

Networking for Policy Change A Participant's Guide



Networking for Policy Change: TB/HIV Participant's Guide

"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 and AIDS, Bangkok, Thailand, July 2004.



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Acknowledgments

This manual is an adaptation of *Networking for Policy Change: An Advocacy Training Supplement (POLICY Project, 1999; available for download at <u>www.policyproject.com</u>). 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

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1. Background on TB/HIV

1.1. TB and HIV: two diseases, one patient

- 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 (Figure 1). HIV is the main reason for failure to meet TB control targets in high HIV settings. Likewise, TB is a major cause of death among people living with HIV/AIDS.

Figure 1. TB notification rates (per 100,000 population) in selected sub-Saharan African countries, 1980-2000.



1.2. Global TB and HIV/AIDS Epidemics

- 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.

1.3. TB/HIV or HIV/TB

A third of the population of the world is infected with *Mycobacterium tuberculosis*, the bacteria that causes tuberculosis. An estimated 14 million people are infected with both TB and HIV. TB/HIV and HIV/TB is used interchangeably to denote the intersecting epidemic of TB and HIV.



1.4. HIV Fuels the Tuberculosis Epidemic

- 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 SE 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 case/100,000 populations. Up to 70% of patients with sputum smear-positive pulmonary tuberculosis are HIV-positive in some countries in sub-Saharan Africa.

1.5. The WHO's Stop TB Strategy and Global Plan to Stop TB

- 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 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, Address TB/HIV, MDr-TB and other challenges, Contribute to health system strengthening, Engage all care providers, Empower people with TB, and communities, Enable and promote research
- 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.
- The Millennium Development Goals embrace the WHO tuberculosis targets and also aim to decrease the prevalence and death rates of TB by 50% of the year 2000 estimates by 2015.

Facts about TB/HIV

- AIDS kills more than 8000 people every day worldwide.
- More than 5000 people die from TB every day.
- TB is the leading killer of people infected with HIV.
- TB causes at least 11% of AIDS deaths and possibly as many as 50%.
- Up to 50% of people with HIV or AIDS develop TB.
- Worldwide, 14 million people are co-infected with TB and HIV– 70% of them are concentrated in Africa.
- In some regions of Africa, 75% of TB patients are HIV-infected.
- TB can be successfully treated even if someone is HIV-infected.
- In a given year, people living with HIV are up to 50 times more likely to develop TB than those who are not HIV-infected.
- More people are dying of TB today than ever before.

1.6. HIV/AIDS Universal Access Strategy

 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 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.

1.7. The International Response to HIV related TB: An Evolving Approach

- 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.

1.8. Collaborative TB/HIV activities

- Collaborative TB/HIV activities are activities recommended by the Interim Policy on TB/HIV to address the dual epidemic of TB and HIV. The activities have the objectives of creating the mechanism of collaboration between TB and HIV/AIDS programs, reducing the burden of TB among People Living With HIV/AIDS (PLHA) and reducing the burden of HIV among TB patients.
- 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.
- HIV prevention, care and treatment should be a priority concern of TB programs and TB treatment, care and prevention should be a priority concern of national HIV/AIDS control programs.

1.9. Recommended Collaborative TB/HIV Activities

A. Establish the Mechanism for Collaboration

A1. Set up a coordinating body for TB/HIV activities effective at all levels

A2. Conduct surveillance of HIV prevalence among tuberculosis patients

A3. Carry out joint TB/HIV planning; conduct monitoring and evaluation

B. Decrease the Burden of Tuberculosis in People Living with HIV/AIDS

- B1. Establish intensified tuberculosis case-finding
- B2. Introduce isoniazid preventive therapy

B3. Ensure tuberculosis infection control in health care and congregate settings

C. Decrease the Burden of HIV in Tuberculosis Patients

- C1. Provide HIV testing and counseling
- C2. Introduce HIV prevention methods

C3. Introduce co-trimoxazole preventive therapy

C4. Ensure HIV/AIDS care and support

C5. Introduce antiretroviral therapy.

1.10. 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 II:** 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.

1.11. Recommendations to commence collaborative TB/HIV activities

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

• **Category III countries:** should implement the activities aimed at decreasing the burden of TB in PLHA (Intensified TB case finding, Isoniazid preventive therapy and TB infection control in health care and congregate settings).

1.12. Collaboration not integration of TB and HIV control programs

- The interim policy on collaborative TB/HIV activities does not call for the institution of a new specialist or disease control program for addressing TB/HIV. Collaboration between TB and HIV/AIDS disease programs, rather than creating a new separate disease control program or integrating the two programs, should be the mainstay to deliver collaborative TB/HIV activities.
- Evidence on program collaboration and joint interventions has largely been generated through the ProTEST projects in Zambia, Malawi and South Africa, other parts of Africa and elsewhere. Strong partnerships were forged within the health system at all levels, and helped to improve health services delivery through improved and expanded referral networks and better use of resources.
- At the service delivery level joint delivery of TB and HIV prevention and care services should be carried out with a patient-centered approach.

