

Networking for Policy Change: TB/HIV Advocacy Training Manual

“TB is too often a death sentence for people with AIDS.

It does not have to be this way.”

-Nelson Mandela, International conference on HIV /AIDS, Bangkok, Thailand, July 2004



CONSTELLA FUTURES



World Health
Organization

Stop TB Partnership

Acknowledgments

This manual is an adaptation of *Networking for Policy Change: An Advocacy Training Supplement* (POLICY Project, 1999; available for download at www.policyproject.com). Constella Futures gratefully acknowledges the contributions of the original authors.

Constella Futures and World Health Organization would also like to acknowledge Ratha Loganathan, Emily Sonneveldt, and Sarah Arnett from Constella Futures and Haileyesus Getahun from WHO Headquarters for contributing the technical portions to this manual and Penney Davis and Linda Gough of Constella Futures for editing and formatting. The authors would also like to acknowledge the following WHO staff for providing comments and participating in the technical review process: Ian Grubb (Headquarters, Geneva, Switzerland), Joumana Hermez (WHO Regional Office for the Eastern Mediterranean, Cairo, Egypt), Pillar Ramond (Pan American Health Organization, Washington DC, USA), Joanne Sheppard (Headquarters, Geneva, Switzerland), Michael Luhan (Stop TB Partnership Secretariat, Geneva, Switzerland), and Carol Francis (Stop TB Partnership Secretariat, Geneva, Switzerland). The authors would also like to acknowledge Leah Wanjama for her technical review and for facilitating the field testing of the manual. Participants of the TB/HIV advocacy training workshops, which were held in July 2003 in Nairobi, Kenya and May 2005 in Cape Town, South Africa particularly Lilian Mwereko from Uganda and Lucy Chesire from Kenya are acknowledged for their valuable contribution to finalize the manual

Table of Contents

Introduction	5
Overview	10
Section I. The Power of Numbers: Networking for Impact	16
Unit 1 What Are Advocacy Networks?	18
Unit 2 Effective Communication: Understanding One Another	28
Unit 3 Cooperation Not Competition: Building a Team	36
Unit 4 Decision Making: Reaching Group Consensus	42
Unit 5 Mission Statements: Creating a Common Purpose	46
Unit 6 Putting It All Together: Managing the Network	50
Section II. Actors, Issues, and Opportunities: Assessing the Policy Environment	56
Unit 1 The Policy Process: Government in Action	58
Unit 2 Decision Making for TB/HIV: Analyzing the Policy Climate	64
Unit 3 Prioritizing Policy Issues: Making the Best Matches	70
Section III. The Advocacy Strategy: Mobilizing for Action	75
Unit 1 What Is Advocacy?	76
Unit 2 Issues, Goals, and Objectives: Building the Foundation	86
Unit 3 Target Audiences: Identifying Support and Opposition	93
Unit 4 Messages: Informing, Persuading, and Moving to Action	99
Unit 5 Data Collection: Bridging the Gap between Communities and Policymakers	109
Unit 6 Fundraising: Mobilizing Resources	120
Unit 7 Implementation: Developing an Action Plan	124
Unit 8 Monitoring and Evaluation	129
Handouts	136
References	225

Introduction

“TB and HIV (TB/HIV)--two diseases--one patient. For the first time, the goal of working together as one community seems truly achievable, with broad representation and contribution from both the HIV and the TB communities. It is a joint action that works – not TB or HIV programs working in isolation.”

Participants, Third Global TB/HIV
Working Group Meeting
Montreux, Switzerland, June 2003

Purpose of the Manual

It is through advocacy—a set of targeted actions in support of a specific cause—that a supportive and self-sustaining environment for TB/HIV (the intersecting epidemics of TB and HIV) goals can be created. This training manual was prepared to help representatives of nongovernmental organizations (NGOs) and other formal groups of civil society to form and maintain advocacy networks and develop effective TB/HIV advocacy skills. The manual’s tools and approaches can be used to affect TB/HIV policy decisions at the international, national, regional, and local levels.

