareness, knowledge, and attitudes as well as behaviors that might put people at risk for HIV. The resulting information allowed IMAU to assess the existing situation and use the findings to inform program and materials development. Another survey conducted two years into the FAEPTI Project revealed increases in HIV/AIDS-related knowledge and decreases in self-reported risk behaviors among people in the areas served by the program.[4]

In 1998, UNAIDS profiled IMAU and its effective approaches as a part of its "Best Practice Collection," a series that highlights best practices and lessons learned that have emerged in the HIV/AIDS field. The president of Uganda has also applauded the work of IMAU. Its increased visibility allows others to learn from IMAU's approach and inspired other Muslim leaders to ask IMAU to organize and host the First International Muslim Leaders' Consultation on HIV/AIDS in Uganda in November 2001. The consultation, which received technical and financial assistance

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[4] Islamic Medical Association of Uganda. 1998. *AIDS Education Through Imams: A Spiritually Motivated Community Effort in Uganda.* Best Practice Collection. Geneva: UNAIDS.

through the USAID-funded POLICY Project, created an opportunity for leaders to share information and learn from each other and produced the report *Jihad on AIDS: Self Discipline Using Allah's Guidance*. Some of IMAU's additional efforts include the development of a training curriculum template for an Islamic approach to HIV/AIDS and the delivery of training internationally. As another next step, IMAU is planning to establish an International Resource Center that will coordinate and promote an Islamic approach to HIV/AIDS prevention, control, and care and support.

◙ Questions for Dialogue

1. Target audiences for IMAU's HIV/AIDS advocacy messages have been faith-based leaders, the Muslim communities they serve, and other partners (e.g., Ministry of Health, international conferences). How did IMAU frame issues to reach its target audiences? What are the target audiences for your organization? How might you frame your advocacy messages to make them relevant for these various groups?

2. IMAU's organizational mission and membership helped define its advocacy approach. Can you identify a distinct niche that is served by your organization? What are your organization's unique strengths, objectives, or approaches?

3. The structure of Islamic institutions and Muslim communities also facilitated IMAU's work. How might you identify and build on existing structures in your community to expand the reach of your advocacy efforts?

This story was based on an interview with Dr. Magid Kagimu, director of IMAU. For further information about the organization, please visit www.imauganda.org.

5.2 The Balm In Gilead
New York City, New York, USA

▣ Background

The Balm In Gilead, a not-for-profit organization, was founded in 1989. Its mission is to mobilize churches serving African American communities to become centers for compassion, education, and prevention in the struggle against HIV/AIDS. It has also expanded its mission globally, seeking to build capacity of faith-based communities to address HIV/AIDS issues in Africa and throughout the African Diaspora.

▣ Advocacy Environment

During the late 1980s, at the height of HIV/AIDS epidemic in New York City, it was commonly thought that HIV/AIDS was a disease confined to gay white men and was, therefore, not something that would affect the African American community. As an immunologist at Harlem Hospital, Pernessa Seele—the founder of The Balm In Gilead—knew differently. She saw black people dying from HIV/AIDS all the time, often alone in the hospital. Because of stigma and denial, those living with HIV/AIDS were left with no family, no community, and no church or spiritual support. It was in this area that Ms. Seele felt she could make a difference. She herself was a church-goer and knew the importance of faith and church within African American communities.

▣ Advocacy Focus and Strategy

In working to mobilize a church-based response to HIV/AIDS in the African American community, Seele faced immediate obstacles. To begin, there was a general lack of awareness of HIV/AIDS within the African American community. In addition, African American church leaders were reluctant to address HIV/AIDS as a consequence of denial, mistrust, and stigma. The challenge was how to engage in a conversation with ministers when many did not know about HIV/AIDS in the first place and, at the same time, were unwilling to recognize that their fellow community members were being infected through unprotected sex and injecting drug use.

Meeting Ministers on the Grounds of Their Faith

Seele knew that ministers might not agree with or feel comfortable discussing the behaviors that increase a person's vulnerability to HIV—such as unprotected sex and multiple sex partners—or acknowledging that groups that had been more heavily affected by HIV/AIDS, such as gay men and IDUs, were also in their communities. But she did have faith that ministers would come together to pray. In 1989, Seele organized the first-ever Harlem Week of Prayer for the Healing of AIDS in New York City; representatives from nearly 60 churches attended. The success of the prayer week

gave rise to the development of education seminars for the church community. Subsequently, when the Centers for Disease Control and Prevention (CDC) approached Ms. Seele to replicate the program in seven cities throughout the United States, The Balm In Gilead's reach began to grow.

In the beginning, as a way to educate ministers, The Balm In Gilead developed a series of seminars on HIV/AIDS. Along with basic facts about HIV/AIDS prevention, transmission, and treatment, the seminars inspired the faith-based leaders to explore questions such as "What would Jesus do?" with regard to HIV/AIDS. By exploring important values of the Christian faith, The Balm In Gilead was able to open a window through which ministers could begin to see and understand the need to develop HIV/AIDS ministries.

Building Support from Within Individual Churches

With a mission of reaching out to and educating black churches, The Balm In Gilead developed its own style for building support. Its members learned about the religious uniqueness of each church and its internal structure and then tried a number of ways to form bonds of mutual trust with the ministers. In some cases, this meant going through an educational committee; in other cases, it meant meeting with a member of the church and then encouraging that member to start a dialogue with the minister. Outreach also involved inviting delegates from a church to an informational meeting. Through these different strategies, The Balm In Gilead learned the value of building relationships and working from within the different churches—understanding their unique contexts and guiding principles—rather than trying to approach the churches as an outsider.

Providing Locally Relevant Information and Encouraging Small Steps

Members of The Balm In Gilead also learned that they needed to know the facts about HIV/AIDS in the communities served by the different churches. The available information made it possible to counter the silence and denial surrounding HIV/AIDS that was rampant in many congregations. The use of statistics compiled by local health departments also enabled members to facilitate learning at the community level through a strategy that emphasized enhancing "factual education" as opposed to trying to show people that they were "wrong."

In addition, The Balm In Gilead found that encouraging people to take that first small step builds the foundation to take the next steps and helps others join the effort. Members of The Balm In Gilead gave ministers suggestions as to how they could start the process of talking openly about HIV/AIDS. For example, a minister might offer prayers during Sunday services or make leaflets available on an information table. Each small gesture would let community members know that they, too, could talk about the issues surrounding HIV/AIDS. When a minister offered a prayer for PLWHA, others from the church would approach the minister to share his or her own story of living with HIV/AIDS, thus further helping ministers understand that the epidemic had indeed touched their own congregations. And church-goers, after having the opportunity to gain a greater awareness of and information on HIV/AIDS, could see that faith-based leaders respond in a compassionate way to the realities of the parishioners' experiences.

Expanding the Network

The Balm In Gilead has been working for almost 15 years to raise awareness of HIV/AIDS in African American communities and to develop strategies for improving health in these same communities. Seele was a member of the group of activists that lobbied the Congressional Black Caucus of the U.S. Congress for $54 million to go to an HIV/AIDS initiative targeting African Americans. To expand its reach further, The Balm In Gilead has convened national and international conferences to help mobilize a diverse community of FBOs to address HIV/AIDS. The Balm In Gilead now has 74 service partners and has earned the endorsement of 17 major church denominations and coalitions and of independent churches. In addition, approximately 10,000 black churches participate in the annual Week of Prayer for the Healing of AIDS—the signature mobilization strategy of The Balm In Gilead. The organization has also branched out and is partnering with other churches in a number of countries, such as Nigeria and South Africa and in the Caribbean.

▣ Questions for Dialogue

1. How was The Balm In Gilead able to overcome the silence, denial, and stigma surrounding HIV/AIDS that was common when it began its work? How might you adapt these tactics to your own advocacy work?

2. The Balm In Gilead's approach of organizing an annual prayer week builds on the values, traditions, and cultures of the communities it sought to reach with HIV/AIDS advocacy messages. How might your organization design symbolic events that raise awareness of HIV/AIDS yet are culturally appropriate for your target audiences?

3. Using local data on people living with or affected by HIV/AIDS was an important aspect of The Balm In Gilead's efforts to build support at the community level. What types of information or data would help promote the issues your organization focuses on? Is it readily available? If not, how could you gather the needed information?

This story was based on an interview with Reverend Alberta Ware, Director of Church and Community Mobilization of The Balm In Gilead. For further information about the organization, please visit www.balmingilead.org/home.asp.

5.3 Wat Norea Peaceful Children
Battambang Province, Cambodia

▣ Background

Wat Norea is a Buddhist monastery that enjoys a long history in Cambodia's Battambang Province. In April 1992, the wat established Norea Peaceful Children (NPC), an NGO that provides shelter and support to children orphaned during times of conflict, children affected by domestic violence and unstable homes, and children who had been trafficked as part of the sex industry. Since 1998, NPC has pursued two additional goals—providing care and support to AIDS orphans and other children affected by HIV/AIDS and establishing a Buddhist leadership network to help communities cope with HIV/AIDS. NPC was among the first faith-based organizations to address HIV/AIDS in Cambodia and has earned recognition for developing successful models and approaches that can be adapted by other organizations.

▣ Advocacy Environment

Cambodia is still working to rebuild and repair both its institutions and national psyche following suppression and mass killings by the Khmer Rouge in the 1970s, occupation by Viet Nam throughout the 1980s, and continuing insurgency and government instability during the 1990s. Several factors—such as displacement, resource constraints, the loss of a generation, the presence of a large United Nations peacekeeping force, and the growth of the sex industry—have all converged to lay the groundwork for the explosive spread of HIV/AIDS. During the mid- to late 1990s, Cambodia witnessed one of the fastest-growing HIV/AIDS epidemics in the world and had the highest HIV prevalence in Asia. Only recently, with prevention interventions targeting groups that practice high-risk behaviors and a National AIDS Authority charged with coordinating a multisectoral response, has the country started to show signs of slowing the tide of rising HIV prevalence.

About 95 percent of the population in Cambodia practices Buddhism, and the country's Buddhist organizations have been undergoing a resurgence after having been forced underground by the Khmer Rouge. Wat Norea is based in Norea Commune of the Sangke District of Battambang Province in northwest Cambodia. Battambang Province has historically been a spiritual and intellectual center and has been able, in some ways, to revitalize more quickly than its neighboring provinces. At the same time, however, HIV/AIDS has ravaged the province. While the government has sought to develop Provincial AIDS Committees and has placed new emphasis on care and support in its latest national strategic plan, a lack of resources—both human and material—continues to impede progress such that much of the response to the epidemic has become the responsibility of civil society groups. As a new culture of citizen participation emerges to advocate for issues such as

peace and the removal of landmines from Cambodia's countryside, so too are community- and faith-based groups responding to the challenge of HIV/AIDS.

▣ Advocacy Focus and Strategy

Building on compassion and reflection, Wat Norea's monks recognized that HIV/AIDS was not an issue about which the faith-based community could remain silent. NPC's decision to take on HIV/AIDS issues arose as a natural extension of its organizational mission and role within the community. By tradition, Buddhist monks are teachers, counselors, spiritual guides, and healers, all roles particularly relevant for HIV/AIDS work. A community's pagodas are sites for pursuing education, enlightenment, meditation, support, and learning. Buddhist monasteries have also historically provided support to orphans, both boys and girls, thus providing NPC's entry point for beginning to address HIV/AIDS. In addition, the Buddhist faith itself—as a religion that is more of a way of life than a passive set of beliefs and with its emphasis on wisdom, loving-kindness, tolerance, and identifying suffering and the paths to end suffering—represents a strong foundation on which to mobilize culturally appropriate efforts to respond to HIV/AIDS.

"One monk can feed seven children. . . . We [also] want to give them a very good education."