1.13. Barriers and Opportunities for TB & HIV/AIDS Program Collaboration

Barriers to TB & HIV/AIDS Program Collaboration

- Lack of political commitment at both international and national level
- Differences in TB and HIV program structure, culture and philosophy
- Reluctance in TB and HIV programs to broaden their focus
- Lack and inequitable distribution of resources between TB and HIV programs
- Lack of awareness of the link between TB & HIV
- Lack of capacity and prioritization within NACP
- Lack of communications between HIV and TB programs at international, national and district level
- Health care staff attitudes to and awareness of the issue of TB among HIV-infected people
- Stigma and discrimination associated with both diseases

Factors to boost collaboration between TB and HIV collaboration

- A National Action Plan
- Utilization of existing organizational structure
- The sharing of expertise and experience between HIV/AIDS and TB programs
- A strengthen referral system
- Joint training of staff
- Sharing of resource sand joint financial planning
- Formulation of joint health education messages
- Issues of HIV/AIDS care and support
- TB and HIV care prevention packages

2. What is Advocacy?

• A major challenge in continuing to harmonize the response to TB & HIV is how to attract and maintain attention for TB on the part of the AIDS

community and vice versa. There are as many definitions of advocacy as there are groups and networks advocating. However, each definition shares common language and concepts. Advocacy is first and

Advocacy *is a set of targeted actions directed at decision makers in support of a specific policy issue.*

foremost a process, occurring over unspecified amounts of time, sometimes brief and often lengthy. Advocacy is also strategic and targets well-designed activities to key stakeholders and decision makers. And lastly, advocacy is always directed at influencing policy, laws, regulations, programs, or funding—decisions made at the upper-most levels of public or private sector institutions.

 Advocacy is both a science and an art. It includes both single-issue, time limited campaigns as well as ongoing work undertaken around a range of issues. Advocacy activities may be conducted at the national, regional, or local level.

2.1. Definitions of Advocacy

• "Advocacy is winning the support of key constituencies in order to influence policies and spending, and bring about social change. Successful advocates usually start by identifying the people they need to influence and planning the best ways to communicate with them. They do their homework on an issue and build a persuasive case. They organize networks and coalitions to create a groundswell of support that can influence key decision-makers. They work with the media to help communicate the message."

- WHO, Practical Guide to TB Advocacy

"Advocacy is the act or process of supporting a cause or issue. An advocacy campaign is a set
of targeted actions in support of a cause or issue. We advocate a cause or issue because we
want to build support for that cause or issues, influence others to support it or try to influence
or change legislation that affects it."

— International Planned Parenthood Federation, IPPF Advocacy Guide

• "Advocacy is the art of influencing individuals or collective decision- or policy-making to effect a positive change in an issue or situation".

- POLICY Project workshop participants, March 1997, Accra, Ghana

2.2. Advocacy and Related Concepts

The following chart illustrates the difference between advocacy and several related concepts. Advocacy can usually be distinguished from other approaches in that the objective of advocacy is policy change.

Approach	Actors/Organizers	Target Audience	Objective	Strategies	Measuring Success
Information, Education, Communication (IEC)	Service providers	Individuals Segments of a community (women, men, youth)	Raise awareness and change behavior	Sorting by audience Mass media campaigns Community outreach Traditional media	Change in knowledge or skills (behavior change) Process indicators Focus groups Service statistics
Public Relations	Commercial institutions	Consumers	Improve the company's image and increase sales	Large-scale advertising (radio, TV, print media) Public events Sponsoring a "charity"	Improved public perception Increased sales Increased market share
Community Mobilization	Community members and organizations	Community members and leaders	Build a community's capacity to rank needs and take action	Door-to-door visits Village meetings Participatory Rural Appraisal (PRA)	Issue- specific process and outcome indicators Quality of participation
Advocacy	NGOs/networks Special interest groups Professional associations	Public institutions and policy makers, Communities/community leaders	Change policies, programs, and resource allocation	Focus on policymakers with the power to affect advocacy objective High-level meetings Public events (debates, protests, etc.)	Process indicators Media scans Key informant interviews Focus groups Opinion surveys

2.3. Mobilizing for action: Advocacy Networks are needed

- Advocacy should be a collective action through networking. Networks are universal. Whether acknowledged as such or not, most people belong to formal or informal groups—or networks—organized around family life, jobs, religious activities, or recreational interests. People routinely use their personal and professional networks for a variety of reasons—looking for a job, raising funds for a school or community center, campaigning for a politician, or pressing leaders to expand the services available at the local clinic.
- Networks are invaluable in policy advocacy because they create structures for organizations and individuals to share ownership of common goals. In TB/HIV advocacy, a network's membership usually will include representatives of PLHA support groups, NGOs, women's groups, community organizations, and professional associations made up of nurses, midwives, networks are invaluent.

physicians, or lawyers. Local religious and traditional leaders are potential members whose perspective influence could be invaluable in achieving the network's objectives.