This document is adapted from *Networking for Policy Change: An Advocacy Training Manual*, a resource for facilitators of family planning and reproductive health advocacy issues worldwide. The training manual includes information on networking, communications, and policy environments; exercises on conceptualizing, implementing, monitoring, and evaluating advocacy campaigns; and relevant materials for advocates. Facilitators can use the training techniques employed in the manual in various contexts. However, this manual is specifically adapted for trainings when TB/HIV is the focus of advocacy.

Why advocacy manual on TB/HIV?

TB and HIV are global emergencies whose deadly interaction affect millions and threaten global public health. HIV infection is a leading risk factor for TB through promoting the progression of latent and recent infections of *Mycobacterium tuberculosis* (MTB) into active disease. It also increases the rate of recurrence of TB. The number of TB cases has been on the rise over the last two decades coinciding with increase in adult HIV prevalence rate particularly in sub-Saharan Africa, amounting up to a ten fold increase in some countries. HIV is the main reason for failure to meet TB control targets in high HIV settings. Likewise, TB is among the leading causes of death among people living with HIV/AIDS.

Collaborative TB/HIV activities can improve TB and HIV control. Collaborative TB/HIV activities have the objectives of reciprocating between TB and HIV/AIDS programs, reducing the burden of TB among persons living with HIV/AIDS (PLHAs) and reducing the burden of HIV among patients with TB. Implementation of collaborative TB/HIV activities need to be

accelerated in countries to address the epidemic of HIV related TB. Sound implementation of these activities requires the collaboration between TB and HIV/AIDS programs at all levels. Joint action is needed now to provide optimum patient centered TB and HIV prevention and care. The creation of this training manual is one of the first advocacy steps to make the joint TB/HIV action effective at global, regional, national and local levels. This manual will serve to solicit political and popular support and resource mobilization to accelerate the implementation of collaborative TB/HIV activities.

Who Should Use This Manual?

This advocacy manual is intended to reach individuals and institutions at national and local levels who advocate for TB and HIV.

How the Manual Is Organized

The manual is based on the principle that advocacy strategies and methods can be learned. It is organized around a well-developed model—tested over time and within diverse cultures—for accomplishing advocacy objectives. The components of the model are the same regardless of the advocacy goals—whether to build district capacity to implement collaborative TB/HIV activities or to enhance and expand PLHAs support group’s involvement in collaborative TB/HIV activities.

Following a general overview of TB/HIV issues, the following three sections are addressed:

- **The Power of Numbers : Network for Impact**
- **Actors, Issues, and Opportunities: Assessing the Policy Environment**
- **The Advocacy Strategy: Mobilizing for Action**

The building blocks of advocacy are the formation of networks, the identification of political opportunities, and the organization of campaigns. The manual includes a section on each of these building blocks, with specific subjects presented in individual units. Each section begins with a general introduction to the topic. Units within each section contain background notes, learning objectives, and handouts. The approximate time required to complete each unit is indicated as are the needed materials and preparation. Within each unit, activities such as role plays, discussions, and brainstorming are presented to help participants internalize their learning. Each unit concludes with a brief summary and a preview of the next unit.

While the manual can be used in its entirety, it is designed to be used in sections depending on the particular needs of the network. For example, if a group of NGOs has already formed a network and has decided it needs a better understanding of both the policy process and how to become skilled advocates, a workshop could be organized on Sections II and III. To take another example, if NGOs are interested in forming an advocacy network or making their existing network function more effectively, it would be appropriate to organize a workshop on Section I. By focusing only on the introduction to each section and the background notes for each unit, networks can also use the manual as a general reference on advocacy without undertaking any specific training activities.

Training Methodology

This manual is based on the following adult learning principles:

- The learning is self-directed.
- It fills an immediate need and is highly participatory.
- Learning is experiential (i.e., participants and the facilitator learn from one another).
- Time is allowed for reflection and corrective feedback.
- A mutually respectful environment is created between facilitator and participants.
- A safe atmosphere and comfortable environment are provided.

Training techniques used in this manual include the following:

Presentations - activities conducted by the facilitator or a resource specialist to convey information, theories, or principles;

Case Study Scenarios - written descriptions of real-life situations used for analysis and discussion;

Role-Plays - two or more individuals enacting parts in scenarios as related to a training topic;

Simulations - enactments of real-life situations; and

Small Group Discussions - participants sharing experiences and ideas or solving a problem together.

