Community-Based Tuberculosis Prevention and Care:

WHY and HOW to GET INVOLVED

An International Handbook for Nongovernmental Organizations and Civil Society Organizations

© 2009 RN Mittal, Courtesy of Photoshare

USAID FROM THE AMERICAN PEOPLE

MCHIP Maternal and Child Health Integrated Program

coregroup Advancing community health worldwide.

Abstract

Tuberculosis is both curable and preventable. The cost of diagnosis and the medicine to treat TB is free for patients in most countries. Yet despite this, women, men, children, and babies are still becoming ill and dying from TB every day.

Amazing progress has been made by governments, health systems, the World Health Organization, the Stop TB Partnership, private sector practitioners and companies, advocates, and other organizations. But one group still needs a stronger presence on the team: civil society. This includes community members, nongovernmental organizations (NGOs) and civil society organizations (CSOs) of all kinds, at all levels—from local to global—including community health, education and development efforts, religious groups, patient advocates, maternal and child health programs, traditional groups including healers, kinship groups and neighborhood associations, national and international NGOs, and many more.

But how can they help—especially if they are not health experts? In many ways. People living with TB often live in places that government services have a hard time reaching. TB spreads in households and communities, ranging from rural villages to urban apartment blocks to schools to workplaces and crowded places like workers' hostels and prisons. Within ALL communities, community-oriented efforts can both help prevent the spread of TB AND support diagnosis and treatment. This happens through educating the public and health workers, finding people with TB symptoms and getting them to diagnostic and other services, reducing stigma, offering daily support for those taking the medicines, advocating for improved services—and in many other ways.

This document is designed to serve as a handbook, or primer, for NGOs and CSOs that are considering joining the fight against TB. It provides information on TB and how it is prevented, diagnosed, and treated, how TB programs work on the ground, how communities and CSOs can get involved, and special populations that need extra attention. Step-by-step guidance on getting started in addressing TB, pitfalls to avoid, and a list of useful resources are included.

Recommended Citation:
CORE Group TB Working Group. *Community-Based Tuberculosis Prevention and Care: Why—and How—to Get Involved. An International Handbook for Nongovernmental Organizations and Civil Society Organizations.* January, 2013. Washington, D.C.: CORE Group.

Acknowledgments

Thank you to all who generously provided interviews, review and comment, and/or documents or other information for this report: Derek Ambrosino (TB Alliance); Charlotte Colvin (USAID); Anne Detjen (The Union); Kayt Erdahl (PATH and CORE Group TB Working Group Co-Chair); Nene Fofana (PSI and CORE Group TB Working Group Co-Chair); Meghan Holohan (USAID); Amy Piatek (USAID); Stephanie Siedel (TB Alliance); Mandy Slutsker (RESULTS); Jeff Starke (Baylor); Lana Tomaskovic (WHO); Laban Tsuma (MCHIP). At the CORE Group Spring Meeting, 2012: Damilola Walker (EGPAF), Paul Robinson (World Concern). Special thanks to Devasena Gnanashanmugam, M.D., (Independent Consultant and CORE Group TB Working Group Co-Chair) for her work writing and updating this document. This document was co-authored and edited by Ann Hendrix-Jenkins of CORE Group.

CORE Group emerged organically, in 1997, when a group of health professionals from non-governmental development organizations realized the value of sharing knowledge, leveraging partnerships, and creating best practices for child survival and related issues. Fifteen years later, we have evolved into an independent non-profit organization with 80+ Member NGOs, Associate Organizations and Individual Associates. This group works in 180 countries, collectively reaching over 720 million people every year—one tenth of the world's population. Much of our dynamism is generated through our lively Community Health Network. CORE Group builds on the energy and knowledge of the Network to take on additional efforts: we run a Practitioner Academy for Community Health, design and administer community health grant programs, advocate for community health approaches, and develop technical guidance and tools—like this report. Learn more, and access our free resources and webinars at www.coregroup.org.

The Maternal and Child Health Integrated Program (MCHIP) is the USAID Bureau for Global Health flagship maternal, neonatal and child health (MNCH) program. MCHIP supports programming in maternal, newborn and child health, immunization, family planning, nutrition, malaria and HIV/AIDS, and strongly encourages opportunities for integration. Cross-cutting technical areas include water, sanitation, hygiene, urban health and health systems strengthening. Visit www.mchip.net to learn more.

This report was made possible by the generous support of the American people through the **United States Agency for International Development (USAID)**, under the terms of the Maternal and Child Health Integrated Program (MCHIP) Cooperative Agreement GHS-A-00-08-00002-000. This publication does not necessarily reflect the views of USAID or the United States Government. It may be reproduced if credit is properly given.

Graphic Design:
Pinky Patel, CORE Group and Gwen Glesmann, Studio G Design

Acronyms and Abbreviations

ACSM	Advocacy, communication, and social mobilization
AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
BCG	Bacille Calmette–Guérin (TB vaccine)
CDC	Centers for Disease Control and Prevention
CHW	Community health worker
CPT	Cotrimoxazole preventive therapy
CSO	Civil society organization
DOT	Directly observed treatment
DOTS	The package of elements that is the foundation the Stop TB Strategy
HIV	Human immunodeficiency virus
IPT	Isoniazid preventive therapy
KAP	Knowledge, attitudes, and practices
MCH	Maternal and child health
MDR	Multi-drug resistant
M&E	Monitoring and evaluation
MOH	Ministry of Health
NGO	Nongovernmental organization
NTP	National Tuberculosis Program
OR	Operations Research
TB	Tuberculosis
TB/HIV	The intersecting epidemics of TB and HIV
WHO	World Health Organization

Table of Contents

I. Introduction 1
How Can This Document Help Civil Society Get Involved in Fighting TB?

II. THE BASICS: TB, ITS HISTORY, AND THE STOP TB STRATEGY 2

A. WHAT IS TB? 2

B. WHO GETS TB? 3

C. HOW COMMON IS TB IN THE WORLD? 4

D. HISTORY OF TB IN SOCIETY, AND TREATMENT 5

E. THE STOP TB STRATEGY 6

F. MORE ON STOP TB STRATEGY ELEMENT #1: PURSUE HIGH-QUALITY DOTS EXPANSION AND ENHANCEMENT 7
1. POLITICAL COMMITMENT WITH INCREASED AND SUSTAINED FINANCING 7
2. CASE DETECTION BY QUALITY-ASSURED BACTERIOLOGY 8
3. STANDARDIZED TREATMENT, WITH SUPERVISION AND PATIENT SUPPORT 9
4. AN EFFECTIVE DRUG SUPPLY AND MANAGEMENT SYSTEM 9
5. MONITORING AND EVALUATION SYSTEM, AND IMPACT MEASUREMENT 10

III. TB PROGRAMMING "NUTS AND BOLTS" INCLUDING COMMUNITY ROLES 11

A. THE THREE BASIC COMPONENTS OF TB PROGRAMMING 11

B. WHAT IS THE PROCESS FOR DIAGNOSING TB? 12

C. HOW IS TB TREATED? 12

D. WHAT IS COMMUNITY? 14

E. WHY CALL ON NGOS AND CSOS TO HELP FIGHT TB? 14

F. SPECIAL POPULATIONS THAT MAY BE BEST SERVED THROUGH COMMUNITY-BASED PROGRAMMING 17

IV. ACTION PLANNING 24

A. STEP ONE: LEARN ABOUT THE TB PROGRAM LANDSCAPE: CONDUCT A SITUATIONAL ANALYSIS 24

B. STEP TWO: ASSESS YOUR NGO'S STRENGTHS 26

C. STEP THREE: DESIGN A SPECIFIC PROGRAM OR ACTIVITY 26

D. POTENTIAL AREAS FOR NGO/CSO INVOLVEMENT IN FIGHTING TB 30

V. CONCLUSION 39

GUIDANCE: HOW TO DEVELOP HIGH-QUALITY TB EFFORTS 41

APPENDIX: RECOMMENDED RESOURCES 43

REFERENCES 45

I. Introduction

"In TB, we need to shake things up, we need a greater feeling of urgency, we need to show if we are unhappy about it... We will never change the figures dramatically unless we scale up, working with and empowering the people suffering, civil society and communities."

—Dr Lucia Ditiu, Executive Director, Stop TB Partnership

Tuberculosis is both curable and preventable. More than 90% of patients with TB are cured if they receive timely diagnosis, are prescribed the correct treatment, and they take their drugs properly: every day for approximately six months. The cost of diagnosis and the medicine to treat TB is free for patients in most countries. Yet despite this, women, men, children, and babies are still becoming ill and dying from TB every day.

Governments around the world have made great strides in tackling the problem. **Global organizations** including the World Health Organization (WHO) and the Stop TB Partnership are drawing attention to the issue, and offering guidance and support. **Private sector companies** are working to create technologies for prevention, diagnosis and treatment. Private sector health services offer TB diagnosis and treatment in many countries. **But one group still needs stronger presence on the team: civil society.** This includes community members, nongovernmental organizations (NGOs) and civil society organizations (CSOs) of all kinds, including community health programs, development organizations, religious groups, patient advocates, kinship groups, traditional healers, midwives, neighborhood associations, and many more.

But how can they help—especially if they are not health experts? In many ways. People living with TB often live in places that government services have a hard time reaching. TB spreads in households and communities, ranging from rural villages to urban apartment blocks to schools to workplaces and crowded places like workers' hostels and prisons. Within ALL communities, community-oriented efforts can both help prevent the spread of TB AND support diagnosis and treatment. This happens through educating the public and health workers, finding people with

TB symptoms and getting them to diagnostic and other services, reducing stigma, offering daily support for those taking the medicines, advocating for improved services—and in many other ways.

How Can This Document Help Civil Society Get Involved in Fighting TB?

This document is designed to serve as a handbook, or primer, for NGOs and CSOs that are considering joining the fight against TB. This document is divided into three sections. Section I describes what TB is, the history of the fight against TB, and The Stop TB Strategy. Section II gets into deeper detail about how TB programs work on the ground, how communities and CSOs can get involved, and special populations that need extra attention. Section III offers a step-by-step guidance on how to plan to take action. The end of the document includes lessons learned, parting words, and a list of resources that you can turn to next as you develop your own strategy to stop TB.