 A network's advocacy issues will depend upon local political realities and

Advocacy network and names

Advocates in different countries use different names for their advocacy groups—some are called networks and others are called coalitions. The structures and procedures ascribed to these groups also vary. For example, in Bolivia, networks are highly structured and ongoing while in Romania coalitions are structured and ongoing and networks are informal and loose. The name chosen by an advocacy group is unimportant. What matters is that the entire membership understands and agrees on the name, the structure, and the operating procedures.

the opportunities for change that exist as well as the specific interests of network members. The possibilities with respect to TB/HIV are numerous, ranging from ensuring that antiretroviral therapy to eligible HIV-positive tuberculosis patients are provided to encouraging stakeholders to support TB/HIV operational research on country specific issues to develop the evidence base for efficient and effective implementation for collaborative TB/HIV activities.

• To be successful advocates, networks need to be well organized and operate efficiently. Their founding members have to bring together the resources, time, energy, and talents of many different people and organizations and then skillfully take advantage of opportunities to influence the policy process on behalf of their goals and objectives. When they succeed, networks help create a supportive and self-sustaining environment for TB/HIV activities

2.4. Examples of advocacy networks

- The Global AIDS Alliance (GAA) is a nonprofit organization dedicated to a collaborative, aggressive Campaign to stop global AIDS. The mission is to hasten an end to the global AIDS crisis through mobilizing enhanced awareness, increased funding, and improved policies. <u>http://www.globalaidsalliance.org/</u>
- Stop TB partnership is a global movement of more than 300 partners to accelerate social and political action to stop the spread of tuberculosis around the world. The partnership's goals are:

(a) By 2005, 70% of people with infectious TB will be diagnosed (latest data for 2004: 53%), and 85% cured (latest data for 2003: 82%) (WHO, 2006); (b) By 2010, the global burden of TB disease (deaths and prevalence) will be reduced by 50%; (c) By 2050, the global incidence of TB disease will be less than 1 per million populations. <u>http://www.stoptb.org</u>

- The Network of African People Living with HIV/AIDS (NAP+) is a forum that links and aims at improving the quality of life of its membership through lobbying and sharing of experiences and skills. The overall aim of NAP+ is to strengthen a regional voice of people living with HIV/AIDS in Africa. <u>http://www.naprap.org</u>
- The Treatment Action Group (TAG) fights to find a cure for AIDS and to ensure that all people living with HIV receive the necessary treatment, care, and information they need to save their lives. TAG focuses on the AIDS research effort, both public and private, the drug development process, and our nation's health care delivery systems. TAG is committed to working for and with all communities affected by HIV. <u>http://www.aidsinfonyc.org/tag/</u>

Benefits of Networks

- \checkmark Keep you up to date on what is going on
- \checkmark Provide a ready made audience for your ideas
- ✓ Provide support for your actions
- ✓ Provide access to varied and multiple resources/skills
- ✓ Pool limited resources for the common goal
- ✓ Achieve things that single organizations or individuals cannot—power of numbers
- ✓ Form the nucleus for action and attract other networks
- ✓ Expand the base of support

2.5. Assessing the policy environment is also essential

- A critical element in the success of any advocacy effort is a thorough understanding of the opportunities that exist for influencing the policy process—nationally, regionally, or locally. Some issues are probably settled by facts, analysis, and persuasion. Others are determined by vote, bargaining, or delegation to someone in authority. In all cases, decision makers are generally forced to make policy choices under conditions of ambiguity and uncertainty. Therefore, policy analysis demands a focus on what is actually done as opposed to what is proposed or intended.
- Policies create a framework by which government affects the behavior of millions of people. For TB/HIV, policies are tools to promote access to services through enhancing collaboration and linkages between TB and HIV services. By providing HIV testing and then the comprehensive HIV care and support for HIV infected patients so as to improve their quality of life and survival for example.
- The efforts to combat tuberculosis and HIV/AIDS have been primarily fought through separate and independent courses. Response to Tuberculosis has largely focused on infectious case finding and cure. With regards to HIV, there is little mention to HIV prevention and the care of

tuberculosis patients with other HIV-related diseases. The response to HIV/AIDS focuses on HIV prevention, and most recently on antiretroviral treatment.