Role of the Facilitator

It is the responsibility of the facilitator to present each unit's background material and activities as clearly as possible. Skills used to enhance communication include the following:

Nonverbal Communication

- Maintain eye contact with everyone in the group when speaking. Try not to favor certain participants.
- Move around the room without distracting the group. Avoid pacing or addressing the group from a place where you cannot be easily seen.
- React to what people say by nodding, smiling, or engaging in other actions that show you are listening.
- Stand in front of the group, particularly at the beginning of the session. It is important to appear relaxed and at the same time be direct and confident.

Verbal Communication

- Ask open-ended questions that encourage responses. If a participant responds with a simple yes or no, ask "Why do you say that?"
- Ask other participants if they agree with a statement someone makes.
- Be aware of your tone of voice. Speak slowly and clearly.
- Avoid using slang or other "special" language.
- Be sure that participants talk more than you do.
- Let participants answer each others' questions. Say "Does anyone have an answer to that question?"

- Encourage participants to speak and provide them with positive reinforcement.
- Paraphrase statements in your own words. You can check your understanding of what participants are saying and reinforce statements.
- Keep the discussion moving forward and in the direction you want. Watch for disagreements and draw conclusions.
- Reinforce statements by sharing a relevant personal experience. You might say “That reminds me of something that happened last year...”
- Summarize the discussion. Be sure that everyone understands the main points.

Effective facilitation includes the following:

Setting the Learning Climate

- Read each unit and review all materials and activities before each training session so that you are fully comfortable with the content and process.
- Start on time and clearly establish yourself as the facilitator by calling the group together.
- Organize all the materials you need for the session and place them close at hand, stay within the suggested time frames.
- Gain participants’ attention and interest by creating comfort between yourself and them.
- Anticipate questions.
- Prepare responses and examples to help move the discussion forward.

Presenting the Objectives

- Provide a link between previous units and the current one.
- Use the background notes that begin each unit to introduce the topic under consideration.
- Inform participants of what they will do during the session to achieve the unit’s objectives.

Initiating the Learning Experience

- Introduce, as appropriate, an activity in which participants experience a situation relevant to the objectives of the unit.
- Let participants use the experience as a basis for discussion during the next step.
- If you begin a unit with a presentation, follow it with a more participatory activity.

Reflecting on the Experience

- Guide discussion of the experience.
- Encourage participants to share their reactions to the experience.
- Engage participants in problem-solving discussions.
- See that participants receive feedback on their work from each other and from you.

Discussing Lessons Learned

- Ask participants to identify key points that emerged from the experience and the discussion.
- Help participants draw general conclusions from the experience. Allow time for reflection.

Applying Lessons Learned to Real-life Situations

- Encourage participants to discuss how the information learned in the activity will be helpful in their own work.

- Discuss problems participants might experience in applying or adapting what they have learned to their own or different situations.
- Discuss what participants might do to help overcome difficulties they encounter when applying their new learning.

Providing Closure

- Briefly summarize the activities at the end of each unit.
- Refer to the objective(s) and discuss whether and how they were achieved.
- Discuss what else is needed for better retention or further learning in the subject area.
- Provide linkages between the unit and the rest of the workshop.
- Help participants leave with positive feelings about what they have learned.

Covering All the Details

- Prepare all training materials (resources for research, reference materials, handouts, visual aids, and supplies) and deal with logistics (venue, tea breaks, and audio-visual equipment) in advance.
- Clarify everyone's roles and areas of responsibility if other facilitators are helping to conduct the training. Meet with the co-facilitators daily to monitor the progress of the workshop and to provide each other with feedback.
- Ask participants to evaluate the training both daily and at the end of the workshop.
- Plan follow-up activities and determine additional training needs.

General Guidance to the Facilitator

- Use the materials flexibly. Many of the notes and handouts can be used in more than one activity.
- In many cases, where the manual uses an approach that is applicable to all audiences, the activities need not be changed.
- Encourage participants to provide examples of their own experiences and advocacy opportunities of TB/HIV issues. The issues vary from country to country and community to community, and the voices of workshop participants will make the subject real and create and maintain the advocacy programs that are so critical to society.
- Many advocates are already fighting for greater attention to TB/HIV concerns and you can bring out these experiences to enrich the training dialogue.