Venerable Muny Vansaveth,
Director of NPC,
Cambodia Daily, Oct. 6–7, 2001

When Actions Speak Louder than Words

NPC began in 1992 as a program of Wat Norea to provide shelter and educational opportunities for orphans and other vulnerable children, such as those who had experienced domestic violence or were involved in the sex industry. Since 1998, NPC has expanded its mandate to provide support for AIDS orphans and to build the capacity of Buddhist leaders and communities to respond to HIV/AIDS. Over the past decade, the monks and nuns at NPC have raised more than 350 children; in fact, AIDS orphans account for the majority of children currently in their care. The monks also visit PLWHA in their homes, accept offerings from those affected, and seek to spread HIV/AIDS awareness and education in villages. In particular, the care provided to AIDS orphans and the monks' personal relationships with PLWHA—visiting them, counseling them, meditating with them, demonstrating no fear in accepting alms from them, and presiding over their funerals—send a powerful message to the rest of the community. These actions help others in the village see that they should not fear or discriminate against those affected and their families.

Early on, NPC recognized the need to build its own internal capacity to take on HIV/AIDS issues, including strategic planning, networking, advocacy and communication skills, training and facilitation skills, basic facts about HIV/AIDS, and greater understanding of Cambodian laws and policies regarding HIV/AIDS. To that end, it has leveraged technical and material resources from local and international organizations and is sharing its experiences with other Buddhist organizations, teaching institutions, and leaders. For example, NPC has established the Buddhist Leadership Network for Coping with the Spread of HIV/AIDS. Developed under the auspices of the National AIDS Authority, the network covers six districts that have been particularly affected by HIV/AIDS. In addition, using a training curriculum that it developed in collaboration with the POLICY Project, NPC has conducted training workshops for about 240 Buddhist leaders on the role of monks in relation to Cambodia's new Law on the Prevention and Control of HIV/AIDS adopted in 2002.

Overcoming Challenges

In conducting its HIV/AIDS work, NPC has had to overcome a variety of challenges and obstacles. To begin, while striving to combat the stigma and discrimination often directed toward PLWHA, monks from NPC soon found that they too were experiencing stigma and discrimination from the community because they were engaging with PLWHA. The monks collected smaller quantities of food during daily begging, community members avoided the NPC office and residential area when visiting the pagoda, and some people directly questioned NPC staff members as to why they were bringing HIV/AIDS into a sacred place. Given the highly revered status of Buddhist monks in Cambodian society, that people might hold negative attitudes toward them for assisting PLWHA and their families illustrates the magnitude of the stigma and silence associated with HIV/AIDS. To address the stigma, the monks have worked day by day to educate the community, holding discussions with those who come to the pagoda and speaking out during community visits and cultural and religious ceremonies. NPC's recent strategic planning process (discussed below), which involved community representatives and prominent individuals from government and the royal family, also helped to reduce stigma.

In addition, discussing HIV prevention and the behaviors that place an individual at risk for the virus has meant that the NPC monks must negotiate some sensitive issues. For example, according to Buddhist custom, monks are not allowed to discuss sex with or in front of women. Such discussions are considered inappropriate for monks, who are viewed as sacred and existing outside the realm of such earthly affairs. Monks may, however, discuss these matters with men in the lay community only if they use a specialized style of the Khmer language—described as the "language of Buddha." To address more sensitive topics or information regarding HIV/AIDS, the monks involve and rely on others from within the community.

Leveraging resources is an important aspect of NPC's ability to conduct its HIV/AIDS programs. Typically, pagodas in Cambodia, especially in rural areas, are resource-constrained institutions. They rely on donations from the community, which itself may have limited resources. NPC has succeeded in drafting proposals to gain support from international donor organizations, such as UNICEF, and from private donors that have heard about NPC's work. NPC also receives support through the regular community mechanisms of donation and contribution. In these ways, NPC has been able to mobilize the resources needed to enhance the long-term sustainability of its efforts to support AIDS orphans, train Buddhist leaders, and care for those affected by HIV/AIDS.

Taking the Next Steps

NPC has developed a three-year strategic plan that will guide its future HIV/AIDS activities. The strategic plan is the result of a community planning workshop held in April 2002 that brought together about 40 key participants, including monks and nuns, village leaders, and government representatives from the district departments for religious affairs and social action. In attendance, too, were the Minister and Secretary for the Ministry of Women's and Veterans' Affairs, the Deputy Provincial Governor, and Princess Rattana Devi, who has become a prominent HIV/AIDS advocate in Cambodia. The strategic plan lays the groundwork for a Buddhist-led response to HIV/AIDS but also seeks to build links with broader community development efforts.

Concerns central to the strategic plan are the importance of promoting human rights, the necessity of addressing the interrelationships between gender inequality and HIV/AIDS, and the need to develop community-level solutions to improve care and support. In particular, the priority action areas for this next phase of NPC's work are to:

- Establish a network of provincial and district government authorities, NGOs, FBOs, media, and other major stakeholders to foster an environment of cooperation and communication in order to strengthen the integration of human rights and gender issues into HIV/AIDS interventions;

- Reduce the gender inequalities in the decision-making processes related to HIV/AIDS issues by initiating dialogue on the Women's Code (the Chbap Srey), a traditional code that describes the proper roles and behaviors for women;

- Encourage attitude and behavior change in rural communities as a way to reduce stigma and discrimination toward PLWHA; and

- Facilitate the development of pagoda-level networks for fundraising and resource management activities to enable communities to self-fund the care and support of PLWHA, their widowed spouses, and orphaned children.

NPC is currently preparing to implement its strategic plan. UNICEF will fund the components of the plan related to service, and the POLICY Project will fund the advocacy components.

The Impact of Monks Working to Address HIV/AIDS in Cambodia

In August 2002, the POLICY Project sought to evaluate the impact of small grants to support HIV/AIDS capacity building for four Buddhist organizations in Cambodia, including Wat Norea Peaceful Children. Here is a selection of what the monks from the different organizations said about the impact of their work:

"A woman with HIV who had left her home with her young child, after being rejected by her husband, stayed in the building area. The child would go begging. No one cared about them. When people saw me visiting them, just staying near them the whole day, conversing and meditating, people started to approach. This was a way of showing the community not to be afraid of people living with HIV/AIDS."

"Now that we have gained knowledge, we can spread this knowledge and help the community gain confidence in and give support to people living with HIV/AIDS."

"In the past, a man in one village would run away every time he saw my truck coming. He was afraid that he will be asked if he has HIV. Now, that has changed. When people see me, they approach me and offer information about people living with HIV/AIDS in their families and community. Previously, we had to ask people to search for people living with HIV/AIDS. Now, people approach us monks. This is the result of greater involvement of monks in HIV/AIDS work, including announcements during ceremonies for people living with HIV/AIDS to avail of support being offered."

"Being monks, we have compassionate hearts, but now we have learned to be more sympathetic to people living with HIV/AIDS and their families."

Source: Milado, C., and D. Singiser. 2002. "Report on the Small Grants Program Review: The POLICY Project in Cambodia." Phnom Penh, Cambodia: POLICY Project.

1. Particularly due to their revered status, NPC monks set a powerful example for confronting stigma and discrimination. Who are the influential leaders (e.g., from FBOs, businesses, women's groups, and so forth) in your community? How might you work with and encourage these individuals to become policy champions and advocates for change?

2. NPC has sought to develop its own capacity to address HIV/AIDS and has designed materials and training curricula to build capacity of other Buddhist leaders. What skills and capabilities could enhance your advocacy work? How could you go about building the capabilities of your organization's staff and your partners?

3. Strategic planning processes have enabled NPC and its partners to take the next steps to address HIV/AIDS in the community. In particular, the inclusion of advocacy as an important part of the plan allows the monks to work to confront the silence and stigma surrounding HIV/AIDS that often serve as barriers to the success of more service-delivery oriented programs. What have strategic planning processes looked like for your organization? Has advocacy been integrated as a central component of your plan? How might integrating advocacy into your plan enhance your organization's ability to meet its objectives?

Due to logistical constraints, this story is based on interviews with POLICY Project staff who have been providing technical assistance to NPC since early 2002. It also draws on information from NPC documents (such as project proposals, workplans, and progress reports) and on newspaper articles.

Lessons Learned

- **Addressing HIV/AIDS is often a natural extension of the FBO's mission and core values.** As with other organizations, successful advocacy by and targeted to faith-based groups requires the identification of issues that fit the groups' values and mission. The core values of many communities of faith—such as compassion, respect for life, tolerance, and care for one's neighbor—are highly relevant to strategies for addressing HIV/AIDS. An important first step is to provide faith-based leaders with a safe and enabling environment in which to explore the natural links between the tenets of their faith and the need to respond to the pandemic. Framing HIV/AIDS issues in ways that are both culturally relevant and appropriate is a pivotal strategy for building support among these communities.

- **Building on their trusted status in communities makes FBOs powerful advocacy messengers.** FBOs are a vital component of comprehensive approaches to address HIV/AIDS, particularly at the community level. Faith-based leaders in particular are in a unique position to confront silence and stigma, to promote behavior change, and to encourage care and support for those affected by HIV/AIDS. In the case of the NPC, Buddhist monks provide care and support to AIDS orphans and welcome them in the daily activities of the monastery, providing an example to others of the importance of reaching out to one's fellow community members. Involvement of and interactions with people living with or affected by HIV/AIDS is a particularly powerful way to help faith-based groups understand the importance of addressing the disease.

- **Using data about their own communities can help faith-based leaders and the communities they serve to understand fully the impact of the pandemic.** In The Balm In Gilead and IMAU stories, groups used data—such as surveys of knowledge, attitudes, and behaviors as well as statistics from the local health department—to highlight the reality of HIV/AIDS within the community. Raising awareness of the local impacts of the pandemic helped to inspire community leaders to see the importance of addressing HIV/AIDS within FBOs.

- **Drawing on existing networks and community ties among faith-based groups provides a powerful infrastructure for advocacy efforts.** FBOs often have existing structures—such as national and community-level institutions, religiously affiliated schools, women's and youth clubs, social service programs, hospices, and coalitions or networks with like-minded groups—that provide tremendous potential for mobilizing broad-based action and support. Starting from a shared faith, as in the case of IMAU and The Balm In Gilead, groups can reach out to and build relationships with mosques, churches, temples, and other FBOs and the communities they serve. Shared beliefs and cultures provide an initial opportunity to develop strong networks with other faith-based and social service organizations. And, beyond reaching out to local communities, FBOs—given their respected status, the number of people they represent, the values they promote, and the strength of their networks—are often well positioned to advocate for change at national, regional, and international levels.

Access to Treatment:
Working Together

SECTION 6

Access to Treatment:

Working Together

> *"[Access to antiretroviral treatment (ART)] can restore hope to both health professionals and patients, and can assist us in regaining control of this epidemic. Therefore, treatment for HIV and AIDS that includes antiretroviral medicines should no longer be withheld as a result of government policy. ART in the public sector is necessary and possible, and a start must be made to implementing it as a matter of urgency in the interests of millions of lives."*

> Bredell Consensus Statement, 2001[5]

Access to treatment is an issue that has galvanized HIV/AIDS advocates around the world. With more than 40 million people living with HIV/AIDS at the end of 2002 and many more families and communities affected, we face an urgent need to improve access to life-prolonging and life-enhancing drugs. It is a cause for which advocates and their allies have achieved impressive gains—some governments and businesses are providing free access to ARVs; pharmaceutical companies are reducing drug prices for developing countries; the Global Fund to Fight AIDS, Tuberculosis and Malaria is funding proposals to improve access; new laws are permitting the production, importation, and exportation of generic brands of ARVs; and more and more people are embracing the concept of a continuum of care, which recognizes the importance of both prevention and care. Despite recent progress, universal access to ARVs among all who need treatment, regardless of their ability to pay for the often-expensive drugs, has yet to be fully realized.

This group of stories on access to treatment is set in South Africa, and it explores the ways in which different organizations have come together to place issues of access, equity, and the right to health care on the national—and even international—stage. In particular, the stories focus on four organizations that represent some of the different sectors that have influenced the access-to-treatment debate:

- The **Treatment Action Campaign** (TAC), a grassroots activist movement that began in 1998 as a mechanism for putting treatment access issues on the national agenda and advocating for improved access to ARV therapy for all who need it;

- The **Health Systems Trust** (HST), an independent research and development NGO with close working relationships with both the government and civil society that is dedicated to promoting evidenced-based solutions to South Africa's health care needs as well as to addressing issues such as equity and infrastructure development;

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[5] TAC. "Bredell Consensus Statement on the Imperative to Expand Access to Antiretroviral (ARV) Medicines for Adults and Children with HIV/AIDS in South Africa." November 19, 2001. Available at www.tac.org.za/Documents/Statements/bredell3.pdf.