By the time you finish reading this document, you'll have learned about:

- TB: What is it? Medical, global, and historical overview.
- TB Services: How do they prevent, diagnose, and treat TB?
- The Stop TB Strategy: What is it?
- The role of civil society: Why you are needed and how you can help stop TB.
- Special issues in TB, including HIV, drug-resistant TB, and women and children and TB.
- Which documents and resources you can trust to offer correct and helpful guidance, from reliable sources such as National Tuberculosis Programs (NTPs), the World Health Organization, the Stop TB Partnership, and global TB, HIV, and community health advocates.

II. The Basics: TB, Its History, and the Stop TB Strategy

A. WHAT IS TB?

Tuberculosis is caused by a bacterium known as *Mycobacterium tuberculosis*. Most people with TB infection have tuberculosis bacteria in their lungs. TB is usually spread when a person with active TB disease coughs, breathes, or sings. The bacteria are projected into the air, where they are then breathed in by others. People can also get TB in other parts of the body, such as the lymph nodes, brain, kidneys, or intestines. TB is also spread by sick cows and their milk.

People may have *M. tuberculosis* in their body, and not have active TB disease. This is called Latent TB Infection (LTBI). These people are probably not infectious, and don't look or feel sick. They don't have any signs of TB disease on chest x-rays or other examinations. Once infected

with TB bacillus, a healthy adult person has a 10% risk of developing TB disease in his or her lifetime, unless the person's immune system (ability to fight sickness) is weakened due to HIV infection or other challenges.

Source: Sri Lanka Daily News

Latent infection can develop into active TB disease when the body faces challenges, including HIV infection, cigarette and cooking smoke, diabetes, malnutrition, living in crowded conditions, or other factors that reduce the body's ability to fight sickness. Given these factors, it is no surprise that people sick with TB are often among the poorest in a society—suffering from yet another burden of poverty.

Drug-resistant TB, which includes multi-drug resistant (MDR) TB or extremely drug-resistant (XDR TB) is a serious—and growing—problem around the world. Drug-resistant TB develops when TB patients aren't able to successfully complete their course of treatment, are receiving inappropriate treatment or low-quality medicines, or live in an area with many MDR cases and are infected with a drug-resistant strain of TB.

B. WHO GETS TB?

Anyone can get TB: men, women, children, and even babies. Rich or poor. From anywhere in the world.

Literature from around the world is full of touching stories of people with TB, and many famous people have suffered from and even died from TB, including Egyptian King Tutankhamen, Pakistan founder Muhammed Ali Jinnah, American presidential wife Eleanor Roosevelt, English Author Jane Austen, South African leaders Nelson Mandela and Desmond Tutu, and Vietnamese leader Ho Chi Minh.

TB disease mostly impacts people in the prime of their lives, from age 15–59, decreasing their ability to contribute to their country's economy and to support their families.

Women are uniquely affected by TB and are often neglected in this epidemic. Women are more likely to have active disease when compared to men, less likely to have access to health care, and often face greater stigma, including being labeled as "unmarriageable."

Children, particularly those under five years of age, also face increased dangers from TB. Diagnosing TB in children is very difficult, so the actual death rate is not clear. Experts believe that the numbers may be extremely high. Infants under one year of age have a 40% chance of developing TB disease if they do not receive preventive therapy when exposed to an adult with infectious TB. Children have a higher chance of developing more severe disease due to their unde-

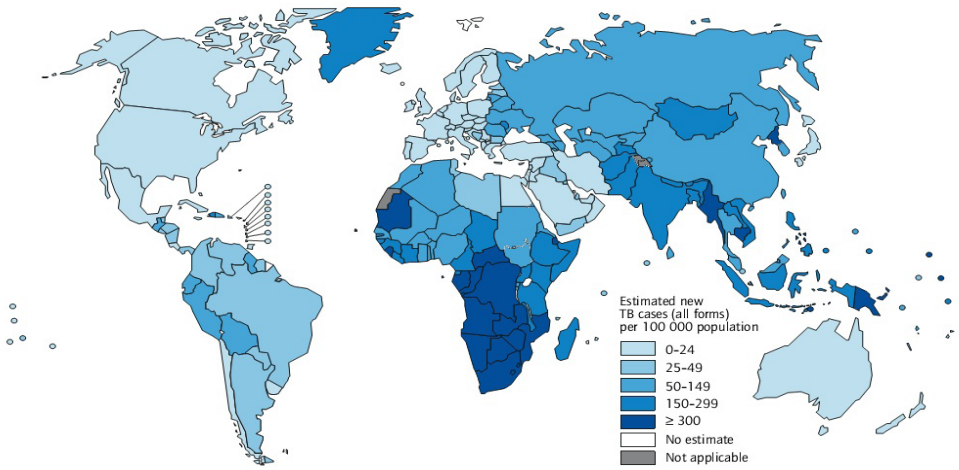
veloped immune systems. In addition to their own physical risk of TB, nearly 10 million children have been orphaned due to TB.

HIV is a driving force in the TB epidemic, and HIV infection is the strongest risk factor for developing TB disease, once infected with TB. People infected with both HIV and TB are 21–34 times more likely to develop active TB disease than those without HIV. Of people with HIV who develop TB, only 70–80% of patients will be cured (compared to nearly 90% who can be cured if they are not HIV-infected). Treating patients for both TB and HIV is not easy: patients have more pills to take and some medicines can react with each other. TB is the leading cause of death of people with HIV, and in 2010, 13% of all TB deaths were in people who were HIV-infected.

Yet in the face of such harsh realities, many programs ARE successfully treating people who are infected with both diseases, and are preventing TB in people with HIV. (Often this happens when HIV and TB programs make the effort to link with each other.)

C. HOW COMMON IS TB IN THE WORLD?

FIGURE 2.5 **Estimated TB incidence rates, 2011**



Source: http://www.stoptb.org/countries/tbdata.asp

One-third of the entire population of the planet is estimated to be infected with TB! That means millions of people have latent TB—the bacillus is in their lungs or body—but they are not sick. Overall, 22 countries account for 80% of the TB disease in the world. (See map above.) Annually, nearly 9 million new cases are reported each year, and about 1.5 million deaths occur each year due to TB.

The total number of cases in the world of drug-resistant TB is about 500,000 per year, but because this type of TB is harder to diagnose, it is very challenging to collect data. Most drug-resistant TB cases occur in China and India, but most countries report rates of drug-resistant TB at 2–5% of existing TB cases. Higher rates are reported in Eastern Europe, especially in countries

of the former Soviet Union, and in Southern Africa.

Despite these large numbers, there is hope. Thanks to the success of advocates, the commitments of governments, donors, and communities around the world, and the courage and perseverance of TB patients, the first report of declining absolute numbers of TB cases (8.8 million) was announced in 2011. Also, there has been a 40% decrease in mortality due to TB since 1990 [9]. To sustain and build on this progress, funding and political commitment need to continue to grow—and community-based efforts as well.

D. HISTORY OF TB IN SOCIETY, AND TREATMENT

Tuberculosis has plagued humans for a VERY long time. Evidence of TB in humans dates as far back as 9000 B.C., and has been found in Egyptian mummies that are 4,500 years old.

"Tuberculosis is a social disease with medical implications."

–Dr. Jeffrey Starke, Global TB Expert

TB has always fueled fears of infection, is often associated with poverty and now linked with HIV. This stigma of TB has social, cultural, and medical roots—and the fruit it bears is poison. The power of TB stigma has always presented a challenge, especially to outsiders and those with a purely medical approach to fighting TB. Throughout history (and to this day) people with TB often suffer, in addition to the illness, from insults, rejection, isolation, and food deprivation, and are sometimes cast out of their homes.

Historically, health care providers were limited in their treatments for TB, aside from prescribing rest, good nutrition, and other basic care. A medical cure for TB came in the 1940s and 1950s. In the 1970s, the development of "short course therapy" with the inclusion of the drug rifampin improved TB treatment in most Western countries, whose rates of TB had simultaneously been declining as their economies improved. Public health programs were also strong, and active screening of patients and case finding helped bring down the rates of TB.

As the HIV epidemic grew, the number of TB cases began to rise again in the 1980s and 90s. As the HIV epidemic overwhelmed (and continues to burden) existing health infrastructure in many countries, especially in Africa, TB advocates have called for the involvement of more sectors and stakeholders to help fight TB.

Karel Styblo of the International Union Against Tuberculosis and Lung Disease developed the DOTS strategy, a method of providing drugs and treatment to TB patients. This five-pillar programmatic strategy includes DOT: Directly Observed Therapy, which refers to having a designated person watch each patient take their medicine (nearly) every day and providing medical support to patients as they do so.

E. THE STOP TB STRATEGY

In 1993, WHO renewed the fight when it declared TB a global health emergency. Global stakeholders created The Stop TB Partnership in 1998. In 2001, the Partnership issued the first Global Plan to map the route to progress in the fight against TB. The Plan, known as the Stop TB Strategy, continues to evolve, and plays a pivotal role as the internationally accepted approach.

The Stop TB Strategy

The Stop TB Partnership (established in 2001) and the World Health Organization developed the Stop TB Strategy, which incorporated the DOTS programmatic approach into a framework that also includes other elements necessary for TB prevention, diagnosis, and treatment.

1. Pursue high-quality DOTS expansion and enhancement

a. Political commitment with increased and sustained financing
b. Case detection through quality-assured bacteriology
c. Standardized treatment, with supervision and patient support
d. An effective drug supply and management system
e. Monitoring and evaluation system, and impact measurement

2. Address TB/HIV, drug-resistant TB, and other challenges

a. Implement collaborativve TB/HIV activities
b. Prevent and control drug-resistant TB
c. Address prisoners, refugees, and other high-risk groups and situations

3. Contribute to health system strengthening

a. Actively participate in efforts to improve system-wide policy, human resources finacing, management, service delivery, and information systems
b. Share innovations that strengthen systems, including the Practical Approach to Lung Health (PAL)
c. Adapt innovations from other fields

4. Engage all care providers

a. Public–Public and Public–Private mix (PPM) approaches
b. International Standards for Tuberculosis Care (ISTC)

5. Empower people with TB, and communities

a. Advocacy, communication, and social mobilization
b. Community participation in TB care
c. Patients' Charter for Tuberculosis Care

6. Enable and promote research

a. Program-based operational research
b. Research to develop new diagnostics, drugs, and vaccines

Many gains in TB prevention, diagnosis, and care have been made due to this strategy, combined with the efforts of WHO, governments, advocates, civil society, the private sector, and other key stakeholders, large and small, around the world. More than 36 million people were cured of TB between 1995 and 2008.