OVERVIEW

TB and HIV/AIDS ISSUES

A. The Global TB and HIV/AIDS Epidemic^{1,2}

- At the end of 2005 a total of 40.3 million people were estimated to be living with HIV/AIDS, of whom 25.8 million (64%) were in sub-Saharan Africa and 7.4 million (18%) in South and South-East Asia.
- Tuberculosis, although curable, is one of the most common causes of HIV-related illness and deaths. By the end of 2005, sixteen million adults living with HIV/AIDS were estimated to be co-infected with *Mycobacterium tuberculosis*, with 79 percent of those co-infected living in sub-Saharan Africa and 13 percent living in South East Asia.

B. How HIV Fuels the Tuberculosis Epidemic^{2,3}

- HIV fuels the tuberculosis epidemic in several ways. HIV promotes progression to active TB both in people with recently acquired and with late *M. tuberculosis* infections. HIV is the most powerful known risk factor for reactivation of latent tuberculosis infection to active disease. HIV infected people are more susceptible to TB infection when they are exposed to *M. tuberculosis*.
- HIV not only increases the number of TB cases, but also alters the clinical course of TB disease. As HIV-related immunosuppression increases, the clinical pattern of TB disease changes, with increasing numbers of smear-negative pulmonary TB and extra-pulmonary TB cases. TB is more likely to be disseminated and more difficult to diagnose as immunosuppression progresses.
- Escalating tuberculosis case rates over the past decade in many countries in sub-Saharan Africa and in parts of South East Asia are largely attributable to the HIV epidemic. Since the mid-1980s, in many African countries, including those with well-organized programs, annual tuberculosis case notification rates have risen up to fourfold, reaching peaks of more than 400 cases per 100,000 population. Up to 70 percent of patients with sputum smear-positive pulmonary tuberculosis are HIV-positive in some countries in sub-Saharan Africa.

C. Current Tuberculosis Control Strategy and Targets^{4,5,6}

- The WHO's Stop TB Strategy has four objectives: achieve universal access to quality diagnosis and patient centered treatment, reduce the human suffering and socioeconomic

¹ UNAIDS & WHO. 2005. *AIDS Epidemic Update*. Geneva: UNAIDS/WHO.

² Adapted from WHO. 2005. *Guidelines for Implementing Collaborative TB & HIV Programme Activities*. Geneva: WHO.

³ Adapted from WHO. 2004. *Strategic Framework to Decrease the Burden of TB/HIV*. Geneva: WHO.

⁴ Adapted from WHO. 2004. *Interim Policy on Collaborative TB/HIV Activities*. Geneva: WHO.

⁵ Adapted from WHO. 2006. *The Stop TB Strategy*. Geneva: WHO.

⁶ Adapted from WHO 2006. *The Global Plan to Stop TB, 2006-2015*. Geneva: WHO

burden associated with TB, protect vulnerable populations from TB, TB/HIV and multi-drug-resistant TB, and support development of new tools and enable their timely and effective use.

The components of the strategy and the implementation approach are:

- Pursue high-quality DOTS expansion and enhancement
 - Political commitment with increased and sustained financing
 - Case detection through quality-assured bacteriology
 - Standardized treatment, with supervision and patient support
 - An effective drug supply and management system
 - Monitoring and evaluation system and impact measurement
 - Address TB/HIV, MDr-TB and other challenges
 - Implement collaborative TB/HIV activities
 - Prevent and control MDR-TB
 - Address prisoners, refugees and other high-risk groups and situations
 - Contribute to health system strengthening
 - Actively participate in efforts to improve system-wide policy, human resources, financing, management, service delivery and information systems
 - Share innovations that strengthen systems, including the Practical Approach to Lung Health (PAL)
 - Adapt innovations from other fields
 - Engage all care providers
 - Public–Public and Public–Private mix (PPM) approaches
 - International Standards for Tuberculosis Care (ISTC)
 - Empower people with TB, and communities
 - Advocacy, communication and social mobilization
 - Community participation in TB care
 - Patients’ Charter for Tuberculosis Care
 - Enable and promote research
 - Program-based operational research
 - Research to develop new diagnostics, drugs and vaccines
- The Global Plan to Stop TB, 2006-2015 is a comprehensive assessment of the action and resources needed to implement the Stop TB Strategy and to achieve the following targets, also found in the Millennium Development Goal 6: to detect 70 percent of sputum smear positive patients and cure 85 percent of those detected by 2005; reduce prevalence of and deaths due to TB by 50% relative to 1990 by 2015; and eliminate TB as a public health problem (1 case per million population) by 2050.