- The **Church of the Province of Southern Africa** (CPSA), which has become a strong voice from the faith-based community to advocate for improving treatment and care, enhancing prevention efforts, and, importantly, breaking the silence and stigma surrounding HIV/AIDS; and

- The **National Health Committee of the African National Congress** (ANC), an entity within the ANC political party that is concerned with researching and developing the ANC-led government's health care approaches and policies.

The selection of these organizations' stories does not suggest that the organizations are the only or necessarily the most important players in South Africa's struggle for universal access. In fact, several organizations and sectors play integral roles in the story of access to treatment, including legal support projects, PLWHA associations, health care providers, international development and humanitarian groups, the media, trade unions, the courts, businesses, international and national regulatory bodies, and provincial health department officials (who, at times, moved faster than the national government to expand access to ARV treatment).

The four advocacy stories in this section do, however, illustrate major concepts for advocates and shed light on the complexities and nuances of the advocacy process. Some of the advocacy issues and strategies that are evident in the stories include the fluid nature of partnerships and alliances over time; the way in which successful advocacy strategies and roles emerge from an organization's mission and goals; how different advocacy styles (e.g., consensus-building and adversarial styles) can come together to promote a common end; the advantage of defining issues that are relevant to the general public and therefore capable of engendering broad-based support; and the way in which messages and issues are framed to advance an organization's goals without alienating either its advocacy targets or its own constituents.

This section strives to demonstrate how a variety of different groups have influenced the debate over access to treatment in South Africa; therefore, the section's organization differs somewhat from that the previous sections. Section 6.1 sets the stage for the access-to-treatment story, discussing the overall advocacy environment and focus. For more background information and context, Section 6.2 presents readers with a timeline of some of the major moments in South Africa's access-to-treatment story, focusing particularly on the four organizations listed above. Sections 6.3 to 6.6 tell the advocacy stories of the four organizations. Because this section focuses on how the organizations worked *together* to advocate for access to treatment, the discussion questions appear at the end of the section after the four stories and emphasize the issue of collective action.

◉ Featured in This Section		
Name of Organization	**Country**	**Advocacy Focus/Strategies**
6.3 Treatment Action Campaign	South Africa	▪ Networking ▪ Grassroots community mobilization ▪ Using the courts to promote the right to health care ▪ Improving treatment literacy (e.g., knowledge of the treatments available for HIV/AIDS)
6.4 Health Systems Trust	South Africa	▪ Evidenced-based health solutions ▪ Consensus-building role between government and civil society ▪ Evaluating the pilot program on preventing MTCT and assessing the feasibility of expanding the program ▪ Ensuring that the public debate includes issues such as equity and infrastructure
6.5 Church of the Province of Southern Africa	South Africa	▪ Breaking the silence and reducing stigma and discrimination ▪ Internal and external advocacy ▪ Demonstrating the links between the need to respond compassionately to HIV/AIDS and the core values and tenets of communities of faith
6.6 National Health Committee of the African National Congress	South Africa	▪ Internal and external advocacy both within the political party and with partners ▪ Policy analysis, development, and reform

6.1 Advocacy Environment and Focus

"I come from a long tradition of collective leadership, consultative decision making and joint action towards the common good. We have overcome much that many thought insurmountable through an adherence to those practices. In the face of the grave threat posed by HIV/AIDS, we have to rise above our differences and combine our efforts to save our people. History will judge us harshly if we fail to do so now, and right now."

Nelson Mandela
Closing Address, XIII International AIDS Conference, 2000

This section discusses the advocacy environment in which the effort to promote access to treatment in South Africa has emerged and explores how prevention of mother-to-child transmission (PMTCT) became a central advocacy focus.

▣ Advocacy Environment

South Africa's multiracial democracy, based on equal rights for all South Africans, took root less than 10 years ago. Reforms initiated in the early 1990s led to the first freely contested elections in 1994 and a victory for the African National Congress (ANC), an anti-apartheid organization founded in 1912. Nearly eight decades of protest and resistance have honed the advocacy skills of ANC members and other groups that, despite a frequently hostile and repressive environment, worked to promote social justice. The various groups are well versed in a range of advocacy strategies, such as network formation, leveraging international/external support and resources, community mobilization, civil disobedience (e.g., marches, demonstrations, strikes, and fasts), and working across racial and political lines. They know what it takes to maintain commitment and long-term sustainability.

In the mid-1990s, those who were once banned from involvement in affairs of state faced a new challenge—realization of the hopes and dreams of a newly freed people and nation. And one the most formidable obstacles to realizing those hopes and dreams has been the HIV/AIDS epidemic. The first AIDS cases in South Africa were identified in 1982. Given the perception that HIV/AIDS was confined to MSM as well as to other groups that practiced high-risk behaviors, the government's response during the 1980s was limited. Moreover, when the ANC came to power, it confronted the task of rebuilding entire systems—for example, health and education—that had been structured around a long-held tradition of racial segregation. Under these circumstances, HIV/AIDS programs had to compete with a range of complex priorities. To complicate matters further, South Africa had become the single country in the world with the highest number of PLWHA. At the end of 2001, HIV/AIDS affected about 5 million people, and HIV prevalence was estimated at 20 percent among adults age 15 to 49.[6]

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[6] UNAIDS. 2002. *Report on the Global HIV/AIDS Epidemic 2002*. Geneva, Switzerland: UNAIDS.

Under the leadership of the ANC, the transition to a multiracial democracy has brought about several unique changes in South Africa's advocacy environment. To begin, former activists—accustomed to challenging the government—now must learn to govern. They are recognizing what it means to be held accountable for meeting the country's needs. At the same time, with South Africa's long history of anti-apartheid activism, many people in civil society enjoy existing bonds and friendships with those now in government, setting the stage for new relationships based on both collaboration and confrontation. In addition, the international resources—human, technical, and financial—that once flowed into the civil society sector to support opponents of apartheid have now been redirected to the government and its effort to rebuild and reform the country's systems, institutions, and policies. Clearly, despite the existence of latent advocacy capacity, civil society groups had to reorganize and adapt to new circumstances.

While the government has established mechanisms (e.g., the Partnership Against AIDS and the South African National AIDS Council) and policies that, at least on paper, encourage a multisectoral, comprehensive HIV/AIDS response, varying degrees of political will and a lack of resources have hampered the success of that response. Furthermore, the advocacy environment itself remains a challenge. Notable incidents speak to the confusion, misunderstanding, fear, denial, stigma, and anxiety that continue to surround HIV/AIDS in South Africa. For example, Gugu Dlamini was stoned to death shortly after she disclosed her HIV-positive status in 1998. President Thabo Mbeki drew attention in 2000 when he sent a letter to world leaders questioning whether HIV is the cause of AIDS. In addition, Minister of Health Manto Tshabalala-Msimang stated at the XIV International AIDS Conference in Barcelona in 2002 that ARVs are a "poison."

▣ Advocacy Focus

Even as the campaign for universal access to treatment in South Africa continues apace, much of the recent debate on treatment access issues has centered on the country's approach to PMTCT programs. In 2001, the government initiated a pilot study of nevirapine as a means of preventing HIV transmission from mother to child. Under the program, provision of the drug was limited to the two pilot sites designated in each of South Africa's nine provinces. In August 2001, TAC, joined by pediatricians, doctors, and the Children's Rights Centre and with support from the AIDS Law Project, Médecins sans frontières (MSF) and others, filed a lawsuit against the Minister of Health and the heads of provincial health departments. In particular, their application contended that limiting the provision of nevirapine to the 18 pilot sites was a violation of the right to health care enshrined in the Constitution. Interestingly, just a few months earlier, TAC had supported the government when it was taken to court by about 40 pharmaceutical companies that argued that South Africa's Medicines and Related Substances Control Amendment Act of 1997 violated their patent protections (the pharmaceutical companies withdrew their complaint in April 2001).

The focus on PMTCT—which came about as a result of several different events and efforts (e.g., government policy, new research findings)—has been an important step in the struggle for universal access. While the primary goal of PMTCT is the prevention of HIV transmission to newborns, advocates have seen PMTCT as an entry point for discussing access to health care for HIV-positive women, which itself is a starting place for addressing larger issues of access to treatment for all in need. The emphasis on protecting infants enabled treatment access activists to gain broad-based support and to build partnerships with individuals and organizations (e.g., children's rights advocates) that might not necessarily have been natural allies in the campaign for universal access to HIV/AIDS treatment.

In December 2001, Judge Botha of the Pretoria High Court agreed with TAC and its partners and ruled that the restriction did violate constitutional rights. The legal decision held that nevirapine should be made available in all state institutions with the capacity to deliver the drug. Furthermore, it set a deadline of March 31, 2002, for the government to present a national PMTCT rollout plan. The South African government appealed the decision, arguing that the issue was of a nature that should be decided by the Constitutional Court and suggesting that the Pretoria High Court had exceeded its jurisdiction by attempting to formulate policy.

In July 2002, the Constitutional Court of South Africa upheld the earlier decision and ruled that the government's policy of restricting the provision of nevirapine only to those sites involved in the pilot program violated the right to health care for women and newborns as enshrined in the Constitution. While some barriers have been lifted and some provincial governments (e.g., Western Cape and KwaZulu-Natal) have announced or initiated plans to move ahead with expanding access to nevirapine, the national government—at the time of publication—has yet to develop an expanded PMTCT rollout plan.

6.2 Key Moments in South Africa's Access-to-Treatment Story, 1990–2002

The following timeline presents some critical moments in South Africa's ongoing efforts to gain universal access to ARVs for all who need the treatment. It highlights the different strategies and roles of the various players and their interrelationships. The timeline also helps to illustrate how different sectors influence an issue and how a national issue is linked to the international environment, events, and stakeholders.

1990

☑ Still in exile, the African National Congress holds a conference in Mozambique and releases the Maputo Statement on HIV and AIDS, which argues for the importance of HIV prevention.

☑ The white-dominated South African government ends the ban against the ANC and other organizations, which had been outlawed and forced to go underground in the 1950s. Nelson Mandela, who first became involved with the ANC and the anti-apartheid struggle in the 1940s, is released after 27 years in prison.

1991

☑ Following the repeal of apartheid-era legislation, such as the Population Registration Act, the Lands Acts, and the Group Areas Act, reformist President F.W. de Klerk releases a proposal for a new constitution that allows suffrage for all South Africans regardless of race.

☑ Delegations from a variety of groups come together to outline steps for establishing a multiracial democracy in South Africa.

1992

☑ Health Systems Trust (HST), an organization committed to evidenced-based solutions to improve South Africa's health care system, is formed.

☑ The ANC and Department of Health organize a conference on HIV/AIDS. One of the recommendations calls for creating a task force to develop a draft national HIV/AIDS strategic plan. In response, the ANC creates the National AIDS Convention of South Africa (NACOSA), which included government officials, NGOs, AIDS service organizations, the ANC Health Secretariat, and representatives from businesses, churches, unions, and other civil society organizations.

1993

☑ De Klerk's government and the ANC agree on a plan to create a transitional Government of National Unity in which both groups will share governing authority.

☑ More than 20 political parties gather and approve a new constitution for South Africa.

1994

☑ The ANC wins the first election in post-apartheid South Africa; one month later, Mandela is inaugurated as President of the Republic of South Africa.

☑ South Africa adopts the NACOSA-developed national HIV/AIDS plan.

☑ The National Association of People Living with HIV/AIDS (NAPWA) is established in South Africa.

1995

☑ The founding declaration of the National Economic Development and Labour Council (NEDLAC) is signed. NEDLAC becomes a leading forum in South Africa to promote social dialogue and includes representatives from government, trade unions, business associations, and civil society.