Subsequently, the Strategy's components were expanded to engage more sectors in global TB efforts by addressing social determinants that impact TB disease. Specifically, component #5, "Empower people with TB, and communities" was added in 2006. This laid the groundwork for yet another important role for civil society.

F. MORE ON STOP TB STRATEGY ELEMENT #1: PURSUE HIGH-QUALITY DOTS EXPANSION AND ENHANCEMENT

As the backbone of the Stop TB Strategy, the five components warrant clear understanding. While civil society is often best-suited to address other elements of the strategy, everyone involved in TB needs to appreciate and at least keep an eye on this element and its components.

1. POLITICAL COMMITMENT WITH INCREASED AND SUSTAINED FINANCING

Around the world, TB advocates are designing activities aimed at securing political commitment to fighting TB. This cornerstone of the DOTS expansion strategy is crucial to the success of TB programs. This commitment is shown through national policies, financing, and human resources allocated to TB programs. Without it, all other progress is difficult.

How civil society can help: After assessing the situation in their country, some NGOs choose to focus on increasing political commitment and advocating for improved access to TB services. They may do this by:

- Mobilizing community members to sign petitions demanding better services and more access to services.
- Engaging with the media to highlight TB issues.
- Focusing on funding sources and reaching out to key government players that can directly authorize increases in funding.
- Working in partnership with NGOs, patients, and health care workers and approaching decision-makers as a larger group (which can exert more influence)

Research suggests that in the absence of public awareness and engagement around TB and TB/HIV, political and financial accountability for TB control efforts falters."

–Public Health Watch

2. CASE DETECTION BY QUALITY-ASSURED BACTERIOLOGY

This refers to the system used to determine whether a person actually has TB. In order for TB to be diagnosed, the following three steps occur:

- Patient has symptoms consistent with TB (such as fever and prolonged cough).
- A health worker or volunteer identifies these symptoms.
- Patient provides sputum (coughed up mucus) sample, which is taken to a proper facility for the microbiologic diagnosis of TB to be made.

In the laboratory, a microscope is used to look at sputum, which has been "smeared" on a slide. When the TB bacillus is found in a patient with TB symptoms, that person is considered to be "smear positive." Those patients with symptoms but who don't have visible bacteria are "smear negative."

In smear negative cases, or if drug-resistant TB is suspected, sputum samples are then cultured to try to grow TB. When the bacteria grow, some patients whose bacteria were not seen by microscope will be identified. Growing bacteria this way also allows labs to identify resistance to currently available drugs (through drug susceptibility testing, or DST). In recent years, newer TB diagnostics have been developed to aid in TB diagnosis, including a tool called GeneXPert MTB/RIF. This machine can diagnose TB and a kind of MDR-TB (rifampicin-resistant) within hours. This technology is relatively new, and only beginning to be rolled out around the world.

How civil society can help: High-quality lab facilities are needed to identify TB bacteria, and importantly, to detect drug-resistant strains, which are increasing in many regions. The NTP in your area may use both private and public labs for TB case diagnosis--however all labs must meet international standards of quality. If your NGO has specialists on staff with technical expertise in clinical management and microbiology procedures, the NTP may have use for your technical support to local laboratory technicians and managers, thus helping with this component of the strategy.

3. STANDARDIZED TREATMENT, WITH SUPERVISION AND PATIENT SUPPORT

If diagnosed with TB, a patient will need to take specific medicines on specific days over many months. The patient should be observed taking each dose, careful records kept and shared with the NTP, and support provided in case any problems arise, like side effects.

How civil society can help: Given the extended time period, and the factors like patient convenience, there is much potential for civil society involvement. NGOs might provide direct observation, help the patient seek help for side effects and get answers to questions, and ensure records are properly kept and data provided to the NTP.

Some NGOs provide food and nutrition support, which can help a patient's health improve, and may decrease side effects. Some regions provide nutrition supplements and food in patient packages along with TB drugs to improve patient outcomes. NGOs with experience in food security or similar areas may also provide this kind of assistance. Methods to provide DOT and patient support will be elaborated in sections below.

4. AN EFFECTIVE DRUG SUPPLY AND MANAGEMENT SYSTEM

A reliable supply of quality assured drugs is an absolute must in TB care. Without this, a patient cannot be cured, and even worse, drug-resistant TB may develop. Ensuring an effective drug supply is the responsibility of the NTP, and this task should not be delegated to an NGO or other provider. **Without a guaranteed continuous supply of drugs, intervening in other areas of TB diagnosis and care may be a wasted effort, while risks of drug-resistant TB grow.**

In 2009, many African human rights groups partnered to form the **Stop the Stock-out Campaign** and bring awareness and accountability to governments that were not procuring essential medicines for TB patients. Using the power of the mobile phone, activists in Malawi drew attention to stock-outs, or lack or depletion of drug supplies, during critical election periods. This effort gained television and radio coverage, which led Ministries of Health to publicly acknowledge the issue. Similarly, the Action Group for Health, Human Rights, and HIV/ AIDS (AGHA) in Uganda publicized stock-outs on World TB Day 2009, with a focus on the lack of TB drugs particularly for children, and the use of expired TB drugs in hospitals. The Ugandan government responded by restructuring drug access policies.

How civil society can help: Global institutions provide quality-assured drugs to countries for TB, and higher-level NGOs may assist NTPs in obtaining funding from these sources. NGOs can assist with drug supply by ensuring that community providers administer correct and high-quality drugs that have been approved or sourced by the NTP or are in compliance with internationally recognized protocols. NGOs can also educate other relevant organizations about the importance of quality drugs. Larger NGOs have also assisted NTPs with drug procurement, distribution, stock management, drug quality assessment and assurance, and training in all of these areas.

5. MONITORING AND EVALUATION SYSTEM, AND IMPACT MEASUREMENT

What is monitoring and evaluation, and why is it so important?

Monitoring is the ongoing process of observing and recording activities and outcomes of a project. Evaluation is the process of judging whether the project has accomplished what it set out to do, including activities and objectives. M&E is important because it tells the program managers where a program needs improvement, and whether the program is meeting its intended goals. Looking at data from these activities at certain times during the life of a program can provide direction for minor and major improvements in quality, sustainability, equity, cost-efficiency, and more. Quality M&E can document successes that are worthy of more funding, and copying in other places.

Monitoring and evaluation (M&E) are systems for keeping track of program activities, results, and whether the program is achieving its goals and objectives. Measuring the impact of DOTS programs on case detection and treatment outcomes is critical to ensuring that resources are being put to good use, and that efforts remain on track to meet goals. Monitoring and evaluation also provide evidence to funders that current programs are achieving results, which is necessary to keep the funding coming. In TB programming, there are well-established indicators (units of measure), many determined through cohort analysis, which measure the success of the TB effort. If this type of analysis is in use in your area, your NGO should coordinate with those conducting that work.

The two key indicators for monitoring and evaluating DOTS programs are:

1. The number of cases (people with TB) diagnosed and notified to the National TB Program, and

2. The percentage of patients successfully treated, that is, cured or completed treatment.

How civil society can help: Any data recorded by your organization—including DOT—will likely feed all the way up into global recordkeeping. This is why it is so important that you work closely with the health authorities to provide them the correct, specific information they need about your efforts.

Any health care worker or volunteer who keeps track of patient data will need training in how to use the proper recording system. Some NGOs can provide training in recording and reporting to TB specialists and primary health care providers. They can train providers on which form to use in certain situations, they can train on verifying the accuracy of the data, and can train on data analysis. NGOs have also trained and supported supervisors and managers in using data to identify, overcome, or eliminate program problems, which will require cooperation with providers and/or laboratory technicians. NGOs with experience in M&E can also assist in other operational (implementation) research, which is research that tests how well an activity works in a real-life setting.

III. TB Programming "Nuts and Bolts" including Community Roles

Now that you know what TB is, who is affected by it, and what the Stop TB Strategy is, it's time to focus on the nuts and bolts, that is, the details of what TB programming is like on the ground. What exactly do TB programs do to help implement the Stop TB Strategy? As you learn more about the details, you can begin to form ideas on how civil society—and your organization in particular— can get involved.

A. THE THREE BASIC COMPONENTS OF TB PROGRAMMING:

1. Finding the people who may have TB and providing access to diagnosis. This is known as **case detection**. It may be done through symptom screening or contact tracing (tracking down people who have been exposed to someone with TB). Typically, sputum (coughed-up mucus) samples are taken to a laboratory for testing. In some places, chest x-rays are also used.

2. Ensuring that those who have TB receive a supply of quality-assured medicine, begin **treatment**, and are able to take the entire course of medicine consistently and completely.

3. Minimizing the spread of TB through **prevention and infection control**.

Health facilities and medical staff alone cannot do all of this work. To reach the goal of eliminating TB throughout the whole world, more people and organizations need to get involved. We

Symptoms of TB in the lungs (pulmonary TB):

- Cough for 2–3 weeks or more
- Fever
- Night sweats
- Fatigue
- Unexplained weight loss
- Blood in the sputum (coughed up mucus)

need a wide variety of organizations and groups to engage communities and work together to help stop TB. As a team, we can help all TB patients get back to good health, and we can prevent many people from ever catching or developing active TB in the first place. These goals are especially urgent in place where many people are HIV-positive, because TB is the biggest killer of people with HIV.

B. WHAT IS THE PROCESS FOR DIAGNOSING TB?

In countries where TB is common, people with TB symptoms are asked to cough up sputum. As described earlier in this document, the sample is then sent to a laboratory, where it is examined under a microscope to find the bacteria, or diagnosed using newer tools. Depending on the setting, results may be available within hours, or may take as long as several weeks or even months. Diagnosis of drug-resistant TB is not always available or may take much longer.

While finding the bacteria is an important part of taking proper care of patients with TB, in many places people are not able to travel the long distances required to visit the proper laboratories to give their sputum samples, and no sputum transport services are available. This is a serious problem that needs urgent attention.

C. HOW IS TB TREATED?

TB drugs are sometimes combined into a single pill to make treatment simpler. Side effects of these drugs may include vomiting, nausea (feeling sick to the stomach), loss of appetite, or skin rash, and patients will have harmless orange or red colored urine. More serious side effects may occur as well: patients experiencing these need to seek help from formal health services.