D. Toward Universal Access: WHO's Priorities in HIV/AIDS⁷

In 2005, leaders of the G8 countries agreed to “work with WHO, UNAIDS and other international bodies to develop and implement a package for HIV prevention, treatment and care, with the aim of as close as possible to universal access to treatment for all those who need it by 2010.” At the June 2006 General Assembly High Level Meeting on AIDS, United Nations

⁷ WHO's Contribution to Scaling Up towards Universal Access to HIV/AIDS Prevention, Treatment and Care: WHO Plan 2006-2010.

Member States agreed to work toward the broad goal of “universal access to comprehensive prevention programs, treatment, care and support” by 2010.

WHO's HIV/AIDS work in the period 2006-2010 is structured around five Strategic Directions, each of which represents a critical area that the health sector must invest in if countries are to make significant progress towards achieving universal access. Within each strategic direction WHO is concentrating its efforts on a limited number of priority health sector interventions, where WHO has demonstrated a comparative advantage and where there is sound evidence that the priority interventions have the potential to make a significant impact.

These strategic directions and their associated priority interventions are:

Strategic Direction 1: Enabling people to know their HIV status through confidential HIV testing and counseling

Priority interventions:

- Voluntary HIV counseling and testing (VCT)
- Provider-initiated HIV testing and counseling (PITC)
- Infant HIV diagnosis and family counseling and testing

Strategic Direction 2: Maximizing the health sector's contribution to HIV prevention

Priority interventions:

- Prevention of sexual transmission of HIV
- Prevention for people living with HIV/AIDS
- Prevention of mother to child transmission (PMTCT) of HIV/AIDS
- Prevention of HIV transmission through injecting drug use (harm reduction)
- Prevention of HIV transmission in health care settings
- Assessment and development of new HIV prevention technologies (including vaccines, microbicides, male circumcision and pre-exposure prophylaxis)

Strategic Direction 3: Accelerating the scale up of HIV/AIDS treatment and care

Priority interventions:

- Antiretroviral therapy for the management of pediatric and adult HIV/AIDS
- Prevention and management of opportunistic infections, other HIV-related conditions and co-morbidities
- HIV/AIDS care, including nutrition, palliative care and end of life care
- Linking HIV/AIDS and tuberculosis services

Strategic Direction 4: Strengthening and expanding health systems

Priority interventions:

- Leadership and stewardship
- National strategic planning and management
- Procurement and supply management
- Laboratory strengthening
- Human resource development and management
- Strategies for sustainable financing

Strategic Direction 5: Investing in strategic information to guide a more effective response

Priority interventions:

- Surveillance of HIV/AIDS and sexually transmitted infections (STIs)
- HIV drug resistance surveillance and monitoring of antiretroviral therapy (ART) programs
- Monitoring and evaluation of and reporting on the health sector's contribution in scaling up towards universal access
- Operational research

For each of the priority interventions, WHO will:

- Advocate for action and mobilize partnerships, including the empowerment of people living with HIV/AIDS
- Synthesize existing knowledge, support operational research and disseminate the evidence base on the effectiveness of each intervention and models of good practice for service delivery;
- Articulate global and regional policy options;
- Set norms and standards and develop, update and adapt assessment, policy, program, training and monitoring and evaluation tools and guidelines for their implementation;
- Provide technical assistance to countries and help build sustainable institutional capacity to scale up national HIV/AIDS responses;
- Support the monitoring and evaluation of the implementation of interventions, including assisting countries to select indicators and set targets; and
- Facilitate the integration of gender and equity issues into the design, delivery and monitoring and evaluation of the interventions.

E. The International Response to HIV related TB: An Evolving Approach³

- The Global TB/HIV Working Group of the Stop TB Partnership was established to coordinate the global efforts to address the dual TB and HIV epidemics. The Global TB/HIV Working Group has been instrumental in coordinating the global response and has developed the interim policy and the minimum package of guidelines to address the HIV-related TB epidemic.
- There is increasing international commitment to improve access to treatment of people living with HIV/AIDS, which accrues its benefits to HIV infected patients with TB.