1996

☑ The Brazilian government begins offering universal, free access to ARVs to all who need the treatment. The program documents dramatic declines in mortality due to HIV/AIDS-related complications.

1997

☑ South Africa passes the Medicines and Related Substances Control Amendment Act of 1997, which allows for parallel importation of drugs, generic substitution, and price controls.

☑ South Africa initiates a comprehensive, province-by-province review of the country's response to the epidemic. A broad-based group of NGOs, PLWHA associations, and government and international representatives conduct the review.

1998

☑ Pharmaceutical companies file a lawsuit to prevent implementation of the Medicines and Related Substances Control Amendment Act.

☑ The U.S. government warns that South Africa may face economic sanctions because of its attempts to regulate drug prices.

☑ South Africa's National Department of Health discontinues trials of AZT to prevent MTCT on the grounds that the government cannot afford to provide the drug nationwide.

☑ The South African government initiates the Partnership Against AIDS, which is designed to help mobilize and coordinate a broad-based response to HIV/AIDS.

☑ The Treatment Action Campaign (TAC) is launched in South Africa.

☑ In KwaZulu-Natal, Gugu Dlamini, a member of NAPWA, is stoned to death three weeks after disclosure of her HIV-positive status on World AIDS Day 1998. She revealed her status in support of NAPWA's Acceptance and Disclosure Campaign, which sought to break the silence and stigma surrounding HIV/AIDS in South Africa.

1999

☑ Western Cape Province launches a pilot program to administer AZT to prevent MTCT.

☑ Results from a research study in Uganda show that administering nevirapine to a woman at delivery and to her newborn within 72 hours can reduce the HIV transmission rate and is more effective than the more complicated short courses of AZT.

☑ Médecins sans frontières (MSF) initiates the worldwide Campaign for Access to Essential Medicines to highlight the need to improve access to treatment for a range of conditions, including HIV/AIDS.

☑ The government adopts the National HIV/AIDS and STD Strategic Plan for South Africa, 2000–2005, which lists prevention, treatment, human and legal rights, research, monitoring, and surveillance as priority areas for action.

☑ Following protests from TAC and international allies, President Clinton rescinds the U.S. government's disapproval of South Africa's Medicines and Related Substances Control Amendment Act. In 2000, Clinton signs an executive order stating that the U.S. will not stand in the way of developing countries' efforts to regulate the costs of essential drugs.

☑ The Southern African Catholic Bishops Conference (SACBC) releases a statement in support of TAC and efforts to improve access to treatment.

2000

☑ April. South Africa's President Mbeki sends a letter to world leaders questioning whether HIV is the cause of AIDS.

☑ May. Five major pharmaceutical companies announce that they will reduce AIDS drug prices for countries in Africa.

☑ July. The XIII International AIDS Conference is held in Durban, South Africa, marking the first time the conference has been held in a developing country. TAC and the Most Reverend Njongonkulu Ndungane, the Anglican Archbishop of Cape Town, lead a global march for treatment access that draws over 5,000 people.

☑ September. The National Health Committee of the ANC develops and delivers a confidential document to the ANC's top party officials urging the President and Minister of Health to acknowledge HIV as the cause of AIDS.

☑ January. The World Health Organization (WHO) releases a statement endorsing the safety and effectiveness of nevirapine as a way to prevent MTCT.

☑ February–March. TAC organizes a national and three provincial treatment congresses. More than 160 organizations participate at the national meeting held in Soweto.

☑ March. The pharmaceutical industry's court case against the South African government's Medicines and Related Substances Control Amendment Act begins. TAC supports the government's legislation and is granted "friend of the court" status in the case. In April, the Pharmaceutical Manufacturers Association and its partners withdraw their court application.

☑ April. South Africa's Medicine Control Council approves the use of nevirapine, deeming it safe and effective for preventing MTCT.

☑ May. MSF begins a pilot program and research study to provide HAART through clinics in Khayelitsha, Cape Town.

☑ June. DaimlerChrysler announces a comprehensive workplace HIV/AIDS strategy and becomes the first South Africa-based company to offer free ARVs to its employees and their families.

☑ June. The UNGASS convenes, resulting in an international action plan for responding to the HIV/AIDS pandemic as outlined in the Declaration of Commitment.

☑ July. The South African government initiates a two-year pilot study of nevirapine and limits administration of the drug to two designated pilot sites in each of South Africa's nine provinces. HST is commissioned to evaluate the pilot program.

☑ August. TAC, joined by pediatricians, doctors, and the Children's Rights Centre, files a lawsuit against the Minister of Health and provincial health officials, arguing that restricting the provision of nevirapine to the pilot sites is a violation of the right to health care guaranteed by the Constitution.

☑ August. Archbishop Ndungane convenes the first ever All Africa Anglican Conference on HIV/AIDS and begins a participatory HIV/AIDS strategic planning process for the Church of the Province of Southern Africa (CPSA).

☑ August–September. The World Conference Against Racism, Racial Discrimination, Xenophobia, and Related Intolerance is held in Durban, South Africa. It highlights the interrelationships between racism, HIV/AIDS, and stigma.

☑ September. TAC, the Congress of South African Trade Unions (COSATU), CPSA, and SACBC release a joint statement on HIV/AIDS that affirms the groups' commitment to build a civil society alliance to help prevent transmission of HIV and ensure treatment for PLWHA.

☑ September. The South African government attempts to stall release of a report by the Medical Research Council that finds that AIDS is the leading cause of death for adults age 15 to 49 and

that life expectancy could drop from 54 to 41 years by the end of the decade.[7] Members of the ANC National Health Committee support the credibility of the report.

☑ October. TAC hosts an expert consultation that brings together health care providers, policy specialists, and activists and results in the Bredell Consensus Statement, affirming the importance of access to treatment.

☑ November. The Doha Ministerial Declaration on the TRIPS[8] Agreement and Public Health, endorsed by members of the World Trade Organization (WTO) at the Doha Ministerial Conference, permits countries to bypass drug patent regulations in cases of national emergency.

☑ December. The Pretoria High Court rules that limiting the provision of nevirapine only to the pilot sites is a violation of the right to health care enshrined in Section 27 of South Africa's Constitution. It also states that nevirapine should be made available in all state institutions that have the capacity to deliver the drug. In addition, it sets a deadline of March 31, 2002, for the government to present an expanded PMTCT rollout plan. The South African government appeals the decision, arguing that the issue is of such a nature that the Constitutional Court should decide it and suggesting that the Pretoria High Court has exceeded its authority by attempting to formulate policy.

> *"About one thing there must be no misunderstanding: a countrywide MTCT prevention programme is an ineluctable obligation of the State."*
>
> Judge Chris Botha,
> Pretoria High Court
> December 2001

2002

☑ February. HST, in partnership with the National Department of Health, releases a research study[9] on the South African government's pilot PMTCT program. While noting that PMTCT is not as simple as just giving a woman a pill and her baby a couple drops of medicine, the report argues that existing infrastructure deficiencies should not be used as a reason to delay expansion of the PMTCT program. Instead, the report suggests that a scaled-up PMTCT program could serve a "broader and catalytic" role not only by meeting the needs of HIV-positive pregnant women and their infants but also by jump-starting efforts aimed at simultaneously enhancing the health care system.

☑ April. A cabinet statement announces that the South African government will no longer oppose providing ARVs to rape victims and that ARVs can be effective if administered according to international guidelines. It also suggests that a national PMTCT rollout plan may be developed by the end of the year.

☑ April. At a meeting in Canterbury, England, the Primates of the Anglican Communion issue a statement that, in part, calls on governments and pharmaceutical companies in particular to respect the basic human right of those in need to have access to treatment.

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[7] Dorrington, R., D. Bourne, D. Bradshaw, R. Laubscher, and I.M. Timaeus. 2001. "The Impact of HIV/AIDS on Adult Mortality in South Africa." Tygerburg, South Africa: Medical Research Council, Burden of Disease Research Unit. Available at www.mrc.ac.za/bod/complete.pdf.

[8] TRIPS refers to the WTO's Trade-Related Intellectual Property Rights Agreement.

[9] McCoy, D., M. Besser, R. Visser, and T. Doherty. 2002. *Interim Findings on the National PMTCT Pilot Sites: Lessons and Recommendations.* Pretoria, South Africa: Health Systems Trust and National Department of Health. Available at www.hst.org.za/pubs/pmtct/pmtctinterim.htm.

☑ June. COSATU and TAC convene a National HIV/AIDS Treatment Congress in Durban to begin outlining a proposed national plan on treatment.

☑ July. The Constitutional Court upholds the major tenets of the earlier ruling of the Pretoria High Court and calls for an end to the government's policy of limiting the provision of nevirapine to the pilot-test sites.

☑ July. TAC and COSATU begin talks within NEDLAC to advocate for a national treatment and prevention plan. A task team is created to develop a draft framework by December.

☑ August. TAC convenes a Pan-African Treatment Access Meeting in Cape Town, bringing together 70 delegates from 21 African countries to help build a pan-African treatment movement.

☑ October. A cabinet statement declares that South Africa's HIV/AIDS policy begins from the premise that HIV is the cause of AIDS.

☑ October–December. Members of NEDLAC develop a draft Framework Agreement for the National Prevention and Treatment Plan.

The following sections present the advocacy stories of four organizations that represent some of the major constituencies and policy actors that have influenced the struggle for access to treatment in South Africa.

6.3 Treatment Action Campaign

▣ Background

The Treatment Action Campaign (TAC) emerged out of a demonstration held on December 10, 1998. Designed to coincide with International Human Rights Day, the purpose of the demonstration was to raise awareness of the treatments available for HIV/AIDS, which was generally perceived as an untreatable, life-threatening disease, and to draw attention to the need for improved treatment access. Illustrating both the personal ties and sense of urgency that often infuse HIV/AIDS activism, the catalyst for the demonstration was the November 1998 death of long-time ANC member and gay rights activist Simon Nkoli. Nkoli lacked access to the ARV drugs that were more commonly available in Europe and the United States. Among those involved with the protest were Zackie Achmat, director of the National Lesbian and Gay Alliance; Mercy Makhalemele, one of the first women in South Africa to disclose her HIV status; and Peter Busse, then director of the National Association for People Living with HIV/AIDS (NAPWA).

What began as a good idea has evolved into an independent grassroots movement that includes PLWHA and their allies, both individuals and organizations. TAC is now one of the leading treatment access advocacy organizations in the world and has inspired other groups to initiate their own campaigns (for example, see the story of W-TAG in Section 3.3).

▣ Role in the Access-to-Treatment Story

TAC has been one of the strongest voices for universal access to treatment in South Africa. Its advocacy work is aimed at reducing the cost of ARVs, improving treatment literacy (some people do not know that drugs can prolong life and enhance quality of life), developing a scaled-up PMTCT program, and making universal access an integral aspect of government policy. Throughout the access-to-treatment struggle, TAC has been both a partner of the government—as in the court challenge brought by the pharmaceutical industry to prevent the government's attempts to regulate drug costs—and an opponent of the government—as in its own lawsuit contesting the government's approach to PMTCT programs and the provision of nevirapine.

▣ Advocacy Focus and Strategy

TAC's efforts to influence government policy regarding PMTCT have taken a variety of forms. Some of the organization's major advocacy approaches include political, economic, and social analysis; high-quality research; mass mobilization; civil disobedience; attention-getting and

awareness-raising events; and litigation. Partnerships have been critical to the organization's ability to develop and implement its advocacy approaches. For example, Médecins sans frontières collaborates with TAC on a pilot ARV program in Khayelistha and provides assistance with treatment literacy efforts; research organizations, such as HST, have improved TAC's knowledge of the health care infrastructure needed to expand access; and the AIDS Law Project has provided legal support and helped strengthen TAC's capacity to address the legal, constitutional, and human rights issues surrounding access to treatment. TAC has also sought partnerships with faith-based groups, trade unions, and others (e.g., the Children's Rights Centre) to build its support base and reach out to different communities.