- No country has yet carried out collaborative TB/HIV activities at the national level. By end of 2002, of the 22 high burden TB countries (HBCs), only 15 HBCs have TB/HIV coordinating bodies, and 12 have carried out small-scale TB/HIV planning activities. The United Republic of Tanzania, Uganda, and Zimbabwe, where HIV is major problem, do not have a coordinating HIV/TB body. Countries do not offer isoniazid or cotrimoxazole preventive therapies or do not routinely provide TB patients with the means to prevent HIV infection or provide ART.
- One of the fundamental reasons for HIV and Tuberculosis resorting to separate response to the disease is the separate funding that has maintained the two programs. The Interim Policy on Collaborative TB/HIV Activities does not call for a separate disease control program to address TB/HIV, but to promote collaboration between the two programs including joint planning and budgeting.

Examples of Recommended TB/HIV Policy Issues

- ✓ Provision of HIV testing to TB patients
- \checkmark Promotion of safer sexual practices and condoms to TB patients
- ✓ Intensified TB case-finding by every HIV/AIDS service providers
- ✓ CPT to reduce the morbidity and mortality of PLHA and HIV-positive TB patients
- ✓ TB preventive therapy (IPT) at VCT centers including in stand alone centers
- ✓ STIs screening at TB diagnosis and treatment centers
- ✓ STIs treatment at TB diagnosis and treatment centers
- ✓ Community involvement in the management of HIV infected TB patients
- ✓ Integrating TB management in home based HIV/AIDS care services
- ✓ PLHA support group involvement in TB activities
- ✓ ART for HIV infected TB patients.
- ✓ TB friendly ART regimens in national ART policy

2.6. Steps in the Advocacy process

Advocacy should be guided by rules. The following 10 elements represent (box) the steps in conducting advocacy. Data collection and Monitoring and evaluation are important activities that need to be conducted through out the advocacy process.

D	• Issue	М
А		0
Т	• Goal and Objectives	Ν
Ā	• Goui una Objectives	Ι
11		Т
C	Target Audience	0
С		R
0	Building Support	Ι
L		Ν
L	Message Development	G
Е	message Development	&
С	Channels of Communication	Е
Т	Channels of Communication	V
I		A
0	 Fundraising 	L
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Ν	Implementation	Ā
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2.6.1. Issues, Goals, and Objectives: Building the Foundation

- The first two steps in any advocacy campaign are selecting the advocacy issue and developing the goal and objective. Completing these steps requires an ability to analyze complex environments and interrelated problems, discern a policy solution for a selected problem, envision a long-term result, and articulate a short-term objective. The quality of the advocacy network's efforts in these areas will have an important bearing on the success of the steps that follow. These elements provide the foundation for an effective advocacy campaign. Without a clear, articulated issue and well-defined goal and objective, the remaining steps of the campaign will lose focus.
- An advocacy issue is the problem or situation that an advocacy group seeks to rectify. Through advocacy, WHO and the Stop TB Partnership has raised awareness on the following issues: devastating impact TB is having on women; the dramatic role it plays in the HIV epidemic; and new developments in the TB epidemic, such as the emergence of new strains, new outbreaks, and successful initiatives to control the disease. The advocacy issue in the context of this manual is accelerating the implementation of collaborative TB/HIV activities as recommended in the interim policy on collaborative TB/HIV activities.

• An **advocacy objective** is a short-term target (one to two years) that contributes toward achievement of the long-term goal. A sound objective is specific, measurable, realistic, and time-bound. Often, networks work on two or more objectives simultaneously in their efforts to achieve a single goal. It is important that an advocacy objective identify the specific policy body with the authority to fulfill the objective as well as the policy decision or action that is desired. Three examples of advocacy objectives in support of the policy goal mentioned above are: (1) By (insert year), Ministry of Health to establish the mechanisms for collaboration between tuberculosis and HIV/AIDS programs; (2) By (insert year), District Council conduct activities to decrease the burden of tuberculosis in people living with HIV/AIDS; and (3) By (insert year), District Council conduct activities to decrease the burden of HIV in Tuberculosis patients.

Example 1:

Advocacy Issue: Need for promotion of safer sexual practices and condoms to TB patients

Advocacy Goal: Safer sexual practices among TB patients promoted. Package of care for PLHA available and disseminated

Advocacy Objective: By (insert year), district authority allocates funds for capacity building of TB officers to discuss sexual issues with TB patients and promote condoms when appropriate.

Example 2:

Advocacy Issue: Need for intensified TB case-finding in HIV/AIDS and outreach services.

Advocacy Goal: Early diagnosis and treatment of TB in high-risk groups intensified; increased number of TB cases detected and treated.

Advocacy Objective: By (insert year), district council put in place a program to train HIV/AIDS service providers and other NTP partners about TB diagnosis and referral.

Example 3:

Advocacy Issue: Lack of Cotrimoxazole preventive treatment (CPT) to reduce the morbidity and mortality of PLHA and HIV-positive TB patients.