F. Objectives and Recommended Activities for Collaborative TB/HIV Activities⁴

- The goal is to ensure that HIV prevention, care, and treatment should be a priority concern of TB programs and that TB treatment, care, and prevention should be a priority concern of national HIV/AIDS control programs.
- The objectives of collaborative TB/HIV activities are: (1) to establish the mechanisms for collaboration between tuberculosis and HIV/AIDS programs; (2) to decrease the burden of tuberculosis in PLHAs; and (3) to decrease the burden of HIV in patients with tuberculosis. The recommended activities are presented in Table 1.

Table 1. Recommended Collaborative TB/HIV Activities.

<p>A. Establish the Mechanism for Collaboration</p> <p>A1. Set up a coordinating body for TB/HIV activities effective at all levels</p> <p>A2. Conduct surveillance of HIV prevalence among patients with tuberculosis</p> <p>A3. Carry out joint TB/HIV planning; conduct monitoring and evaluation</p>
<p>B. Decrease the Burden of Tuberculosis in PLHAs</p> <p>B1. Establish intensified tuberculosis case-finding</p> <p>B2. Introduce isoniazid preventive therapy</p> <p>B3. Ensure tuberculosis infection control in health care and congregate settings</p>
<p>C. Decrease the Burden of HIV in Patients with Tuberculosis</p> <p>C1. Provide HIV testing and counseling</p> <p>C2. Introduce HIV prevention methods</p> <p>C3. Introduce co-trimoxazole preventive therapy</p> <p>C4. Ensure HIV/AIDS care and support</p> <p>C5. Introduce antiretroviral therapy.</p>

G. Definition of Countries for Collaborative TB/HIV Activities

- **Definition of Category I:** Countries in which the national adult HIV prevalence rate is greater than or equal to 1 percent (generalized epidemic level) **OR** in which the national HIV prevalence among a certain population group (tuberculosis patients, injecting drug users, etc) is greater than or equal to 5 percent (concentrated epidemic level).
- **Definition of Category II:** countries in which the national adult HIV prevalence rate is below 1 percent **AND** in which there are administrative areas with an adult HIV prevalence rate of greater or equal to 1 percent.
- **Definition of Category III:** Countries in which the national adult HIV prevalence rate is below 1 percent **AND** in which there are no administrative areas with an adult HIV prevalence rate of greater than or equal to 1 percent.

H. Recommendations to commence collaborative TB/HIV activities

- 1. Category I Countries:** should implement all collaborative TB/HIV activities described on the table above.
- 2. Category II Countries:** should implement all collaborative TB/HIV activities in those administrative areas with adult HIV prevalence rate $\geq 1\%$ and should implement activities as category III countries in other parts of the country.

3. Category III Countries: should implement the activities aimed at decreasing the burden of TB in PLHAs (intensified TB case finding, isoniazid preventive therapy, and TB infection control in health care and congregate settings)

I. Priority countries for TB/HIV (2006)

The TB/HIV priority countries list in 2006 contained 63 countries including all countries with an adult HIV prevalence $\geq 1\%$, and five additional countries (Brazil, China, India, Indonesia and Viet Nam), which together make up 98% of the global TB/ HIV burden.

The complete list includes:

African region: Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Central African Republic, Chad, Côte d'Ivoire, Congo, DR Congo, Djibouti, Equatorial Guinea, Eritrea, Ethiopia, Gabon, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Liberia, Madagascar, Mali, Malawi, Mozambique, Namibia, Niger, Nigeria, Rwanda, Sierra Leone, South Africa, Somalia, Swaziland, Sudan, Togo, UR Tanzania, Uganda, Zambia and Zimbabwe.

Region of the Americas: Bahamas, Barbados, Belize, Brazil, Dominican Republic, Guatemala, Guyana, Haiti, Honduras, Jamaica, Suriname, Panama and Trinidad & Tobago

South-East Asia Region: India, Indonesia, Myanmar, and Thailand

Western Pacific Region: Cambodia, China, and Viet Nam

Europe Region: Ukraine, Russian Federation and Estonia.