People with latent TB infection (TB is in the body but not causing sickness) can receive preventive medicine to eliminate the infection, so that they don't ever develop TB disease. This is known as *Isoniazid Preventive Therapy* or IPT. In many places, IPT is also given to HIV patients and children who have been exposed to TB—often because someone in their household has active TB disease. A vaccine to prevent TB, known as BCG, is available and is given at birth in most countries. While this vaccine does prevent severe TB illness in children, it does not prevent TB in the lungs, and wears off by adulthood. New medicines and a better vaccine are in development (but will not be available for years).

Common "first-line" TB drugs used for treating standard TB:

- Intensive phase (approximately two months): isoniazid (INH or H), rifampin (RMP or R), ethambutol (EMB or E) and pyrazinamide (PZA or Z)
- Four months: only INH and RMP

The "Cough to Cure" diagram on the following page lays out the ideal route to cure (in green), and problems that might interfere (in blue).

From Cough to Cure: A Path of Ideal Behaviors in Tuberculosis Control

COMMON BARRIERS TO SUCCESSFUL TB CASE DETECTION AND TREATMENT

Individual, Group, & Community Level Barriers	• Poor knowledge of TB symptoms • Poor knowledge of TB care and cure • Stigma related to TB diagnosis • Low risk perception	• Misperception of costs • Preferences for non-DOTS health services • Attitudes about services • Stigma • Social norms	• Poor knowledge of diagnostic steps • Expectations about medical services (get meds not tests) • Stigma (don't want bad news/ label)	• Poor knowledge of length of treatment • Stigma • Side effects: real and perceived	• Poor knowledge of length of treatment • Stigma • Side effects: real and perceived • Change location	• Poor knowledge of length of treatment • Stigma • Side effects: real and perceived
Ideal Behaviors	**Seek Care**	**Go to TB Treatment Program Offering DOTS**	**Complete Diagnosis**	**Begin Treatment**	**Continue Treatment** and follow-up smear	**Complete Treatment** and final smear
System Level Barriers		• Time, costs, distance to DOTS facility • Lack of linkages between DOTS and other providers (non-DOTS & HIV care) • Missed diagnosis and /or lack of referral by non-DOTS providers	• Providers' poor knowledge of correct procedures • Providers' poor interpersonal communication • Lack of resources, including human resources • Poor quality of services (hours, wait-time) • Time, cost and distance	• Time, cost, distance to DOTS facility • Poor quality of services • Health provid-ers fail to give adequate information • Lack of medications	• Time, cost, distance to DOTS facility • Poor quality of services • Health provid-ers fail to give adequate information • Lack of medications	• Time, cost, distance to DOTS facility • Poor quality of services • Health provid-ers fail to give adequate information • Lack of medications

Source: Silvio Waisboro, Susan Zemicki, AED

Adherence to treatment (taking medicines as prescribed) is not only for patients. Providers need to be adherent and correctly prescribe and supervise treatment. In order to be cured, patient will also need to "adhere" to the plan—that means taking all medicines on the proper schedule, until the very end. When patients don't take their medicine properly, they are in serious danger of renewed TB and, even worse, drug-resistant TB. Everyone involved should understand that unfinished or improper treatment can be WORSE than no treatment.

Drug-resistant TB requires longer treatment time, is more expensive, and is more difficult for patients to handle, including very serious side effects. All organizations getting involved in TB should clearly understand that a secure supply of quality-assured, standardized medicines is needed for ALL TB patients. Patients should be linked to government or quality TB services that will be responsible for this supply.

D. WHAT IS COMMUNITY?

A community is "a group of people who have something in common and will act together in their common interest" (WHO 2003). Communities may find unity through common backgrounds, geography, ethnicity, education, experiences, language, and with other social themes. Community-based TB programming can make a unique contribution to national TB programs.

For too long, communities, households, and individuals have been ignored—even though they are obviously the central actors in their own health. Historically, health efforts have focused mainly on the formal health system of clinics and hospitals, and biological approaches. These are obviously vitally important—but they do not represent the whole picture of health.

E. WHY CALL ON NGOS AND CSOS TO HELP FIGHT TB?

Nongovernmental organizations (NGOs) and civil society organizations (CSOs)—of all types—are in a unique position with respect to the populations they serve and represent. They know and care about their communities and already have relationships with influential people and important stakeholders. They understand local systems, and know the history, relationships, and "back stories" (the fuller picture, over time). Many NGOs and CSOs already honor the WHO's principles of patient-centered TB care: dignity, equity, subsidiarity (locally driven solutions), and solidarity.

As a facet of communities, NGOs and CSOs have a long history of significant contributions to global health efforts, in HIV, family planning, and vaccination programs, just to name a few. They often reach the poorest and most vulnerable populations that formal health services are not reaching, and the segments of society most vulnerable to stigma and neglect—exactly the popu-

What is an NGO/CSO?

Non-governmental organizations (NGOs) and civil society organizations (CSOs) are independent, often humanitarian groups that may be as formal as a 50-year-old international health NGO or as simple as a women's self-help group based in a village. They usually are organized around a common interest, cause, or goal, which may include health, education, religion, gender, culture, community development, or simple solidarity.

Some large NGOs are international or national organizations tackling poverty and promoting development for children, families, and communities. Other examples include local grandmothers' groups, women's self help groups, associations of people with HIV, nurses' associations, age-mate cohorts, church clubs, sport clubs, farmers' clubs, student activist groups, private schools, and more.

lations that TB impacts the most. As described above, NGOs and CSOs are often well-positioned to mobilize populations, as this type of work typically requires face-to-face communications in order to succeed. Many NGOS and CSO could benefit from additional capacity-building in this area, given that they are so well-placed and well-connected.

NGOs and other CSOs offer unique advantages that can support and strengthen TB prevention, diagnosis, and care efforts. They have experience and a history of empowering people with chronic disease and are mindful of creating sustainable programs. Many are experienced in aspects of advocacy, communication, and social mobilization—areas long-neglected in global TB efforts until the development of the Stop TB Strategy in 2006. They can help the voices of TB patients and families be heard. They support linkages between community health workers, families, and health authorities, and can become skilled in designing diagnosis and treatment plans that account for the needs of families and households. Such organizations often have more adaptable methods and have a deep understanding of local customs and beliefs.

TB care needs to be crafted to fit patients' lives; not the other way around. Community-based TB care is a model that can do exactly that.

What Exactly Can NGOs and CSOs Do to Support the Stop TB Strategy?

As early as 1974, WHO leaders have noted that "the community should be involved in the program, including its leaders, such as village elders, tribal chieftains, or other influential persons, and the welfare organizations, including the voluntary agencies and laity." (Community TB WHO

2003) For decades, the literature includes examples documenting many groups involved with TB care, including village doctors, traditional healers, church members, and other volunteers. Groups focused on patients' rights, HIV, health, and other development themes have also become involved in the fight against TB.

> *"An important ingredient that has been largely lacking in advocacy and social mobilization efforts to date: input from the communities and populations most affected by TB. These voices—those of patients, health workers, community volunteers, and other members of civil society—are vitally important because they offer first-hand experience on the gaps between policy and practice, the social and economic impact of the disease, and—on a more hopeful note—successful interventions that should be replicated or scaled up. The battle against TB cannot be won by health care workers and doctors alone…[we] sound a clarion call for increased action, by a wider range of actors, and more quickly."*
>
> *—Dr. Jorge Sampaio, former president of the Portuguese Republic and UN Secretary General*
> *First Special Envoy to Stop Tuberculosis*

Three critical areas of TB programming are a natural fit for NGO and CSO community-level work. As NGOs and CSOs are often already positioned to serve as a bridge between the health system and the community, they are natural candidates to fill these roles. Health expertise is not a requirement—just a willingness to learn the basics of TB and to link to government TB services. Below is a brief overview of these areas. In the next section, more detail is provided about how the actual program or activities might be designed.

- **Case finding or case detection.** Local people and organizations are in a good position to help identify people with symptoms of TB and link them to services. As people go about their daily lives, at home, work, and school, and participate in cultural, political, economic, and religious activities, there are many opportunities to find out who might have symptoms of TB. Case-finding practices also help find people who have been exposed to TB, so that they can receive Isoniazid Preventive Therapy for latent TB infection.

- **Treatment support.** TB treatment entails taking pills regularly over the course of six months to several years. This can present challenges including experiencing side effects, forgetting, losing, or running out of medicine, and having social and emotional complications. Treatment supporters help overcome these obstacles.

  The medicine-taking routine is often easiest when integrated into the patient's everyday life. Historically, and still in many places, TB patients are expected to report to a health facility every day to take their medicine. Too often, the patient doesn't have the time, energy and/or resources to make that daily journey—and treatment fails. The patient does not get better, may develop dangerous drug-resistant TB, and meanwhile, TB continues to spread in the community.

- **Advocacy, communication and social mobilization** (ACSM). ACSM activities help build public knowledge, and foster positive attitudes and practices that contribute to efforts to stop TB. Such efforts are most powerfully organized "from the inside," by people who really know and belong to the community. What wrong beliefs do people have about TB? What keeps sick people from seeking help? What pressures, beliefs, and stigmas might be getting in the way? (Stigma is the unfair disapproval or prejudice against a person, in this case, because the person has or may have TB.) What is the best plan of action to create positive change, in this community, at this time?

Addressing Traditional Stigma in Senegal
During community-based TB programming from 2003–2006, the local staff of Child Fund Senegal learned that many villagers believed offending ancestors caused TB. Death from TB broke ancestral ties, and the victim was denied access to proper funeral rites—resulting in eternal isolation. Hence, people were afraid to admit the possibility of having TB even to themselves, and may have preferred to die undiagnosed and untreated. By working with traditional healers, grandmothers, and others, the project was able to directly counter these beliefs. Traditional healers agree to help by addressing the spiritual issue while at the same time referring people with symptoms to the local "health hut." TB was also included in school curricula to increase students' understanding of TB and reduce stigma.

F. SPECIAL POPULATIONS THAT MAY BE BEST SERVED THROUGH COMMUNITY-BASED PROGRAMMING

Women with TB, Including during Pregnancy

> *"Positive TB diagnoses have damaging consequences for women. Socially, the stigma of having TB falls more heavily on women than men. In some communities, a positive TB diagnosis may force women into divorce or, if unmarried, create difficulty in finding a marriage partners."*
>
> *—Results*

TB is the third leading cause of death among women of reproductive age. Despite this reality, many health systems do not reach women with TB effectively, and women may have greater delays in diagnosis, often due to difficulties accessing care. Cultural norms can affect TB progression in women: in some areas, women in families will be the last to eat, impacting their level of nutrition and vulnerability to disease. Women are also less likely to cough publicly, resulting in hiding their disease state and disease progression. Women often face more stigma from TB, resulting

in being considered "unmarriageable," in some societies, and TB of the genital tract can result in infertility, increasing stigma in women.