One of TAC's more prominent advocacy strategies was its decision, in 2001, to file a lawsuit against the Minister of Health and provincial health authorities in response to the government's pilot program in selected communities to test nevirapine as a means of preventing PMTCT. TAC's lawsuit was premised on the drug's lack of availability to the larger at-need population. The movement's leaders decided to approach the courts once they felt that they had exhausted all other alternatives. TAC and its partners argued that restricting the administration of nevirapine to the pilot sites violated the right to health care for both women and children as articulated in the country's new Constitution. Both the Pretoria High Court and Constitutional Court sided with TAC and its allies; the courts also called on the government to develop a national PMTCT rollout plan—a dramatic policy change, even though the plan has yet to be developed.

> *"Every one of us has the duty to speak out when our government is wrong and to assist the government in every way possible when it is right."*
>
> Zackie Achmat,
> Chairperson of TAC
> *Address to the AIDS in Context
> International Conference on HIV/AIDS
> University of Witwatersrand
> April 7, 2001*

Importantly, TAC realized that the government was not a monolithic entity with all decision makers sharing the same opinions regarding appropriate policy and program responses to the HIV/AIDS epidemic. While TAC has had both friendly and adversarial relationships with the National Department of Health, it has established solid working relationships with the Departments of Finance and Trade and Industry as well as with the Director-General of Health. Many others could work from within government as internal advocates for HIV/AIDS policy change. In fact, one of TAC's ongoing efforts is to identify and build the capacity of these potential allies.

TAC has also used national, regional, and international forums to advocate for universal access to treatment. In 2000, for example, Durban hosted the XIII International AIDS Conference, marking the first time that the conference was held in a developing country. At the conference, TAC helped organize a Global March for Access to HIV/AIDS Treatment, which drew about 5,000 people. Prominent leaders from South Africa joined the march, including the Most Reverend Njongonkulu Ndungane, the Anglican Archbishop of Cape Town and Metropolitan of Southern Africa. Throughout the conference, participants wore the t-shirts designed for the march; the shirts read "H.I.V. Positive" and were a symbol that kept treatment access messages alive and helped reduce stigma. Through alliances with international groups, such as MSF, Health GAP (Global Access Project), and the Treatment Action Group, TAC helped organize a day-long satellite session on access to treatment.

▣ Challenges

TAC's decision to mount a legal challenge to the PMTCT pilot program was a bold move. Given that a civil society group rarely takes its own government to court, the lawsuit helped

generate media attention, yet it also demanded careful framing of the issues. TAC had to balance the need to hold the government accountable for meeting public health needs against the possibility of alienating the general public (and its own members), which likely was extremely eager to see the post-apartheid liberation government succeed.

With PMTCT and universal access linked to so many complex issues, TAC often faces the challenge of determining which issues to address. For example, when President Mbeki questioned whether HIV was the cause of AIDS, TAC initially remained silent and tried to stay outside the controversy. Even though the issue is important in terms of treatment access—if HIV does not cause AIDS, then investing in ARV treatment to target the virus will not ease the burden of disease—TAC's leaders felt that engaging in the debate would give too much credence to the arguments of AIDS dissidents who questioned the HIV–AIDS link and suggested that ART is more harmful than beneficial. In retrospect, TAC members decided that, given confusion over the issue within government and local communities, the failure to speak out on the HIV–AIDS link was an error in judgment. They are in the midst of formulating a strategy to enter the debate and present the evidence while trying to avoid embarrassing the government.

Finally, TAC has had to meet the challenges of sustaining and expanding its treatment access movement. Since 1998, TAC has grown tremendously in terms of both staff size and the demands made on the organization. When it began to run short of funds, TAC appointed a treasurer charged with, among other tasks, leveraging additional resources. In 2001, TAC convened its first national congress and used the event, which brought together representatives from more than 160 organizations, to rewrite its own constitution and to include an array of civil society groups in the development of new programs and resolutions. In addition, it identified potential partners, particularly FBOs and trade unions. While TAC had succeeded in gaining the support of international groups, it recognized the need to build relationships within Africa and, therefore, in 2002, organized a Pan-African Treatment Access Meeting in Cape Town. In 2002, TAC reorganized again in order to meet the needs of the growing treatment access movement, such as addressing the needs of PLWHA, working with the media, and assessing and adapting to the political environment.

6.4 Health Systems Trust

◩ Background

The Trust for Health Systems Planning and Development, or Health Systems Trust (HST), was established in 1992. Its mission is to facilitate the development of South Africa's health system, particularly by promoting equity and efficiency. In its organizational role, HST enhances development efforts in the health care sector, supports health systems research, advocates for evidence-based solutions to public health needs, and improves awareness of these approaches across a variety of constituencies (e.g., government, the public, media, and civil society groups). An autonomous NGO, HST also enjoys close working relationships with the government and is often commissioned to conduct evaluation research and provide recommendations on government-supported programs. Some of its funding sources include the Commission of the European Union, the U.S.-based Kaiser Foundation, the Department for International Development (United Kingdom), and South Africa's National Department of Health.

◩ Role in the Access-to-Treatment Story

HST's role in the access-to-treatment story evolves from its mission as a health systems research institution. Beyond functioning as an organization concerned with equity and development of the public health system in general, HST assumed responsibility for evaluating implementation of the government's pilot PMTCT program that was underway in two sites in each of South Africa's nine provinces. Its interim report, released in collaboration with the National Department of Health,[10] highlighted some of the infrastructure deficiencies that hampered effective implementation and expansion of the PMTCT program. The report noted that the matter was not as simple as administering a pill to new mothers and a few drops of medicine to newborns; rather, it involved the development of a range of service delivery and management capacities and infrastructures. At the same time, the report suggested that current deficiencies should not be taken as a reason not to expand administration of nevirapine beyond the 18 pilot sites. Instead, it argued that a scaled-up PMTCT program could serve as the "engine" that drives the development of the country's public health system. That the report was released in collaboration with the National Department of Health was an important achievement and demonstrated the ability for NGOs and government to develop some consensus on the way forward. It also exemplified the sense of trust and partnership between HST and the National Department of Health.

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[10] McCoy, D., M. Besser, R. Visser, and T. Doherty. 2002. *Interim Findings on the National PMTCT Pilot Sites: Lessons and Recommendations.* Pretoria, South Africa: Health Systems Trust and National Department of Health. Available at www.hst.org.za/pubs/pmtct/pmtctinterim.htm.

▣ Advocacy Focus and Strategy

For HST, it was important that treatment activists understand the legitimate obstacles to expanding the PMTCT program, that the government recognize the need to move forward with expansion, and that certain issues—such as infrastructure development and equity in rural and urban access to services—did not get lost or glossed over in the public debate. HST was able to use its existing relationships with the government to inform and raise awareness among policymakers. By providing evidence on the feasibility of expanding the PMTCT program, HST was also able to initiate dialogue with treatment activists. As a consequence of that dialogue, TAC adopted a broader advocacy perspective that included the need to develop the health system infrastructure as an integral aspect of improving care for PLWHA. In addition, as an independent research-focused NGO, HST was able to position itself as an intermediary between government and civil society advocates, attempt to promote social discourse, help both government and civil society advocates understand the other group's perspectives, and build consensus on next steps.

Another strategy adopted by HST was to use relationships with the media to highlight some of the more complex issues involved in expanding access to treatment. For example, HST partnered with Health-E, which is an independent agency supported by the Kaiser Foundation that is dedicated to providing news and analysis regarding public health issues and the health care system in South Africa. Through Health-E, other independent news outlets, and the more mainstream media, HST and other NGOs were able to promote social dialogue as well as raise concerns relating to infrastructure and gaps in the quality and access to services for rural and urban populations. This expanded dialogue allowed equity and infrastructure development of the health care system to become important aspects of the push to expand the PMTCT program.

▣ Challenges

In advocating for improved PMTCT programs in particular and greater development of the health care system in general, HST had to overcome several challenges. To begin, HST had to maintain its credibility as an independent, objective research organization while working to inform treatment activists, serving the government as a client, and striving not to alienate either constituency or the broader public. In addition, HST had to consider when and how to speak out or take sides on issues, especially as the organization commanded a reputation as a nonpolitical group that did not or should not have a particular agenda.

Helping the various players, including the public, understand that the sometimes heated debates over access to treatment were not so much personal attacks as an important part of the democratic political process was also a challenge—especially since the media often portrayed well-reasoned differences in opinion as confrontations. HST had to work to ensure that the media clearly communicated the complexities involved in expanding the PMTCT program rather than merely simplifying or reducing issues to catchy "sound bites." The goal of HST was to direct attention to the public health issues involved, as opposed to the politics surrounding those issues. HST was able to develop responses to these various challenges by, in part, building on the faith that all of the affected parties ultimately were working toward the same goals—to prevent MTCT, to ease the burden on families, and to reduce the number of children affected by HIV/AIDS.

This advocacy story is based on an interview with a former HST staff member familiar with the campaign to expand the PMTCT program. For further information about HST, please visit www.hst.org.za.

6.5 Church of the Province of Southern Africa

▣ Background

The Church of the Province of Southern Africa (CPSA)—the Anglican Church as constituted in Angola, Lesotho, Mozambique, Namibia, South Africa, and Swaziland—has a long history of involvement in social issues. Under the leadership of then-Archbishop Desmond Tutu, the CPSA became a strong voice in the struggle against apartheid; for example, Archbishop Tutu was the chairperson of the Truth and Reconciliation Commission. Now led by the charismatic Most Reverend Njongonkulu Ndungane, Archbishop of Cape Town and Metropolitan of Southern Africa—who was also an anti-apartheid activist and political prisoner—the Anglican Church is taking a proactive role in responding to the HIV/AIDS epidemic.

▣ Role in the Access-to-Treatment Story

The CPSA has been one of the leading religious voices for social justice and economic development, and it is from this commitment that the organization became involved in advocacy efforts to help prevent HIV transmission and improve care and support for those already affected by HIV/AIDS. In particular, the CPSA, under Archbishop Ndungane's leadership, has sought to break the silence and stigma surrounding HIV/AIDS, promote values of compassion and tolerance, and encourage open dialogue among different groups—both within the church and other faith-based communities and across sectors. The CPSA has taken on these roles in a climate of much political controversy not as a political posture but rather because of its moral authority and its belief that people's lives are at stake and that all life is sacred.

▣ Advocacy Focus and Strategy

At its core, the CPSA's advocacy approach begins with the words and deeds of the individual and seeks to build on the values and tenets that are central to followers of the faith. In advocating for a more compassionate response to HIV/AIDS, Archbishop Ndungane has sought to lead by example. He publicly underwent an HIV test, he led the Global March for Access to HIV/AIDS Treatment at the XIII International AIDS Conference in Durban in 2000, and he conducted church services at St. George's Cathedral on World AIDS Day and declared that HIV/AIDS is not a punishment from God. Through efforts such as the Jubilee 2000 Campaign, he has also emphasized the links between HIV/AIDS and broader development issues, including poverty alleviation, food security, land redistribution, and the need for debt cancellation.

Internal advocacy within the faith-based community in Southern Africa is central to Archbishop Ndungane's campaign to mobilize communities in response to HIV/AIDS. Charged by the Archbishop of Canterbury to coordinate an Africa-wide effort to address HIV/AIDS, Archbishop Ndungane convened the first-ever All Africa Anglican Conference on HIV/AIDS in Boksburg, South Africa, in August 2001. The conference brought together participants from 12 African Anglican provinces and 33 African countries, the CPSA, and leaders from the worldwide Anglican Communion as well as PLWHA, international donors, observers, international NGOs, and pharmaceutical companies. Using a participatory planning process, participants articulated a vision statement; identified women, children orphaned by AIDS, and PLWHA as groups of particular concern; and established six focal areas that would further guide the strategic planning process. The next steps called for going out to communities and extending the planning process to each diocese, using the guide *Planning Our Response to HIV/AIDS: A Step-by-Step Guide to HIV/AIDS Planning for the Anglican Communion*.[11] By July 2002, more than 1,000 people had participated in the process, resulting in 23 diocesan HIV/AIDS plans and finalization of the overall strategic plan for the CPSA.