Advocacy Goal: Cotrimoxazole available for PLHA and HIV positive TB patients

Advocacy Objective: By (insert year), MOH to procure adequate cotrimoxazole through the central system and distribute it through existing channels.

Example 4:

Advocacy Issue: Lack of STIs screening and promotion at VCT centers (and PLHA support groups) and VCT promotion by STIs treatment services.

Advocacy Goal: Screening and treatment of new STIs available for VCT clients, and promotion of VCT to patients at STIs services strengthened.

Advocacy Objective: By (insert year), MOH put in place a training program for VCT counselors about STI symptoms, how to screen for STIs symptoms, and how to refer clients with STI symptoms

2.6.2. Target Audiences: Identifying Support and Opposition

- To increase the chances of success, advocacy networks must identify and study all of the individuals and groups that may support the network's issue and goal as well as those that may oppose the issue and goal. Several decisions are based on a thorough and sound analysis of the advocacy campaign's target audience.
- The advocacy campaign's target audiences are determined for each advocacy objective and include the **primary** and **secondary** target audience.
- **Primary target audience** are persons and/or institutional bodies that themselves have decision making authority. **Secondary target audience** are persons and institutional bodies that can influence the decision makers. Documenting information on these audiences helps the network target its advocacy activities, develop effective messages, and select appropriate channels of communication.
- While the categories of people in the target audience are not identical in every setting, the TB/HIV policy target audience is likely to include political leaders, national (i.e. NTP and NACP) and local government officials, private and public sector service providers, the media, religious and traditional leaders, NGOs, women's organizations PLHA, professional associations, and business and civic groups. In some places and for some issues, the range of audiences is even wider and may encompass groups that are unlikely ever to meet each other, such as foreign donors or traditional healers.
- Once the target audiences are identified, the network must determine the level of support or opposition to be expected from those representing the primary and secondary target audiences. For many reasons—lack of political commitment at both international and local level, differences in culture and philosophy between HIV and TB, inequitable distribution of resources—TB/HIV issues are often controversial. People on both sides of the issue feel strongly that their position is the right one; therefore, they are willing to devote considerable resources to supporting that position.
- On the other side of the coin, advocacy networks often dedicate themselves to broadening their base of support. The larger the number of persons or groups working to achieve the advocacy objective, the greater are the chances of success. Networks can create coalitions with other networks or formal groups, expand their own membership, create alliances with commercial or private sector entities, and/or generate public and community support to enlarge their support base.
- Finally, advocacy networks cannot afford to forget the "undecideds" or neutral parties. In some cases, the best investment of time and energy is to appeal to the neutral public. Public opinion can exert powerful pressure on decision makers. In other cases, the network may find policy makers and public officials who appear neutral but in fact hesitate to voice an opinion due to the challenges faced in unifying TB and HIV activities; they may support the advocacy efforts in private but prefer to appear neutral. The network may direct its efforts to convincing these influential "neutrals" to join and publicly support the campaign.

2.6.3. Messages: Informing, Persuading, and Moving to Action

- In today's society, we are bombarded by messages every day. The intent of the message may be to sell us a product, inform or educate us in some way, or change our opinion about an issue. An advocacy communication strategy follows many of the same principles as an advertising or social marketing campaign. It is essential to know your audience thoroughly and to deliver a concise, consistent message that is tailored to your audience's interests.
- Most people shape their messages to the needs and interests of a particular audience as a matter of common sense. In other words, the message communicated to a PLHA groups about access to ART would differ from the message transmitted to officials in the Ministry of Health.

Characteristics of Effective Messages

- ✓ Simple
- ✓ Concise
- ✓ Appropriate language
- ✓ Content consistent with format Credible messenger (spokesperson)
- ✓ Tone and language consistent with the message (i.e., serious, humorous)
- Audience research—particularly qualitative research such as focus group discussions and indepth interviews—helps identify appropriate messages for various policy audiences. Whoever the target audience may be, it is important to remember three other points about advocacy message development.
- First, there should ideally be only one main point communicated or, if that is not possible, two or three at the most. It is better to leave people with a clear idea of one message than to confuse or overwhelm them with too many.
- Second, messages should always be pre-tested with representatives of the target audience to ensure that the message sent is the one received. When a network develops an advocacy message directed toward the Minister of Health, for example, it is always useful to practice delivering the message to a supportive Ministry official as a test run. The Ministry official may offer valuable feedback about how the message is interpreted.
- Third, the message should not only persuade through valid data and sound logic, but it should also describe the action the audience is being encouraged to take. The audience needs to know clearly what it is you want it to do, e.g., include HIV related TB in the national health insurance package, and support an advocacy campaign by attending a rally on the steps of Parliament.