Given these obstacles, TB programs can be designed to be more mother- and woman-friendly. Screening for TB, collection of sputum samples, and follow-up TB visits can be conducted during family planning visits, or other visits for gynecologic or child health care. Employing female community health workers may encourage more communication and opportunities for knowledge-sharing among other female patients. Targeting mothers as a source of communication and knowledge can be effective in increasing case detection and improving referrals because they are usually the "first responders" within families.

Women under treatment for TB should be counseled not to get pregnant while on treatment, and referred to family planning services. TB medications may harm a fetus.

Women who are pregnant face many challenges if they are exposed to TB. TB is more common in women during and shortly after pregnancy [62]. Pregnant women also run the risk of transmitting TB to their newborn. Babies of women with TB may be premature, of low birth weight, and are at higher risk of fetal death [48]. Pregnant women with TB and HIV are another special group: these women are 10 times more likely to develop active disease when compared to women were are not HIV-infected, and TB doubles the chances that their new babies will be HIV-infected [45].

People with Both TB and HIV

People who are infected with both TB and HIV are at great risk of complex health problems and death. Ideally, every newly diagnosed TB patient should be tested for HIV, and HIV-infected patients should be regularly assessed for TB. If they have been exposed to someone with TB, they should receive preventive therapy.

Both diseases often compound patients' stigma: patients with HIV may be seen as immoral or less deserving, and TB patients may be perceived as cursed. Dually infected patients may also belong to more impoverished groups with less access to health care. Unfortunately, many HIV patients still do not have access to proper treatments, including antiretroviral therapy (ART) and cotrimoxazole preventive therapy (CPT). Those who can receive services are burdened with

higher pill counts for medications for both illnesses, and may suffer more side effects because of drug interactions between ART and TB drugs. HIV-infected patients may also get other infections, may have an increased need for hospitalization, and may have to take medicine for a longer period of time.

Often, co-infected people need to navigate two separate health systems, one for TB and one for HIV, which likely evolved differently within national health care systems, and often do not have collaborative services. These patients can benefit greatly from patient-centered and home health care services. They need quality support and close monitoring for taking both ART and TB medications, and nutrition assessment, counseling, and support as well.

Thus, collaboration is crucial for NGOs supporting people with HIV/TB co-infection. NGOs can help navigate and link both health care systems. Often NTPs wiltest and track patients sent for HIV screening, but national HIV programs do not track patients tested for TB as routinely. Integrated services require training staff and other workers in both diseases. Although this training calls for more investment from the NGO and national programs, it will increase human resource pools in both areas, and strengthen health systems for both programs.

Three key factors that must be addressed for co-infected patients include the following, known as the 3 "I's":

1. Increased case detection

2. Attention to infection control

3. Provision of isoniazid preventative therapy (IPT) (IPT is medication to prevent TB infection in those who have been exposed to someone with TB. This includes children.)

In addition, recommendations from WHO from March 2012 include the following:

1. Routine HIV testing of all TB patients, people with symptoms of TB, and their partners or family members.

2. Provision of co-trimoxazole for all TB patients who are infected with HIV.

3. Starting all TB patients on ART as soon as possible (and within the first two weeks of starting anti-TB treatment) regardless of immune status.

4. Prevention of HIV for TB patients.

HIV advocacy groups have had impressive successes increasing awareness of HIV, mobilizing communities and influencing policy to improve HIV services globally—and are an amazing model. Establishing linkages with HIV advocacy groups can therefore increase TB capacity and awareness. In addition, influential TB groups can also advocate for more ART, IPT, and CPT for co-infected patients.

People with Drug-Resistant TB

Patients may suffer from drug-resistant TB either by direct exposure to someone else with drug-resistant TB, or as a result of incomplete or inadequate therapy—meaning they didn't finish their course of medication, were prescribed an incorrect regimen, received low-quality drugs, or it simply didn't work.

Longer therapy, unfamiliar drugs, and fear of transmission all make managing patients with drug-resistant TB more difficult. However, community-based management is still possible even for these patients. In fact, these patients often need more community support and involvement, considering that they will be on therapy longer, and will have more complex regimens. Such patients will need a real bridge between hospital-based and community-based care, and often want and will need treatment at home. NGOs have a distinct role in assisting this group.

The spread of drug-resistant TB is a serious public health threat and the correct taking of all medications is very important, both for the patient and for everyone else.

Community workers will need intensive training and refresher courses on drug-resistant TB, the multiple medications available, and their related side effects. They will have more reporting responsibilities than the workers caring for those with standard TB. Every dose of drug should be observed for these patients, even if this means observing therapy more than once a day. Patients with drug-resistant TB have a high likelihood that they were unable to complete a previous course of therapy, which means they may need more treatment support. In addition, they sadly now have a more complicated regimen and they might need help sorting through more medicines and keeping track of all the different pills they have to take.

Those administering drug-resistant TB therapy will need more advanced clinical skills and must be able to administer injections. Patients will require a clear plan for integrated care, including management of diabetes, HIV, family planning, etc. **Women on treatment for drug-resistant TB should not become pregnant**, as many medications given can be harmful to the fetus. Considering these duties, a strong case can be made to pay DOT supporters and community workers who care for patients with drug-resistant TB.

Attention should be given to the supporters' needs and to community health workers in this setting, because they are at occupational risk of acquiring drug-resistant TB themselves. Such workers should be educated clearly about infection control and monitored to ensure they are using their knowledge correctly.

Children with TB

> *"The time has come for the hidden epidemic of childhood tuberculosis to emerge from the shadow of adult tuberculosis and be seen as a neglected child health problem of considerable proportions in precisely those communities that do not have the resources to deal with it adequately."*
>
> *—Peter Donald, Childhood Tuberculosis: The Hidden Epidemic*

TB in children can be challenging because children often do not produce enough sputum to diagnose smear positive TB, and are often not infectious, which has historically led public health programs to overlook them. But in fact, children, including infants, with TB still suffer from their illness, and can be successfully diagnosed and treated.

Children with TB can have different signs and symptoms from adults. The younger the child, the more likely he or she will have widespread disease, such as TB meningitis, or TB involving the spine (which may take years to develop). Importantly, children under five years old with untreated TB can rapidly progress to severe disease and often die, especially if they also have malnutrition, live in poverty, or are co- infected with HIV. Therefore, childhood TB significantly contributes to child morbidity and mortality.

There are a variety reasons for addressing childhood TB at the community level. Childhood TB reflects TB in the community and the functioning of the health program: the presence of a child with TB is a measure of ongoing transmission. Child contacts of each case of active TB should be assessed and referred for preventive therapy or treatment. At the same time, diagnosis of a child with TB indicates that an active, infectious adult is present in a family or household and that active case finding is needed.

Although efforts should always be made to find TB bacteria in sputum samples in children, clinicians should also rely on signs and symptoms of possible TB in children. Physicians from *Médecins Sans Frontières* consider the heavy cost—likely death—to children of not treating TB where there is a high TB burden, and a high likelihood that an exposed child with typical symptoms has TB, even though the bacillus is not detected in the sputum. [69]. Often these physicians will treat these children presumptively (that is, by assuming they probably have TB, based on symptoms and exposure), and the children improve.

According to WHO, *Isoniazid Preventive Therapy* (IPT) should be provided to all children under

five years of age as well as to HIV-infected children of any age who have been exposed to an infectious adult and who do not have TB disease [70]. Yet, this is not happening in most places—an urgent problem. The development of active disease mostly happens within one to two years after infection and can be successfully averted if preventive therapy is provided. Children who do not receive IPT remain a lifelong pool for future disease, so if not dealt with immediately, the problem will be dealt with later, at a higher cost.

The quicker a child with TB gets on treatment, the better the odds that he or she will be cured.

Although children with TB have been ignored across nearly all health sectors, from advocacy to policy and from implementation of programs to provision of child-friendly drugs, recent advances have been made in pediatric TB. New guidance on the appropriate dosage of drugs has been issued [71], more data have been made available on how much disease there is in children, and more support on making clinical diagnoses in children has been made available.

The possibility of pediatric TB should be addressed in integrated maternal and child health programs. NGOs are badly needed to help increase awareness and knowledge of pediatric TB. All providers who treat children should be included and engaged in the fight against TB.

Vulnerable or "Hardly Reached" Populations

Marginalized and neglected groups often live in remote areas, or other settings that are "invisible" or overlooked. Little formal health care, either by the government or otherwise, is provided in these areas. In addition, this segment of society is often the most impoverished, further complicating their TB disease if they have TB by malnutrition, poor underlying health, and unique problems with stigma. Their conditions expose them to nearly all the risk factors of acquiring TB, such as overcrowding, and also to those that favor progression from latent to active disease, once infected. In addition, if these populations have limited health care access, this predisposes them to spotty care, which translates into taking intermittent doses of TB drugs, resulting in high rates of drug-resistant TB. All of these conditions provide fertile ground for TB to thrive.

NGOs and other local organizations often work with marginalized populations, and this interaction can be the starting point for these underserved communities to learn about tuberculosis. NGOs can employ health workers or train volunteers to conduct active case detection and contact investigations in these areas. The visits by trained personnel offer the opportunity for communication about TB and other illnesses to this group. NGOs in Brazil and India worked with volunteers to increase case detection and adherence in urban slums. Health agents after one month of training performed contact tracing, sputum collection, and transport, INH preventative therapy, and DOT directly to the slum inhabitants, through door-to-door visits. The Programme for Community and Association Support (PAMAC) in Burkina Faso partnered with other local

organizations that had a deeper reach into more vulnerable populations to improve DOT and case detection through the region. Home care providers, traditional healers, and health care workers all contributed to improving contact tracing and case detection.

Many organizations have ties to refugees, sex workers, drug users, prisoners, and other marginalized populations. NGOs currently working with these populations can serve as an intermediary between marginalized populations and policymakers, giving these groups a way to influence the political process. Additionally, NGOs can use their knowledge of cultural norms and beliefs to address TB-related stigma. In Moldova a community organization, *Speranta Terrei,* not only provided treatment support to those with TB, but also housing and shelter to former prisoners and the homeless with TB. Leaders also directly engaged municipalities to tell patient stories and effectively helped 625 patients receive treatment over six years. If NGOs are not currently working with these groups, they can identify others that are and partner with them to provide TB services to these populations and strive for health equity.