Emerging from its experience in addressing HIV/AIDS issues, the CPSA has found that its internal advocacy efforts can contribute to external advocacy as well. For example, after a presentation on the CPSA's progress in April 2002, the Anglican Consultative Council and the Archbishop of Canterbury asked the CPSA and Archbishop Ndungane to assist the worldwide Anglican Communion in meeting its goal of completing HIV/AIDS strategic plans and implementation strategies by 2005. Another example of how internal advocacy reached a broader audience is the membership of the CPSA itself. Interestingly, an analysis of church membership found that members included individuals from Parliament, local government departments, health care facilities, educational institutions, and other organizations; in other words, messages of compassion, openness, tolerance, and mercy were reaching many levels.

> *"It is not time to give up, but time for all sectors to rise above their agendas. For the good of those already living with HIV or AIDS and for future generations, we need action now."*
>
> Archbishop Ndungane,
> *Address at the Rhodes Trust Centenary Reunion and launch of the Mandela Rhodes Foundation*
> *University of Cape Town*
> *February 1, 2003*

With specific regard to access-to-treatment issues, the CPSA's external advocacy has had noticeable impacts. In April 2002, after learning about the progress of the CPSA's efforts to address HIV/AIDS, the Primates of the Anglican Communion issued a statement recognizing that the church had, at times, been silent on HIV/AIDS and calling on governments and pharmaceutical companies in particular to respect the basic human right of those in need to have access to treatment. The statement also urged FBOs to demonstrate compassion by standing by those living with HIV/AIDS and their families. In addition, because he has developed relationships with both pharmaceutical companies and activists, Archbishop Ndungane offered to be an intermediary between the two groups on issues regarding drug pricing and availability. Initially, the pharmaceutical companies declined the offer. However, recent proposals have adopted some of the principles the Archbishop had put forward—such as the need for compassionate use of drugs and the need to make generic brands available; the pharmaceutical companies have since asked the CPSA to become involved in developing a drug distribution plan.

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[11] Available at www.policyproject.com/pubs/countryreports/AIDSps.pdf.

▣ Challenges

Part and parcel of the efforts to advocate for increased access to treatment for PLWHA has been the need for the CPSA to explore sometimes sensitive issues, including attitudes surrounding sex and sexuality, how and why people come to be affected by HIV/AIDS, the role of the church, and the nature of the relationship between God and people. In part, Archbishop Ndungane and other CPSA leaders have sought to frame the church's new, open response to HIV/AIDS within the context of its broader work to challenge apartheid, end indebtedness, fight for social justice, and fulfill the church's mandate to meet the needs of the communities it serves. The CPSA has also sought to build on the values and traditions of the church and of African cultures, which have an ethos of open dialogue and togetherness. In particular, Archbishop Ndungane has emphasized "ubuntu," a principle positing that who we are as individuals emerges from our interdependence and relationships with others.

Another challenge has been to build the capacity of church leaders to respond appropriately to HIV/AIDS while confronting the silence and stigma surrounding the disease. For example, church leaders have buried many parishioners who died of HIV/AIDS-related complications without acknowledging at the gravesite that the person died of AIDS. The church has a moral and spiritual obligation to help people die with dignity. It would seem that such an obligation requires the church to be open about why a person died. These are examples of some of the issues the CPSA has explored during its strategic planning process, pastoral training initiatives, and capacity-building activities.

Defining the role of the church has also required some careful negotiation. On the one hand, for Anglicans, the role of the clergy is to inform, not to dictate. On the other hand, the church should provide a safe environment where all people—including those affected by HIV/AIDS—can come to be cared for and nurtured. The CPSA found that it needed to empower itself to speak clearly about the nature of compassion and mercy and to help others understand that it is up to God, not human beings, to judge. As a result, the church has sought the appropriate balance between serving as a strong, proactive voice and encouraging open dialogue and allowing others to explore their faith.

This advocacy story is based on an interview with Reverend Canon Ted Karpf, who has helped facilitate and coordinate the CPSA's strategic planning process. For further information about CPSA and its HIV/AIDS programs, please visit www.anglicancommunion.org/special/hivaids/.

6.6 National Health Committee of the African National Congress

▣ Background

The National Health Committee is part of the ANC's institutional party structure. The committee, established in 1990, does not have decision-making authority, but it is an influential policy advisory board. Its members comprise a range of health professionals who provide recommendations on the development of the ANC's health policies, including playing an active role in the National AIDS Convention of South Africa (NACOSA),[12] which developed the first post-apartheid strategy and plan on HIV/AIDS.

▣ Role in the Access-to-Treatment Story

In terms of the access-to-treatment story, the National Health Committee has persistently worked to strengthen and expand the government response to HIV/AIDS, often in the context of misunderstandings and a lack of political will within the ANC. In 2000, President Mbeki questioned whether HIV causes AIDS, saying that immune deficiency could also be caused by malnutrition and poverty. The country's Minister of Health has also suggested that ARVs are a "poison" while some AIDS "dissidents" have contended that the epidemic is a conspiracy against African people. Given the legacy of the apartheid era, when science was at times used against African populations (e.g., research on ways to induce sterilization), the doubt and caution that have characterized the reaction to HIV/AIDS in South Africa are perhaps not entirely surprising. At the same time, however, the National Health Committee found that it needed to advocate within its own party for policies and programs that it felt had been clearly shown to reduce transmission of HIV and improve the lives of those already affected.

▣ Advocacy Focus and Strategy

Before becoming the Secretary of the National Health Committee, Dr. Saadiq Kariem had been the head of the provincial AIDS program in Western Cape. In 1999, under his leadership, the AIDS program initiated a pilot project in Khayelitsha – a township near Cape Town – to provide AZT to prevent transmission of HIV from mother to child. This was a bold decision, and one that required leveraging resources at the provincial level, because the ANC-led national government recently decided to discontinue provision of AZT for PMTCT programs on the grounds that providing the drug nationwide was too costly. Dr. Kariem and his team endured much criticism from within the party at this time. Later, working through the National Health

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[12] The official name of NACOSA later changed to Networking AIDS Community of South Africa.

Committee, Dr. Kariem and others played an instrumental role in convincing the government to support at least two PMTCT sites in each province.

In mid-2000, the National Health Committee drafted and internally distributed a document calling on ANC party leaders, including the President and Minister of Health, to acknowledge HIV as the cause of AIDS. The committee further applied internal pressure in 2001 when the ANC-led government tried to delay release of a report that found AIDS to be the leading cause of death for adults age 15 to 49, and again in early 2002 when the ANC sent a document to its top officials questioning the HIV–AIDS link and the safety of ARVs. On these occasions, members of the National Health Committee also spoke out in the media. As Dr. Kariem explained to journalists, "The implications of this are enormous and disastrous. People have already come to me and said, 'If HIV doesn't cause AIDS and AIDS isn't sexually transmitted, why am I wearing a condom?'"

> *"Small as it was, [establishing two PMTCT sites in each province] was a major step for South Africa at the time. Of course, with hindsight, it may seem a simple task – but [we had] to negotiate the politics, bolstering support from the ministers of health of each province – and all this was against the backdrop of, shall we say, inertia and statements that MTCT programs will fail in South Africa …"*
>
> Dr. Saadiq Kariem,
> National Health Committee

In April 2002, the position of some top ANC leaders seemed to shift a little when a cabinet statement indicated that ARV treatment, when administered according to international guidelines, could be an effective way to improve the health of PLWHA and that the government would no longer oppose provision of ARVs to survivors of rape and sexual assault. It was also reported that party insiders were working to develop more direct contacts between the ANC's top leadership and the National Health Committee in order to promote further dialogue and clarify the party's response to the epidemic.

This story is based on interviews with Dr. Saadiq Kariem, Secretary of the ANC's National Health Committee, as well as the following articles:

Fassin, D., and H. Schneider. 2003. "The Politics of AIDS in South Africa: Beyond the Controversies." *British Medical Journal 326*: 495-497.

Paton. C. "ANC Rebels Defy Mbeki on AIDS." *Sunday Times*. Oct. 7, 2001. Available at www.sundaytimes.co.za/2001/10/07/politics/pol01.asp.

Schneider, H., and J. Stein. 2000. "Implementing AIDS Policy in Post-apartheid South Africa." Johannesburg, South Africa: University of Witwatersrand, Center for Health Policy.

Swarns, R. "An AIDS Skeptic in South Africa Feeds Simmering Doubts." *New York Times*. March 31, 2002. Available at www.nytimes.com/2002/03/31/international/africa/31AIDS.html.

United Press International. "South African Government Takes Out AIDS Ads." *AIDS Education Global Information System*. Sept. 15, 2000. Available at http://host65.aegis.com/news/upi/2000/UP000902.html.

◙ Questions for Dialogue

1. The various groups involved in the campaign for universal access to treatment in South Africa chose PMTCT as their first winnable issue, one that would lay the groundwork for future advocacy victories. What risks and opportunities are associated with the selection of an advocacy issue?

2. Many organizations were part of the campaign. Each occupied a different advocacy niche. Are some advocacy tactics appropriate for certain groups, but not for others? What strengths and challenges are associated with each tactic? How do these strengths and challenges relate to the niche occupied by your own organization?

3. TAC used the courts to raise awareness of treatment access issues and to influence government policy. What are the advantages and disadvantages of legal challenges as an advocacy approach? Under what circumstances might it be appropriate to use the judicial process to advance your advocacy goals?

4. While the struggle for universal access to treatment continues in South Africa, advocates have won several important victories, including the passage of the Medicines and Related Substances Control Amendment Act, the court ruling recognizing the right to health care, and the expansion of the availability of nevirapine at the provincial level. How might you envision and approach your long-term advocacy goal as a series of smaller steps or objectives? What are the benefits of this approach?

5. An important part of the success of South Africa's access-to-treatment campaign has been the ability of different groups to come together in coalitions. Alliances among groups working on the campaign required the groups to assume a strategic position in identifying where they could find common ground and when, even if they might not agree with another group, to maintain their silence. What are some of the critical elements and decisions that helped forge and sustain these coalitions? Thinking about your organization's history, what challenges have you experienced in negotiating partnerships while maintaining your organization's primary advocacy goals and values? How have you addressed these various challenges?

Lessons Learned

- **Identifying shorter-term, winnable advocacy objectives lays the groundwork for long-term victories.** Universal access to treatment in South Africa is an ongoing, long-term goal whose achievement involves the resolution of issues relating to infrastructure, resources, capacity, and international trade. In light of the depth and complexity of these issues, advocates must identify smaller, achievable objectives. By initially focusing on the government's approach to PMTCT, TAC and other advocates have built new partnerships, leveraged resources, and demonstrated the positive impact of their efforts. These important victories position advocates to succeed in the next steps in their long-term campaign.

- **Carefully crafting advocacy approaches and using different advocacy tactics have been important aspects of the ongoing effort to win universal access to treatment.** Each organization occupied a unique advocacy niche and adopted strategies that were consistent with its mission and roles. The CPSA was able to appeal to faith-based values of compassion and care to help reduce the stigma and discrimination experienced by PLWHA and their families. TAC, a grassroots movement, was able to be outspoken and adversarial, applying public pressure to address treatment access issues. HST, a health systems research organization, was able to raise awareness and build consensus between government and activists. The National Health Committee of the ANC has worked from within the party structure to influence government policy, alternatively providing policy advice and applying pressure when necessary.

- **Identifying common ground for advocacy efforts within and among constituencies requires constant negotiation and careful framing of advocacy messages.** As demonstrated by the stories in this section, HIV/AIDS advocates have had to negotiate complex issues and relationships—even within organizations. For example, TAC's strategy of holding the government accountable for meeting health needs had to be balanced against concerns that challenging the government in court would alienate both its own constituency and the general public, both of which were eager to see the liberation government succeed. The ANC's National Health Committee struggled to find ways to advocate internally for changes in its own party leaders' sometimes controversial and confusing positions regarding HIV/AIDS. And, leaders of the CPSA had to develop approaches that break the silence surrounding HIV/AIDS by maintaining safe places for open dialogue while challenging beliefs that contributed to the stigma associated with HIV/AIDS.