Five Elements of Messages

- ✓ Content/ideas
- ✓ Language
- ✓ Messenger/source
- ✓ Format/medium
- ✓ Time/place

Message Medium				
Face-to-face meetings Executive briefing packets Public rallies Fact sheets Policy forums	 ✓ Poster, flyers in public places ✓ Petition ✓ Public debate ✓ Press release ✓ Press conference ✓ Contests to design posters, slogans 			

2.6.4. Data Collection: Bridging the Gap between Communities and Policymakers

- Data, quantitative and qualitative, is fundamental for TB/HIV advocates as it plays a role in moving the agenda forward in providing TB and HIV joint services.
- To be effective advocates for TB/HIV issues, networks must understand and accurately represent the needs, priorities, and interests of their constituencies. Knowing the community means finding out what people think about TB/HIV issues and how they are personally affected by the policies governing the provision of TB/HIV services. It doesn't make sense, for example, to organize an advocacy campaign in support of adolescent reproductive health services if the community considers TB/HIV as its primary concern.
- At the national level, the first step is to develop a collaborative TB/HIV strategic plan. In developing the effective plan, TB/HIV networks can play a fundamental role as the intermediary in promoting the translation of data into policy. The fundamental issues to be addressed for the strategic plan re: recognizing the burden of the overlapping TB/HIV epidemics, recognizing the strengths and weaknesses of the NTP and NACP, and lastly defining the opportunities that exist between the NTP and NACP at the central and district levels.
- At the district level, TB/HIV networks can also play a crucial role in promoting the establishment of TB/HIV services. Translating the following type of data into policy statements is one of the ways TB/HIV networks can contribute to the TB/HIV joint effort: baseline TB/HIV statistics, identifications of groups at particular risk of TB and/or HIV infection, and survey of existing district TB and HIV/AIDS service providers.
- By collecting and disseminating data on community needs, a network demonstrates the
 importance it places on both listening to the people and gathering the information needed to
 substantiate its advocacy actions. The more information and data a network possesses, the more
 realistic and representative its policy demands will be. Furthermore, data-based advocacy
 messages enhance the professionalism and credibility of the network in the eyes of decision
 makers and other influential persons.

- When initiating a data collection activity, the network should consider its own information
 needs and those of the relevant policymakers. It is also important to estimate the time and costs
 involved in the data collection effort as well as the human resources required to design the
 methodology and collect, analyze, and present the data. Selection of the actual data collection
 technique or techniques depends on the type of data required.
- Data collection can involve qualitative or quantitative techniques or a combination of both. Qualitative data are descriptive or narrative and convey impressions or opinions. They provide information on what people think, feel, and do and are helpful in identifying issues of importance to a particular target group or community.
- Quantitative data can be counted or quantified to give numeric estimates and generate conclusive findings. They can tell us how many people of different demographic characteristics live in the target area, verify the number of times something happens, or document differences between things that can be measured in numbers, for example, the annual risk of developing TB in a PLHA who is co-infected with M. Tuberculosis ranges from 5 to 15 percent. This unit focuses on selected qualitative and quantitative data collection techniques and their applications in developing a better understanding of community needs and priorities and communicating these needs and priorities to policymakers. Participants will explore baseline surveys, conversational interviews, focus group discussions, and secondary data analysis and determine how to use the results to advance the work of the advocacy network.

QUALITATIVE	QUANTITATIVE
✓ Surveys	✓ Surveys
✓ Questionnaires	✓ Questionnaires
✓ Focus Groups	✓ Census
✓ Interviews	✓ DHS
✓ Observation	✓ KAP (Knowledge, Attitude,
	Practice)
	✓ Baseline Studies

2.6.5. Fundraising: Mobilizing Resources

- The ability to mobilize resources is a valuable skill for advocacy networks. Access to financial resources expands the options available to the advocacy network and gives members the freedom to try new, creative, or even higher-risk activities than would be possible with limited funds. But no matter how much an advocacy campaign benefits from financial resources, it is entirely possible to launch a successful campaign with the resources and energy of network members alone.
- Effective fundraisers understand the importance of setting realistic goals based on their particular setting and advocacy issues. They know how to target potential contributors and

develop persuasive appeals to reach them. They forge innovative strategies to raise money from seeking small grants from bilateral development organizations to targeting private sector concerns within their own communities. They also know how to leverage contributions from one source to gain additional resources from another and thus pave the way for future advocacy activities.