People in Urban Settings

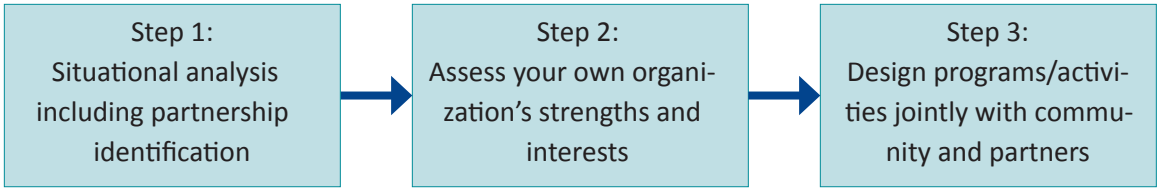
Those in urban settings with TB may also face unique challenges. Primary health care may be weaker in cities, and urban dwellers may be more mobile and difficult to locate, resulting in infrequent health visits. Weaving community-based care into their lifestyles may require more creativity. Some NGOs have used employment settings as a way to manage patients by giving treatment at work, while being cautious about confidentiality. Shopkeepers may be trained to identify those with TB, and tea stall workers have also been trained to detect TB or support patients with adherence.

Cured Patients and Communities Help Out in India

Operation ASHA provides TB care to inner cities in Delhi. Staff recruit former TB patients and community members to conduct door-to-door case detection and refer possible patients to hospitals for TB diagnosis. Once TB is detected, the community workers become DOT providers to residents in urban slums. TB drugs are directly obtained from the NTP in Delhi, so quality drugs are provided both for treatment and preventive therapy. Engaging former TB patients reduces stigma and sends the message that TB can be cured; having DOT centers within the slums allows patients to have access to quality drugs for TB treatment.

IV. Action Planning

Now that you know about TB, its history, the global Stop TB Strategy, how programs are designed and implemented on the ground, and which populations may warrant special attention, it's time to begin to plan how your organization will get involved. As you work through this exciting process, remember: TB efforts should not be designed in isolation.



Modified from Community Involvement in Tuberculosis Care and Prevention: Towards Partnerships for Health (2008)

Two logical steps can get you started: learning about the overall TB program landscape in your area and country, and looking at your organization's strengths and skills, and how these can be integrated with TB efforts. This effort will likely include addressing infection control, understanding NTP recommendations, understanding sources of stigma in the community, and more.

A. STEP ONE: LEARN ABOUT THE TB PROGRAM LANDSCAPE: CONDUCT A SITUATIONAL ANALYSIS

A situational analysis of current TB activities, including national involvement, will provide the intelligence needed to lay the foundation for your organization's efforts: partnership. As you conduct the situational analysis, you can also begin building productive relationships with key stakeholders, including NTP and MOH staff, public and private health care workers and managers, other CSOs and NGOs, local government staff, community groups, and others.

Your program will need to coordinate and collaborate with the NTP and/or the MOH in your area. Your team should reach out to key people to learn about NTP policies, guidelines, and work plans. Ultimately, the responsibility for TB diagnosis and care rests with the government. It is both a potential implementing partner and a possible target for advocacy.

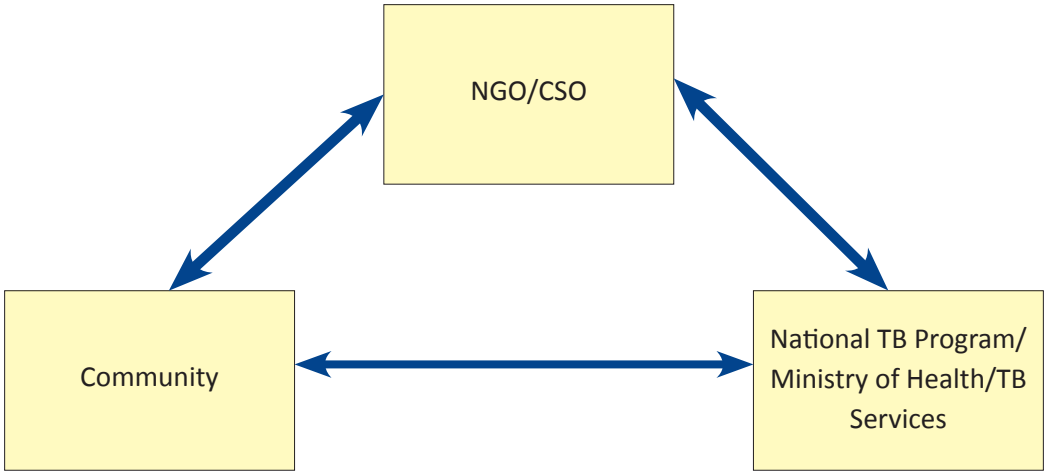
Situational analysis involves learning about the current range of TB services available to people in your community, and what individuals and groups (including other NGOs/CSOs) are involved. As part of finding out about current services and providers, explore their motivations, goals, and objectives. Some providers may be from the private sector. Links between the private and public sector may be weak; nevertheless, your organization will need to learn about and ideally link with all existing players.

Gaining a sense of a country's commitment to TB is also important. For example, if the political

commitment of health officials and policymakers in a given region is lacking, a good first step might be to drum up support for the issue. In addition, you should assess current needs and gaps in TB care in your region. If treatment outcomes are good and the program has achieved a very high cure rate, your organization may contribute more to case detection. On the other hand, if treatment outcomes are weak and there is a high death rate and many patients are lost to follow-up, treatment support activities may be prioritized.

In addition, assess who the key stakeholders in a community are in general, their knowledge, attitudes and beliefs, and how best your NGO might enrich this picture. Your group will need to engage with current stakeholders in your area of work. A dialogue between these three groups should begin early, and continue throughout the design, implementation, and assessment phase of the program.

Effective communication should flow between key groups:



Supporting two-way linkages between the NTP and other providers is important. Effective marketing and community-based service outreach should be designed in collaboration with health authorities. This should include a referral system that will refer potential TB cases to the NTP or appropriate services.

Partnership building for TB programming in Mexico

To increase human resources for a TB program in Mexico, Project Concern International partnered with ISESALUD, the state health service in Mexico, to create a two-level DOT provider system. Tensions between the facility-based care system and the community were lessened by having two types of TB care providers: promotoras (community-based) and DOT (facility-based). These providers worked together and became an integrated part of the larger TB program. As a result, treatment success rates increased from baseline levels of 48% in 2004 to over 70% in 2007.

B. STEP TWO: ASSESS YOUR NGO'S STRENGTHS

After meeting with the NTP/health services personnel and stakeholders and learning about gaps in TB services, work with your team and others who know your organization to assess how well-equipped your NGO is to engage them. Do you have existing links in the Ministry of Health, Education, or other relevant entities? Are you well-placed to identify people with TB symptoms and refer them for care? Or are you better positioned to provide treatment support after people with TB start treatment?

After assessing the TB landscape, you may consider the following questions: What is your current area of expertise? How might you best integrate TB with your current activities?

Consider your NGO's location: what are the local rates and patterns of TB? Will this involve drug-resistant TB? Are you in one of the high-burden countries? Will you need to consider HIV co-infection?

If your expertise is advocacy (promoting interest and understanding of an issue) in another area: can you use your advocacy/ messaging for consistent messaging or training in advocacy or other communication strategies in TB? Can you leverage your capacity to reach out to inaccessible and remote areas, including conflict zones?

C. STEP THREE: DESIGN A SPECIFIC PROGRAM OR ACTIVITY

This step describes cross-cutting issues that will apply to any TB work you do (such as infection control) and then provides examples of specific activities you may decide to engage in. Starting simple is recommended. As your organization grows in understanding of TB and how it affects your community, region, and country, you can begin to build up a more complex program.

CROSS-CUTTING ISSUES

No matter what your organization decides to do to help stop TB, certain issues apply, and should be considered. These issues "cut across" all activities.

Infection Control

Before doing anything, an NGO must consider infection control. On the one hand, you don't want to promote stigma, but the reality is, until treatment is under way, TB can be infectious. If your organization decides to implement a community-based program, it is likely that staff or volunteers will be exposed to TB, so every effort is needed to ensure that infection control measures are in place.

Everyone should understand that TB is an airborne, transmissible disease: staff and volunteers within organizations are susceptible to TB as are the patients they want to treat, especially if

HIV-positive. All those engaged in TB efforts should practice basic infection control measures to minimize risk. Patients with suspected TB should be taught to cover their mouth with a cloth or tissue when coughing, and wear surgical masks if available.

Ideally, staff and volunteers meeting with people who might have TB should meet with patients outside, stay far from a person who is producing sputum, and follow other simple measures. Indoor spaces, if used, should include open windows and doors, and be arranged to allow airflow away from the staff and volunteers. Exhaust fans may also be used to move air from within a room to the outside.

When available facility-based staff are advised to wear the appropriate masks (known as N95 and N99). However, this isn't common among those doing work in the community—often because they are able to do much of their work outside. Banners and posters describing cough etiquette can also be helpful.

Simple ideas can make a big difference. For example, communities have built sputum production booths with no roof, far from any building or gatherings of people. Resources and guidance on TB infection control describe many valuable tools and concepts.

Cough etiquette: Guidance for staff, volunteers, and clients

To help stop the spread of germs

- Cover your mouth and nose with a tissue or handkerchief when you cough or sneeze.
- Put your used tissue in the waste basket.
- If you don't have a tissue, cough or sneeze into your upper sleeve or elbow, not your hands.
- You may be asked to put on a facemask to protect others.
- Wash your hands often with soap and warm water for 20 seconds.
- If soap and water are not available, use an alcohol-based hand rub, if available.

—Adapted from Centers for Disease Control guidance.