Lessons Learned (continued)

▪ **Recognizing the fluidity of advocacy partnerships and maintaining trust among partners, especially when issues involve multiple players and interests, are two crucial factors in an advocacy environment.** Organizations must find ways to build and sustain relationships with other groups that may be important allies on some issues but opponents on others. South Africa's transition to a multiracial democracy in the mid-1990s changed the nature of the advocacy environment. Those who had once been partners in the anti-apartheid struggle sometimes found themselves on opposing sides when it came to responding to HIV/AIDS. Relationships between organizations also have been fluid as groups formed alliances around some issues while disagreeing on others. Because issues of access to treatment engage so many players, organizations need regular strategic meetings to assess the changing political landscape and identify new advocacy opportunities as they emerge.

Annexes

ANNEX A

Glossary of Terms

Antiretroviral drugs (ARVs)—Drugs that suppress the activity or replication of retroviruses such as HIV. Antiretroviral drugs, for example, reverse transcriptase inhibitors (e.g., AZT, ddI, 3TC) and protease inhibitors (e.g., saquinavir, ritonavir), interfere with various stages of the virus's life cycle.

Bactrim (TMP/SMX)—An antibiotic used to prevent and treat pneumocystis carinii pneumonia (PCP) as well as many other infections.

Compulsory license—Issued when the government takes away the exclusive rights of a company holding a patent and allows generic competition.

Cotrimoxazole—A generic form of the sulfa drug Bactrim (see Bactrim).

Country Coordinating Mechanism (CCM)—As defined by the Global Fund to Fight AIDS, Tuberculosis and Malaria, a CCM is a body that functions as a forum to promote true partnership development and multisectoral programmatic approaches. A CCM's membership should include a representative number of members who reflect the interests and commitments of the relevant consitutencies and who are able to access the best available technical expertise in the relevant diseases. The CCM should ensure that all relevant actors are involved in the process and that all views are taken into account. The CCM should be as inclusive as possible and seek representation of the highest possible level from various sectors and place great value on local solutions. Above all, all members of a CCM are expected to be treated as full partners in the CCM, with full rights of participation, expression, and involvement in decision making in line with their areas of expertise.

ddI: didanosine (also called Videx)—An antiretroviral used for the treatment of HIV infection.

Disclosure—In the context of HIV/AIDS, disclosure refers to the act of informing an individual or organization (such as a health authority, an employer, or a school) of the HIV status of an infected person. It may also refer to the fact that such information has been transmitted by the person him or herself or by a third party, with or without consent. Except in exceptional circumstances, when disclosure to another person is required by law or ethical considerations, the person with HIV has the right to privacy and to exercise informed consent in all decisions about disclosure of his/her status.

Discrimination—The practice of making some type of distinction about a person that results in unfair and unjust treatment on the basis of the individual's belonging or perception that the individual belongs to a particular group. Discrimination is defined in terms of legal and human rights; discrimination limits a person's or group's enjoyment of rights and freedoms on an equal basis.

Generic medicines—Drugs with the same active ingredients as the original patented medicine.

GFATM—The Global Fund to Fight AIDS, Tuberculosis and Malaria works to attract, manage, and disburse additional resources through a new public/private partnership in order to make a sustainable and significant contribution to the reduction of infections, illness, and death, thereby mitigating the impact caused by HIV/AIDS, tuberculosis, and malaria in countries in need.

Kaposi's sarcoma (KS)—A normally rare type of cancer that starts as pink or dark, flat or raised marks on the skin that gradually spread; internal organs may later become infected. Karposi's sarcoma is a common problem with people living with HIV/AIDS and occurs unrelated to AIDS in a mild form in some elderly people.

Nevirapine (NVP)—Currently, the most affordable and widely used ARV to prevent HIV transmission from mother to child.

Opportunistic infection (OI)—Infection by an organism that causes disease only when the immune system is weak, as in advanced HIV infection.

Parallel importation—Shopping around for medicines and buying them from the company that holds the patent, but in the country where they are cheapest.

Patent protection—The first company to register a new drug is granted a patent for 20 years, which prevents other companies from manufacturing or importing that drug.

Pneumocystis carinii pneumonia (PCP)—Type of pneumonia seen only in people with weakened immunity from illnesses such as AIDS.

Prophylaxis—Treatment to prevent the onset of a particular disease or the recurrence of <u>symptoms</u> in an existing <u>infection</u> that has been brought under control.

Stigma—A powerful social label or marker that "significantly discredits" a person or group. Stigmatization is a process. Within a particular culture or setting, certain attributes are distinguished as discreditable or unworthy. Often these attributes are linked to socially marginalized behaviors, such as men having sex with men, drug use, sex work, or having multiple partners.

Tuberculosis (TB)—Serious, chronic bacterial disease of the lungs and sometimes other organs; common with AIDS. TB is treatable with various antibiotics, although multidrug resistant TB is an increasing problem worldwide.

Voluntary license—The pharmaceutical company holding the patent to a drug gives up its exclusive right to a drug, allowing another company to manufacture or import generics during the period of patent protection.

ANNEX B

Declarations

Women and HIV/AIDS: The Barcelona Bill of Rights
The Barcelona Bill of Rights was drafted as a working document by several women living with and affected by HIV/AIDS—researchers, scientists, and advocates from all regions and all perspectives—during the International AIDS Conference of July 2002.   The Women at Barcelona/Mujeres Adelante Planning Group, a coalition of individuals committed to advancing the gender and human rights agenda at the International AIDS Conference, facilitated the compilation of the document.
www.ipas.org/english/press_room/2003/03072003.html

Denver Principles
Written in June 1983 by the advisory committee of the People with AIDS Coalition in the United States, the document is considered by many to be the launching point of the PLWHA self-empowerment movement. The document is a valuable reminder of AIDS history in this 20th year of the epidemic.
www.beingalivela.org/news598/598_denvp.html

"A Focus on Women" Declaration
Over 130 community women of Uganda attending the Third International Conference on Global Strategies for the Prevention of HIV drafted the declaration and presented it at the conference held on September 9–13, 2001, in Kampala, Uganda. The document, presented by Faith Akiki of the Network of People Living with AIDS, calls for doctors, researchers, governments, and world health organizations to implement PMTCT programs and include women in their treatment plans and to work with grassroots groups on long-term goals that include the economic, social, and political empowerment of women.
www.gawh.org/women_hiv/pmtct/kampala_declaration.html

Kampala Declaration on Gender and HIV/AIDS
UNAIDS, UNIFEM, and Intergovernmental Authority on Development (IGAD) held a regional conference on Gender and HIV/AIDS on November 27–28, 2001, with participants from the seven IGAD countries (Djibouti, Eritrea, Ethiopia, Kenya, Uganda, Somalia, and Sudan) together with participants from Burundi, Comoros, and Rwanda. At the conference, they adopted the Kampala Declaration, which recommends that HIV/AIDS prevention, care, and treatment programs should be guided by principles of women's empowerment, gender equality, human rights, and the participation of women and their communities.
http://allafrica.com/stories/200112040446.html

Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) Principle
In 1994 at the Paris AIDS Summit, 42 countries signed on to a declaration supporting the greater involvement of people living with HIV/AIDS in the formation of policy and service delivery; the declaration became known as the GIPA principle. The document, *From Principle to Practice: GIPA*, includes the original Paris Summit Declaration and discusses how the GIPA principle is currently used.
www.unaids.org/publications/documents/persons/gipa-8.doc

International Conference on Population and Development (ICPD)
During this United Nations conference held on September 5–13, 1994, in Cairo, Egypt, world leaders, high-ranking officials, UN leaders, and representatives of NGOs agreed that population and development are inextricably linked. A 20-year Program of Action, which bears the signatures of 170 countries, states that empowering women and meeting people's needs for education and health, including reproductive health, are necessary for both individual advancement and balanced development.
www.iisd.ca/linkages/Cairo/program/p00000.html

United Nations Special Session on HIV/AIDS: Keeping the Promise: Declaration of Commitment on HIV/AIDS
On June 25–27, 2001, heads of state and representatives of governments met at the United Nations General Assembly Special Session (UNGASS) dedicated to HIV/AIDS. UNGASS acknowledged that, in only 20 years, the HIV/AIDS pandemic has caused untold suffering and death worldwide, calling it a "global crisis" requiring "global action." At the meeting, heads of state and representatives of governments issued the Declaration of Commitment on HIV/AIDS with individual governments' detailed goals and plans for implementation as well as with the UN's commitment for assistance.
www.unaids.org/UNGASS/

Other Resources for HIV/AIDS Advocacy

▣ Publications/Training Resources

Advocacy in Action: A Toolkit to Support NGOs and CBOs Responding to HIV/AIDS. International HIV/AIDS Alliance, June 2002. www.aidsalliance.org

Advocacy Guide to the Declaration of Commitment on HIV/AIDS (UNGASS). International Council of AIDS Service Organizations (ICASO), 2001. www.icaso.org

Advocacy Guide for HIV/AIDS. International Planned Parenthood Federation (IPPF), June 2001. www.ippf.org

An Advocate's Guide to the International Guidelines on HIV/AIDS and Human Rights. International Council of AIDS Service Organizations (ICASO), 1997. www.icaso.org

HIV/AIDS NGO/CBO Support Toolkit. International HIV/AIDS Alliance, 2002. Website and CD-ROM can be accessed at www.aidsalliance.org

Networking for Policy Change: An Advocacy Training Manual. POLICY Project. Futures Group International, October 1999. www.policyproject.com

A New Weave of Power, People and Politics: The Action Guide for Advocacy and Citizen Participation. VeneKlasen, L. with V. Miller. World Neighbors, 2002. www.wn.org

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+)/Healthlink Worldwide, 1998. Single copies free. www.gnpplus.net and www.healthlink.org.uk

Training for Transformation, Book 4. Hope, A. and S. Timmel. Mango Press: Zimbabwe, 2000.

▣ Organizations

AEGiS (AIDS Education Global Information System): San Juan Capistrano, CA, USA
www.aegis.com
Home to the *HIV Daily Briefing*, AEGiS is probably the definitive online resource for HIV/AIDS-related information. AEGiS offers a keyword-searchable knowledge base with cutting-edge information via HIV/AIDS-specific publications and news sources from around the world, including a fact sheet section and a law library as well as collections of first-person narratives and bulletin boards by those living with HIV/AIDS.

Asian Harm Reduction Network (AHRN): Chiang Mai, Thailand
www.ahrn.net
AHRN works to reduce the harms associated with injection drug use in Asia, especially HIV infection, through networking, information sharing, advocacy, and program and policy development. AHRN makes available an extensive collection of harm reduction advocacy and training presentations and documents, including its own manual for preventing HIV infection among people who inject drugs. Indonesian and Thai versions are available for download from the website.

Asociación para la Salud Integral y Ciudadanía en América Latina y el Caribe (ASICAL): Guatemala City, Guatemala
www.sidalac.org.mx/asical/asical.html
ASICAL is a Latin American and Caribbean (LAC) regional technical resource network originally founded in 1997 by six organizations working in the areas of HIV/AIDS and MSM. Its members currently include organizations from Argentina, Brazil, Chile, Columbia, Ecuador, Guatemala, and Mexico and will expand to include organizations in other LAC countries. Its mission is to develop strategies and actions to achieve comprehensive health and full citizenship among gay men and other men in LAC who have sex with men. ASICAL's website includes situation analyses for different LAC countries, research, and advocacy tools.

The Body: New York, NY, USA
www.thebody.com
The Body uses the Internet to lower barriers between patients and clinicians, demystify HIV/AIDS and its treatment, improve patients' quality of life, and foster community through human connection. Documents are easy to find through a comprehensive site map, which contains a wealth of information from various sources in over 550 subject areas.

The Canadian HIV/AIDS Legal Network: Montréal, Canada
www.aidslaw.ca
The Canadian HIV/AIDS Legal Network produces and facilitates access to accurate, up-to-date information and analysis on legal, ethical, and policy issues related to HIV/AIDS in Canada and internationally. The network offers extensive resource collections on topics including HIV/AIDS and criminal law, confidentiality, prostitution, aboriginal communities, and immigration as well as online versions of all articles ever published in the *Canadian HIV/AIDS Policy & Law Review* and an annotated bibliography and literature review on legal, ethical, and human rights issues related to HIV/AIDS. The entire site is produced in French and English, and some materials are available in Romanian.