The Fundraising Process

- **Fundraising Methods:** Successful advocates have used many different methods to obtain the resources they need for their work. Examples include the following:
 - Setting membership dues for the network or alliance generally based on a sliding scale;
 - Soliciting in-kind contributions;
 - Holding special fundraising events such as dinners, film festivals, picnics, raffles;
 - Cultivating large individual contributors;
 - Seeking corporate donations;
 - Selling merchandise such as crafts, artwork, t-shirts;
 - Obtaining international, national, or local government grants;
 - Promoting donations around a particular holiday;
 - Auctioning donated goods and services; and
 - Selling advertising space in newsletters or other publications.
- **Donations:** Contributions to advocacy efforts can be varied and creative. Individuals or organizations can donate (money, labor, equipment, office space, supplies, printing services, technical expertise, administrative support and space for meetings and events).
- **Legal Issues:** Laws that govern the giving and receiving of donations vary from country to country. Local research will provide answers to the following questions:
 - What laws govern the solicitation of contributions?
 - Are there restrictions related to the use of donations for advocacy or political action?
 - Are the amounts that individuals or organizations can contribute for advocacy limited?
 - What are the requirements for reporting donated income? Are there specific rules for accounting? Are donations taxed?
- **Potential Donors:** Funding may come from many different sources, including
 - Individuals
 - Private sector companies (including multinational firms)
 - Philanthropic/donor agencies and foundations
 - Government-sponsored initiatives
- **Donors as your Audience:** Certain types of information, language, and presentation styles will elicit a positive response from funding sources. Donors generally like to see
 - A well-run and efficiently managed organization or effort;

- Financial stability and budget information;
- Examples of successful efforts;
- A good strategy and a reasonable chance of success;
- Traits that distinguish the network from other organizations in the same field;
- Why the work is important and necessary;
- The achievements associated with any previous contributions; and
- Information on the network's activities and successes; if the network is new, information on its strategy and goals.

• General Fundraising Suggestions

- It is important to find out what types of organizations the donor has funded in the past, how much it typically donated, and what is the nature of its current interests. An annual report, if available, will provide the needed information.
- To avoid donor control over the advocacy agenda or strategy, it is important not to accept donations, grants, or contracts for activities that do not match specific advocacy objectives.
- All donors—especially foundations—have their own programmatic and ideological agendas, and it is important to match funding sources and advocacy objectives.
- Strive for a diverse funding base to avoid dependence on a few sources.
- Appoint qualified individuals to lead fundraising efforts.
- As in advocacy itself, relationships are central. Invest time and energy in getting to know potential contributors.
- Include staff of multinational organizations in the membership of the network. These individuals may be helpful in obtaining support for advocacy efforts.

2.6.6. Implementation: Developing an Action Plan

- Based on a selected TB/HIV advocacy objective, the network should design specific activities for implementation in order to achieve the network's objective. Members of the network provide details describing needed resources, responsible person(s), and an appropriate timeframe, expected outcome and the indicator for each activity.
- Developing the action plan provides an excellent opportunity for network members to work as a team. The implementation plan should be developed with input from and the consensus of the entire membership in order to create a sense of shared ownership and commitment to the plan and the strategy.

Advocacy Implementation Plan (Example)

Advocacy objective: To pressure for the formulation of a national TB/HIV policy by (insert year)					
Activity	Needed Resources	Responsible Person(s)	Timeframe		
Prepare a fact sheet presenting the magnitude of the TB/HIV problem among PLHA including the number of members of the association dually affected by TB and HIV (if any)	Background documents (e.g. WHO documents) Contact a known researcher to gather country specific information	Network's research/data team and communication team	2 week		
Write letter (enclosing the global interim TB/HIV policy document) to the Head of State of the country asking for his support for the formulation of a national TB/HIV policy	The Global TB/HIV interim policy TB/HIV fact sheet	Chairperson of the advocacy network	3 weeks		
Meet the National HIV/AIDS Commission head, minister of Health, HIV/AIDS and TB program managers and present the global interim TB/HIV policy and discuss about national TB/HIV policy.	The Global TB/HIV interim policy TB/HIV fact sheet	Advocacy network chairperson and coordinator of communication team	1 Month		
Prepare a media event highlighting the importance of TB/HIV policy.		Advocacy network chairperson and coordinator of communication team	2 weeks		
Prepare a sensitization session of PLHA group leaders about the importance of national TB/HIV policy so that they will include it in their HIV/AIDS advocacy related activities (e.g. media interviews, high level official meetings etc)		Advocacy network chairperson and coordinator of communication team	2 weeks		

2.7. Monitoring and Evaluation

- The ability to acquire and use relevant information is as important for an advocacy network as it
 is for an individual NGO. A sound monitoring and evaluation component helps the network
 track its successes, build credibility with donors, and motivate members to sustain momentum.
 If a network's advocacy activities bring about a desired policy change, the network will want to
 demonstrate a clear connection between its objectives and activities and the policy outcome.
- **Monitoring** is the process of routinely gathering information on all aspects of an advocacy campaign and using the information in network management and decision making. A monitoring plan is a basic and vital management tool that provides network members and other stakeholders with information that is essential to designing, implementing, managing, and evaluating advocacy activities. To fulfill the monitoring function, the monitoring plan must include systems for collecting data and information on key activities as well as systems for summarizing, analyzing, and using the information to make decisions and take action. Monitoring information can help
 - Demonstrate innovative and effective strategies;
 - Generate financial and political support for advocacy activities; and
 - Market the network.
- **Evaluation** involves a systematic, objective analysis of the network's performance, efficiency, and impact in relation to its objectives. Its ultimate purpose is to
 - Draw lessons from experience in order to improve the quality of an advocacy campaign;
 - Improve the design of future campaigns; and
 - Demonstrate the network's merits to supporters, policymakers, donors, members, etc.