Too often health staff and volunteers are reluctant to be evaluated for suspected illness, including HIV and TB, and resist diagnosis and treatment services. Management and project leaders should foster a supportive and open atmosphere that addresses this issue. All who work with TB patients should know their own HIV status. HIV-positive patients, staff, and volunteers are at extra risk of catching TB and suffering serious illness, even death. It is a common mistake for many patients and staff to be crammed into meeting spaces and waiting rooms where possible

HIV and TB patients are together. Those with HIV, whether they know their status or not, should be educated and protected

Mastering the Facts, Starting with Your Own Staff and Volunteers

> *"The Patients' Charter for Tuberculosis Care practices the principle of Greater Involvement of People with Tuberculosis. This affirms that the empowerment of people with the disease is the catalyst for effective collaboration with health providers and authorities and is essential to victory in the fight to stop tuberculosis."*
>
> *—Patients' Charter for Tuberculosis Care*

Your organization's staff and/or volunteers will need proper training—on a regular basis—and ongoing support. Once your NGO decides to move forward on TB, a host of creative training, learning, and supervision techniques can help staff learn what they need to know, retain it, and perform in a high-quality, consistent, and satisfying way.

A key issue they should understand is stigma against people who have or may have TB. Sadly, rude and disrespectful treatment of patients by health workers or volunteers is not uncommon.

Change begins at home—don't let your people make the same mistake. Staff and volunteers have a great deal of power to lead and influence the community. When used well, this power promotes health and well-being. When this power is misused, and stigmas are promoted and incorrect information is spread as a result of negative attitudes or ignorance of the facts, it can cause a great deal of damage.

Attitudes should be explored early, and ideas of rights, fairness, respect, and dignity should be agreed upon and promoted. The Patient's Charter for Tuberculosis Care is an excellent document to work from when exploring these issues.

Staff and volunteers should master correct information. The NTP is also an important source of information and all organizations need to consult with NTP guidance to ensure they are operating within the national guidelines. They often have communication materials that the audience should use so that they are consistent with NTP guidelines.

Written materials, including checklists, can help learners remember and refer back to the facts. Many online resources exist that can be helpful—if they are not consistent with your country's guidelines, you can adapt them. Staff knowledge of the following should be properly demonstrated on a periodic basis:

- What causes TB?
- Who can get TB?
- What are the symptoms of TB?

- How is TB transmitted?
- How is TB cured?
- Where and how can a person get TB diagnosis and treatment? How much will it cost? How long will it take?
- Why is it important that people who might have TB get proper services and care?
- Why is it important for people with TB to take all of their medicine as prescribed?
- What is drug-resistant TB?
- What are local beliefs and practices related to TB?
- What are the connections between TB and HIV?

Empowering staff and volunteers with this information is the first step in empowering the larger community.

A Powerful Tool: TB Clubs

Patient organizations of former and non-infectious TB patients, such as TB clubs, have been very effective in communication; they can be mobilized further for many TB activities. In Malawi, within the Mwanza AIDS Support Organization (MWASO), three to 10 patients with TB form a "TB club." They support each other by attending outpatient visits together, support each other with adherence to treatment, identify possible adverse drug reactions in other members, and seek the help of influential community elders and priests to persuade suspected TB patients to seek diagnosis and adhere to treatment. [80]

Engaging Current and Former TB patients

A host of community representatives should inform your work, but one group is especially important. Former and current TB patients (who are no longer infectious) have been a largely untapped but vital resource in TB prevention, diagnosis, and care. Community programs that actively seek to include them in design and implementation have brought more self-reliance and empowerment to communities by having those most affected by TB participate in their TB programs.

The voices and stories of patients with tuberculosis are not heard enough. Patients who have suffered from TB place a human face on the disease and can remove stigma. They become a communication pathway for the community and increase awareness by sharing their experiences and stories in schools, religious meetings, and other community gatherings.

TB patients can assist others on an individual level. Due to their own experiences, they may be well-informed about the clinical presentation of disease, and can perform case detection and referrals. They can promote community and public health sector DOTS services. They can be called to become treatment supporters for other patients, accompanying them for follow-up visits, to collect medications, or make sputum collection visits. They are also well-positioned to detect adverse events in others on therapy and refer those patients appropriately.

D. POTENTIAL AREAS FOR NGO/CSO INVOLVEMENT IN FIGHTING TB

Now that you've conducted a situational analysis, planted the seeds of partnerships, and learned about cross-cutting issues, it's time to zero in on what specifically your organization can do that is both realistic and has potential to make a real difference. The following pages outline a host of possibilities. As counseled before, starting simple is usually the wisest way forward.

1. Active Case Finding and Contact Investigations

> *"Look at case detection, which has stagnated…for the past several years. How do we reach the difficult cases and engage them into treatment?"*
>
> *—Dr. Lucica Ditiu, Executive Director, Stop TB Partnership*

Active case finding and contact investigations are the efforts to track down people who show symptoms of TB or have been exposed to a person with infectious TB. NGOs and CSOs often have strong ties to the communities they serve and some reach even the most remote areas within communities, complementing the services of public health programs. Home care providers, community leaders, nurses, and community health care workers can be trained to recognize symptoms of TB, and to perform door-to-door inquiries to identify potential TB cases. They may also collect and transport sputum samples to lab facilities to assist in case detection.

Other community members can also be trained to identify signs of TB and how to refer possible TB patients to the appropriate facilities. Hair stylists, tea stall workers, shopkeepers, and traditional healers have all been enlisted to help. Training is needed for these potential volunteers, ranging from one day to one month. Re-assessment and refresher training should happen regularly.

Currently, important gaps in TB diagnosis exist that will impact the level of increase in case detection. Ideally, the laboratory capacity for diagnosis should be able to handle referred

cases. If this is not so, advocacy for better or expanded services, as appropriate, may be called for before overburdening a lab or creating unrealistic expectations among the public.

2. Treatment Support and Directly Observed Therapy (DOT)

In the Global Plan, the crucial "value added" of DOT is characterized as "the addition of the human element—having health-care workers or volunteers form a close bond with their patients to help them successfully complete treatment." This goal is often not realistic in health facility-based DOT, but much more realistic in community-based DOT.

Community-based TB care projects in Africa in the 1990s showed patients can receive DOT in their homes, and that this patient-centered approach improved adherence (proper pill taking) and treatment completion. [19]

Treatment supporters are the backbone of community-based TB care. Simply described, a treatment supporter is enlisted to accompany patients to facilities to receive drug supplies, and to personally watch and record when each dose of medicine is taken.

The debate as to who should be a treatment supporter for a patient continues, but it is generally agreed that who is best suited for this role depends on the region and cultural context. In some instances, family members may be appropriate for this task; in other cases, neighbors or other guardians may be better, or paid community health workers may be best suited. The patient should play an active role in making this decision. Strong links to the NTP are as important here as they are for other aspects of TB prevention, diagnosis, and care. These links can help ensure good quality care and accurate reporting and monitoring.

In some regions, such as urban slums, DOT centers (a facility-based model) may be the accepted, convenient model for receiving therapy, and some patients may still opt for centralized services, and agree to report to a facility every day. Stigma around TB may be strong in other areas and patients may not want daily home visits. Many organizations have been successful in training residents, shopkeepers, or others in central locations to be the DOT providers.

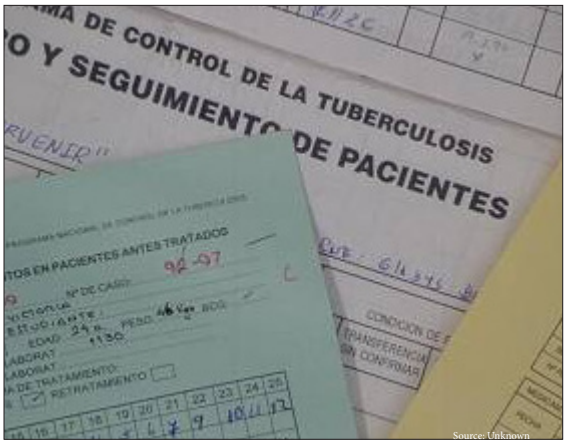
What works in one place may not in another. Regardless of the model adapted, the central theme remains the same: use a patient-centered approach! If treatment is designed to be as easy and acceptable to the patient as possible, success is more likely.

Fundamentals of Treatment Support

A key piece of treatment support is learning **which drugs have been prescribed for each patient, and the schedule for taking them**—how often, and for how long. Some patients will need to take medicine every day, while others may take the medicine three times per week, depending on NTP guidelines. This calls for working closely with those providing TB drugs, and helping to

monitor a patient's taking of the medicines. If a private provider is involved, this provider should be following explicit guidance of the NTP.

Record keeping is also critical. An important part of taking the medicines is keeping careful track of what has been taken, and when. This information is important for good patient care, as well as for recording data that help everyone understand how common tuberculosis is in a place, and how successful treatment efforts are.



Each NTP has its own requirements and forms on all levels of the program, and NGOs will need to know how to complete them properly if they are providing treatment support services or have the responsibility of monitoring specific patients or all patients in a specific community. Patients usually have an identity card and a treatment card, and each dose the patient takes is recorded on the treatment card. In some places, electronic reporting and recording are being used.

At times, TB patients may need help **dealing with side effects**. These might occur during a patient's therapy, and can be minor, such as vomiting and nausea, or may be more serious, such as tingling and numbness, or visual disturbances. Side effects should be reported to the health facility and NTP, and any changes made by prescribers to the patients' medicines should be recorded. Improving food and nutrition can often decrease side effects. Some regions provide nutrition supplements and food in patient packages along with TB drugs to improve patient outcomes. NGOs with experience in food security or similar areas may also provide this kind of assistance.

Other factors can also make TB therapy successful. Providing nutritional supplements and assisting patients with transportation help patients stay on treatment. Communication and education with patients are also important. Patients are more likely to complete therapy if they understand how long they are likely to be infectious while they receive treatment, and how to avoid infecting others. They should also understand how long therapy will be, what side effects they may experience and how to handle them, and, of course, that they can be cured with treatment!

3. Community Health Workers and Volunteers Involvement

As in many other aspects of health programming, community health workers can play a pivotal role in community-based TB care. They can serve as a link between the patient, families, and treatment supporter, and formal health systems. Community health workers (CHWs) may provide DOT, serve as treatment supporters, advocate for improved TB programs, serve as health

educators, and conduct home visits for general support. They can conduct door-to-door visits for contact tracing, case detection, and following up on treatment interruptions (e.g., patient has stopped taking the medicine before it is completed).

The selection of CHWs should take into account local attitudes and practices. Traditional healers, village doctors, and nurses have all effectively worked as CHWs.