CDC National Prevention Information Network (NPIN): Rockville, MD, USA
www.cdcnpin.org
Formerly the National AIDS Clearinghouse, NPIN is the U.S. reference, referral, and distribution service for information on HIV/AIDS, STIs, and TB. A huge amount of information is available on this site, newly available in both English and Spanish. Highlights include tips and tools for a health communication strategy, information on at-risk populations and cultural competency, weekly updates on conferences and new funding opportunities, program evaluation materials, and surveillance data. NPIN also makes hundreds of informational brochures, fact sheets, and posters on HIV/AIDS, STIs, and TB available at no cost.

Church of the Province of Southern Africa HIV/AIDS Ministries: Bishopscourt, South Africa
www.anglicancommunion.org/special/hivaids/
With the tagline "HIV/AIDS is not a punishment from God," this visually appealing website includes a host of resource documents, including *Planning Our Response to HIV/AIDS: A Step-by-Step Guide to HIV/AIDS Planning for the Anglican Community* and *Our Vision, Our Hope: An All Africa Anglican AIDS Planning Framework*, which includes a pledge to the vision of future generations born and living in a world free from AIDS. The site has information on current initiatives in African countries and explains the steps for "putting HIV/AIDS on the map" in the Anglican community, with supporting interviews and documents at every step.

Global Health Council, Global AIDS Program: Washington, DC, USA
www.globalhealth.org
The mission of the Global AIDS Program is to share information and influence policy on global AIDS activities and issues, strongly supporting the critical role of NGOs in responding to the AIDS pandemic. *AIDSLink*, an excellent bimonthly newsletter reporting on global AIDS activities and issues related to the work of NGOs, is available on the program's website, along with a large volume of information about the Global Fund to Fight AIDS, Tuberculosis and Malaria. The program also publishes the annual *Global AIDS Directory*, which is available for purchase.

Global Network of People Living with AIDS (GNP+): Amsterdam, The Netherlands
www.gnpplus.net
Created and run by and for PLWHA, GNP+ works in three areas: advocacy (promoting access to treatment and combating stigma and discrimination); capacity building (grassroots organizing and training); and communication (co-organizing the international conference for PLWHA and maintaining an online forum). Its publication *Positive Development: setting up self-help groups and advocating for change. A manual for people living with HIV* is available on the website, which also has a newsletter and an excellent links section. The central secretariat of GNP+ has a board of 12 members representing various international regions. The network has six operational regional secretariats:

- Network of African People Living with HIV/AIDS (NAP+)
  Côte d'Ivoire, Kenya, and Zambia

- Asia-Pacific Network of People Living with HIV/AIDS (APN+)
  Singapore

- Caribbean Regional Network of People Living with HIV/AIDS (CRN+)
  Trinidad, West Indies

- European Network of People Living with HIV/AIDS (ENP+)
  ENP+ is the youngest of the regional networks affiliated with GNP+ and does not yet have a regional office

- People Living with HIV/AIDS in Latin America (REDLA+)
  Cali, Colombia, www.redla.org

- GNP+ North America (GNP+ NA)
  Washington, DC, USA

HIV/AIDS Advocacy Network (HAN): San Francisco, CA, USA
www.sfaf.org
The HIV Advocacy Network (HAN) is the grassroots community-organizing program of the San Francisco AIDS Foundation's (SFAF) Public Policy Department (click on the "Policy" tab on the website), organizing advocates to lobby effectively for rational and humane HIV-related policies at

the local, state, and federal levels. Issues of the *HIV Policy Watch* are available on the website along with legislative contact information, policy-related press releases, and HAN's advocacy manual *Standing Our Ground: Protecting Our Future Through Community Partnerships* (also available in Spanish). You can sign up to become a member of HAN on its website and receive action alerts via email that make it easy to send elected officials emails about an important HIV issue at the click of a button.

International Community of Women Living with HIV/AIDS (ICW): London, UK
www.icw.org
ICW is an international network open to all HIV-positive women regardless of age, ethnicity, religion, or sexuality. It produces *The Positive Woman's Survival Kit* that provides education, support, and resources by and for HIV-positive women, targeting women in developing countries who have little to no access to printed materials. The survival kit covers issues such as relationships with family and children, grief and loss, nutrition, staying healthy, safer sex, pregnancy and breastfeeding. The kit is available on the website in English, Spanish, and French.

International Council of AIDS Service Organizations (ICASO): Toronto, Canada
www.icaso.org
Based in Canada with regional secretariats on all five continents, ICASO connects international NGOs and works to strengthen NGOs with fewer resources so they can all better respond to the HIV/AIDS pandemic. ICASO is a good source for up-to-date information on vaccine development, GFATM, and UNGASS and makes available the *Advocacy Guide to the Declaration of Commitment on HIV/AIDS.*

International HIV/AIDS Alliance: Brighton, UK
www.aidsalliance.org
The alliance provides technical and financial support to NGOs and CBOs in developing countries. Its *HIV/AIDS NGO/CBO Support Toolkit* is a vast library of resources from a variety of organizations, well organized and designed for those establishing, managing, or studying NGO/CBO support programs.

The International Lesbian and Gay Association (ILGA): Brussels, Belgium
www.ilga.org
ILGA is a worldwide federation of national and local groups dedicated to achieving equal rights for lesbians, gay men, bisexuals, and transgendered people everywhere. Its website boasts an excellent and extensive country-by-country world survey database of the legal situations for gay, lesbian, and transgendered people. ILGA has more than 350 member organizations with representation on every continent. For region-specific information, visit www.ilga-europe.org and www.ilga-asia.org; for Latin America and the Caribbean, visit www.ilgalac.org. Many of its documents are also available in Spanish, and there is a sister Spanish-language site at www.cogailes.org that is available entirely in English, Spanish, Castellano, or Catalan.

National AIDS Treatment Advocacy Project (NATAP): New York, NY, USA
www.natap.org
NATAP works to educate individuals about HIV and hepatitis treatments and to advocate on the local, national, and international levels on behalf of all people living with HIV/AIDS and hepatitis. NATAP runs several programs in the New York City area: a community treatment education program that targets underserved communities of color throughout New York City, providing on-site services in English or Spanish; a monthly treatment training for case managers and other professionals working with people infected with HIV and hepatitis; a women's program at prisons and other venues that addresses barriers to treatment and women-specific issues, including disclosure, raising children, and negotiating safe sex; and regular public forums for medical

professionals and patients, including continuing medical education events. Resources available on the NATAP website include Daily Worldwide E-mail Treatment Updates on both HIV and HCV, downloadable archives of the radio show *Living Well with HIV and Hepatitis,* and newsletters, all available free.

Naz Foundation International (NFI): Lucknow, India
www.nfi.net
NFI promotes sexual health among MSM in South Asia and provides assistance to local networks of MSM to develop services aimed at reducing the risks of STI/HIV transmission. NFI offers a wide variety of culturally relevant educational materials in Bangala, English, Gujarati, Hindi, Kannada, Malyalam, Marathi, Oriya, Punjabi, Tamil, and Telegu and supports information-sharing between CBOs through SAMAN (South Asia MSM AIDS Network.)

Network of Sex Work Projects (NSWP): Mowbray, South Africa
www.nswp.org
NWSP provides opportunities for information sharing among organizations and projects that provide services to men, women, and transsexuals who work in the sex industry. It also works to promote the health and human rights of sex workers worldwide. Divided into sections, such as health and safety as well as rights and ethics, NWSP offers a resource collection that includes guides on HIV/AIDS and STI prevention, violence prevention, and issues particular to MSM and sex workers as well as links to relevant charters and sex workers' rights groups.

Project Inform: San Francisco, CA, USA
www.projinf.org
Project Inform provides free, confidential information on the diagnosis and treatment of HIV to anyone who asks; advocates for enlightened regulatory, research, and funding policies; and works to inspire people to make informed choices amid uncertainty. All of its publications are free, including *Introductory Treatment Packet* for people newly diagnosed with HIV and those exploring their treatment options for the first time. The packet is designed to help people overcome their initial anxiety about HIV and understand how they can take charge of their own health. Other publications include the journal *PI Perspectives; WISE Women,* a three-times-a-year newsletter by and for women living with HIV/AIDS; and fact sheets and other materials, most of which are also available in Spanish. Project Inform also runs the National HIV/AIDS Treatment Hotline at 1-800-822-7422.

Society for Women and AIDS in Africa (SWAA): Dakar, Senegal
www.famafrique.org/swaainter/anglais/sommairea.html
SWAA is a women-led Pan-African NGO that operates through country-specific chapters. It recognizes that women in Africa are critically affected by HIV/AIDS and that their vulnerability can be reduced through economic development, the formulation and implementation of appropriate policies, and respect of basic human rights. SWAA seeks to promote women's access to affordable, high-quality services and programs for reducing the risk of HIV infection and increasing women's capacity to cope with the impact of the HIV/AIDS epidemic.

UNAIDS (Joint United Nations Programme on HIV/AIDS): Geneva, Switzerland
www.UNAIDS.org
As the main advocate for global action on HIV/AIDS, UNAIDS draws together UNICEF, UNDP, UNFPA, UNESCO, WHO, the World Bank, UNDCP, and the ILO to catalyze, strengthen, and orchestrate the unique expertise, resources, and networks of influence that each of these organizations offers. UNAIDS has an extensive resource collection, including an excellent best practices case study library; a large collection of press releases, speeches, audio/video clips, and HIV/AIDS information; and an enormous searchable database of publications.

United Nations Development Program (UNDP): New York, NY, USA
A cosponsor of UNAIDS, UNDP offers knowledge, resources, and best practices from around the world to help build national capacity for managing initiatives aimed at people and institutions not usually involved in public heath. It also places HIV/AIDS at the center of national planning and budgets and promotes decentralized responses that support community-level action. Publications available for download from UNDP's website include a series on gender and the HIV/AIDS pandemic; issue papers on policy, programming, and sociocultural impact; books and workbooks on community-based responses; reports on integrating human rights with sustainable human development; and several training manuals.

Organization: _____

Contact Name: _____

Title: _____

Address: _____

_____

_____

Telephone: _____

Email: _____

Date: _____

Does your organization have an HIV/AIDS advocacy story you would like to share?

___ Yes   ___ No

If yes, please use the space below to briefly tell your story (e.g., goal, target audiences, challenges, successes, strategies used, partners). Please attach an additional sheet of paper, if necessary.

Evaluate the Manual

1. **How much do you agree or disagree with the following statements?**

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
I found the manual to be informative.	○	○	○	○	○
I found the advocacy stories to be inspiring.	○	○	○	○	○
I found the layout and format easy to use.	○	○	○	○	○

2. **Have you used the *Moments in Time* manual in the following ways?**

   a. In a training session? ___ Yes ___ No

   b. To help design an advocacy campaign? ___ Yes ___ No

   c. To assist in forming a network or partnership? ___ Yes ___ No

   d. Other? Please explain: _____ ___ Yes ___ No

3. **What were the three most useful advocacy stories? Please use the numbers 1, 2, and 3 to indicate your top choices, with "1" being the most useful.**

Women's Groups	*PLWHA Networks*	*FBOs*	*Access to Treatment*
___ FEIM	___ ACT UP	___ IMAU	___ TAC
___ NACWOLA	___ NAP+	___ The Balm	___ HST
___ W-TAG	___ NGEN+	___ In Gilead	___ CPSA
___ SWAK	___ TNP+	___ NPC	___ ANC National
___ SANGRAM			___ Health Committee

4. **The *Moments in Time* manual focused on women, associations of people living with HIV/AIDS, faith-based organizations, and access to treatment. What priority areas, sectors, or issues should we focus on in the future?**

5. **Did you use the companion manual, *Networking for Policy Change: An Advocacy Training Manual*?**

   ___ Yes   ___ No   If no, why not?

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