Evaluation can be thought of as an assessment at a critical period or a process of looking at impacts or achievements.

We monitor activities and we evaluate results.

Annex 1. HIV/TB Internet Resource List¹

- Brown University TB-HIV Research Laboratory
- <u>Case Western Reserve University Tuberculosis Research Unit and HIVNET Projects</u>
- <u>CDC Global AIDS Program (GAP) Center for Disease Control and Prevention</u>
- <u>CDC Division of TB Elimination</u>
- CREATE
- <u>EuroTB</u>
- Family Health International
- Free Medical Journals
- <u>The Global Alliance for TB Drug Development</u>
- Global Fund to fight AIDS, tuberculosis and malaria (GFATM)
- International AIDS Economics Network
- International AIDS Society
- International Union Against TB & Lung Disease
- Japan Anti-TB Association
- Johns Hopkins Center for Tuberculosis Research
- Liverpool School of Tropical Medicine
- London School of Hygiene & Tropical Medicine
- National Institute of Allergy and Infectious Diseases, NIH, US
- National Institutes of Health free access to largest source of published medical information
- National Tuberculosis Center, The University of Medicine and Dentistry of New Jersey
- <u>NIH Tuberculosis Research Materials and Vaccine Testing</u>
- PHRI Russian TB Control Program
- Princeton Project 55 Tuberculosis Initiative
- Regional AIDS Training Network
- Royal Tropical Institute (Koninklijk Instituut Voor de Tropen)
- Stanford Center For Tuberculosis Research
- <u>Stop TB Canada Initiative</u>
- Stop TB Partnership
- <u>Tuberculosis Antimicrobial Acquisition and Coordinating Facility (TAACF)</u>
- TB Alert
- <u>TB Alliance</u>
- <u>The Tuberculosis Coalition for Technical Assistance (TBCTA)</u>
- Tuberculosis control India
- <u>Tuberculosis Information Management System (TIMS)</u>
- <u>United Nations Joint Programme on HIV/AIDS</u>
- <u>World Health Organization</u>
- World Health Organization, TB/HIV Working Group
- World Health Organization, 3 by 5 Initiative

¹ Clicking on the underlined phrase will send you to the website.

References

The Policy Project, 1999. Networking for Policy: An Advocacy Training Manual. Washington, DC: Policy Project.

The Policy Project and Maternal & Neonatal Health Program, 2003. Networking for Policy: An Advocacy Training Manual. Maternal Health Supplement. Washington, DC: Policy Project.

World Health Organization (WHO). 2004. Global Tuberculosis Control – Surveillance, Planning, Financing. Geneva, Switzerland: World Health Organization.

World Health Organization (WHO). 2004. Interim Policy on Collaborative TB/HIV Activities. Geneva, Switzerland: World Health Organization.

World Health Organization (WHO). 2003. Guideline For Implementing Collaborative TB & HIV Program Activities. Geneva, Switzerland: World Health Organization.

World Health Organization (WHO) & Global Partnership to Stop TB. 2003. Strategic Framework to Decrease the Burden of TB/HIV. Geneva, Switzerland: World Health Organization.

World Health Organization (WHO). 2003. An Analysis of Interaction Between TB & HIV/AIDS Programmes in Sub-Saharan Africa. Geneva, Switzerland: World Health Organization.

World Health Organization . What is DOTS? WHO/CPC/TB/99.270. Available athttp://www.who.int/gtb/publications/whatisdots/index.htm

World Health organization. The Human Face of TB. Available at http://www.who.int/gtb/publications/Colors_report/index.htm

World Health organization (WHO). Tb advocacy : a practical Guide. WHO/TB/98.239 downloadable from http://whqlibdoc.who.int/hq/1998/WHO_TB_98.239.pdf

World Health Organization (WHO). 2005. The Stop TB Strategy. Building on and Enhancing DOTS to meet the TB-related Millennium Development Goals. Available at http://www.who.int/tb/hiv/en/.

World Health Organization (WHO). 2006. Tuberculosis: The Global Burden. Available at http://www.who.int/tb/hiv/en/.

World Health Organization (WHO). 2006 b. Evaluation of WHO's Contribution to "3x5". Main Report. http://www.who.int/hiv/topics/me/3by5%20Evaluation.pdf.