The CHW often plays a separate role from the treatment supporter, and these roles need to be clear. In some cases, those community workers who provide drugs are more highly valued than those who are involved only in health promotion and prevention. Differing levels of respect given to different community health care provider roles should be discussed and addressed when designating positions in community-based programs. CHWs are often motivated by support from other health providers and by reasonable levels of activity. Their services may require many hours. Some programs elect to provide monetary compensation for these workers, and NGOs should consider carefully how such incentives will be provided, who will bear the cost, and what effect it might play on sustainability—that is, the ability of the effort to keep going over time without running out of funds.

When feasible, CHWs can offer a value added to TB programs. In many cases, employing CHWs has resulted in lower dropout rates and better adherence globally.

4. Integration of TB with Other Services

There are many opportunities to provide TB care, be it prevention, contact tracing, case detection, or treatment, in other sectors. NGOs working in other development or health care programs can incorporate TB activities into their existing programs. This is an asset for NGOs, because they frequently take a holistic approach to programming by focusing on social factors that influence health, and this can create synergy.

Reproductive health is an avenue to provide TB care. Women who visit clinics for family planning or antenatal care should be asked about TB exposure: do they or anyone in their household have TB or TB symptoms? Short questions on TB symptoms can be integrated with health questionnaires. Women undergoing treatment for TB should be counseled to finish treatment before becoming pregnant. The APHIA II

project in Kenya successfully integrated TB care into postnatal care visits, screening women for TB symptoms during the postpartum period and also linking with the national TB program to provide TB treatment. The project also provided TB screening within immunization, nutrition, and well-child care because of the demand for this service.

Child care, immunization visits, and sick child visits are untapped opportunities not only to clinically diagnose pediatric TB, but also to make inquiries of the family of other members who may have TB or TB symptoms. These visits can serve as the starting point for identifying infectious cases of TB—which present a direct threat to the health of children in the household, and may provide insights into the child's health issues.

Patients receiving care for other issues that are linked to TB, such as respiratory care for smoking-related illness, diabetes, and other non-communicable illnesses, can also be screened for TB during these visits. The NGO can provide awareness campaigns and messaging about TB throughout the health care sector, as well as to groups that may be galvanized around another health issue.

TB can be integrated into other aid programs. *The Center for Woman and Child Health* improved detection of childhood TB in Bangladesh by educating communities about the illness and included education in schools and for people in micro-credit programs. Other complementary project areas include micro-finance, education, other social support projects, voluntary counseling and testing (VCT) services, and advocacy for other public health mandates.

What is Integration?

The World Health Organization describes it as "the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system" (WHO 2008). Integration can mean different things to different people, ranging from providing a "one-stop shopping" of many kinds of care (such as prevention and curative services in the same place) to linking between sectors, such as education and health. In general, integration is a good idea for patients and providers: ideally, patients can visit one or a few health care workers who understand their illness(es) and can take care of them. And, providers can provide more well-rounded care. Integrated services can also often results in health systems strengthening, by providing more services to communities, and also improving training of health care workers.

5. Advocacy, Communication, Social Mobilization

"My interest in TB stems from the fact that in my 30 years in the medical profession, I have seen every kind of suffering because of TB, and a steady deterioration in the situation. This is in spite of free treatment and diagnostics. So something is missing somewhere, and a critical need is to find the missing link and fill the gaps.

TB needs much more advocacy. We need to express a sense of urgency and anguish, and most important, tell everyone that there is a cost-efficient, self-sustaining model already in place that is giving outstanding results. More and more, from different walks of life, have to join this movement, in order to make an impact. This is why your work is of tremendous importance."

-Dr. Shelly Batra, Operation ASHA, India

Advocacy, communication, and social mobilization (ACSM) underlie nearly every aspect of community-based TB care. These tools and approaches have been underused in TB prevention, diagnosis, and care but when employed skillfully, they can increase case detection, reporting of cases, knowledge of TB in a community, treatment success, and stigma reduction.

Advocacy refers to influencing key decision-makers to ensure that TB is addressed on political agendas to sustain political commitment and funding for TB. NGOs with ties to Ministries of Health, other international organizations, and funding sources can use these relationships to increase political will and resources for struggling TB programs. They may be well-positioned to advocate at higher political levels for the communities they serve. In addition, data gained from their programs should be used as an evidence base for further scale-up.

Communication can be described as any process people use to exchange information about TB. Communication should emphasize a two-way process of dialogue and participation. Communication can include education about TB disease and awareness-raising about programs and services that are available to the community. Communication is also a powerful way to combat stigma.

Social mobilization draws together communities affected by TB to increase self-reliance and sustainability of TB care programs. Social mobilization fosters a range of activities that empower communities. This may include involving in local leaders from religion, government, associations, traditional culture, schools, children, and others.

Key concepts and ideas related to behavior change communication can be used to communicate and educate about TB. Targeting leaders and influential personalities in a local area with sensitivity and respect, and introducing new ideas to them over time, can result in dissemination of these new ideas by these leaders within the community and improved TB related knowledge, attitudes, and practices. The Axshya Project in Bihar, India, includes TB education and messaging via community-based groups created and led by women. Women in villages meet monthly and discuss personal and financial concerns. Women later become community leaders in the village,

and empowered with the knowledge that TB is curable, they encourage other women and villagers to get tested for TB if they are symptomatic, and to seek treatment.

The initial stages of community engagement will set the stage for mobilization and empowerment. Participatory processes are key. Focus on partnership-building with the community from the onset: many examples exist of programs that have failed due to lack of attention to this, and others that have witnessed success when they have done this correctly. The tone and attitude of engagement should be respectful, wherein all players recognize the role of community in health and development, and the relationship based on principles of social justice and human rights. The community also should clearly understand that this new effort is a partnership, and not just a decentralization of TB services. Solicit political commitment and support from local leaders early.

6. Stigma Reduction

> *"Researchers all found low levels of awareness of the basic facts about TB and TB/HIV coinfection among political officials and the general population, including within high-risk groups such as people living with HIV/AIDS. Widespread ignorance of how TB is spread and the fact that the disease can be cured contribute to high levels of stigma and discrimination against people living with TB."*
>
> *–Civil Society Perspectives on TB Policy , Public Health Watch*

NGOs that are able to see the real and powerful problems caused by stigma can do something about it. Stigma describes many emotions and ideas targets against individuals, often most deeply fueled by fear and shame. Stigma can be deeply rooted in community structures and deconstructing it takes time. During the process, trust and respect are the foundations for change—starting with the NGO.

Stigma impacts TB care in many ways. In some regions, TB is considered "untreatable," so those who have TB become isolated and shunned by their families and communities. Patients with TB do not seek care for an illness because they do not believe they can be treated or don't want to face the terrible truth. In other remote areas, there is no TB care provided to people, which also causes people to believe that TB is untreatable. In these remote regions, lack of exposure to new ideas or outside influences that challenge harmful beliefs is a common problem.

Education and knowledge about how TB is transmitted, that it is curable, and awareness of TB services can lessen stigma. Communication activities that reach many people have resulted in more mobilization and reduced stigma in many programs. In the central region of Ghana, TB is perceived as due to bad spirits; so community leaders were included in TB advocacy and training to address stigma, resulting in increased treatment success rates, increased case detection, and decreased treatment interruption. In Senegal, TB was associated with ancestral curses, and sharing stories and ideas in grandmothers' communities gave rise to more community support. Later,

TB was considered to be a health problem rather than a personal curse.

Formative research—research that helps to plan or form an activity or intervention—is a good start to addressing stigma. Then, as NGOs defuse stigma, changes in knowledge, attitudes, and practices can be assessed over time with surveys and participatory research. Many helpful tools and strategies exist to support such work.

7. Training and Supervision to Build Local Capacity

NGOs can provide training assistance to increase local capacity for health system and NGO programs. NGOs have used their expertise in relevant subjects to create training on case detection, DOT, and ACSM, to name a few, and increase human resources available for multiple tasks within TB programs. They can train their own staff and community workers, as well as provide training assistance to NTPs. Joint training sessions can strengthen partnerships between the community and the NTP. Public health workers can train NGO workers or volunteers on storing drugs properly, maintaining treatment records, and referring those with suspected TB. All personnel should have an understanding of the referral system in place and know when to refer patients to the NTP.

8. Public-Private Partnerships: Joint efforts that May Include Government, Private Sector Providers, and Others

Private doctors, clinics, or other healers may be the first place TB patients seeks help. In some places, this applies to more than half of all TB patients. The private sector includes private practitioners who provide modern medical care, those who provide alternative medical services (such as herbal medicine), traditional healers, and pharmacists.

The private sector may be the first choice of patients because the public sector has a reputation for being rude, ineffective, or hard to access, or if entrenched, stigma and shame prevents people from using the services. While some private care may be of good quality, other private sector services may be problematic; some of these private services may fail to collaborate with the NTP or to report TB cases accurately, or may be hindered by slow diagnostic functions or poor management. Given the scale and influence of the private sector, they cannot be ignored in the fight against TB—indeed they represent a potentially powerful ally.

Engaging these providers and establishing a public-private partnership mix has become a priority for TB diagnosis and care. Within these partnerships, the basic requirements of the DOTS strategy can be successfully met. Private providers may help in many ways, including simple referral of possible TB patients to public sector TB clinics, and by treating patients under direct observation with free anti-TB medications provided by the government. In all cases, the NTP is kept informed and linked in as an integral component of TB care

Unfortunately, some private providers are not properly trained and don't offer effective treatment. NGOs can help address that problem as well by talking to those providers, working with local authorities to ensure that these providers are linked to the appropriate systems, or even monitoring whether or not the providers are prescribing correctly.

Pharmacists enlisted in Cambodia
With support from the Cambodian government, a PATH program taught pharmacists to send people who might have TB to a government referral hospital. PATH provided training, designed advocacy campaigns, and created booklets to help pharmacists identify patients. The project resulted not only in increased TB training for pharmacy and health care staff, but also increased referrals to health facilities for suspected TB.

9. Operations/Implementation Research

Operations Research (OR) on TB prevention, diagnosis, and care is specifically aimed at developing interventions that result in improved policymaking, better health system design and implementation, and more efficient methods of service delivery. NGOs might conduct a baseline assessment of available TB care services and map out how current efforts might improve in quality, sustainability, equity, and scalability.

Several parameters may be used to monitor community-based care and measure effectiveness. For example, research might compare outcomes for patients who choose community-based care with those who choose formal health services. OR can identify approaches to improving treatment adherence and document effective incentives for patients and health care providers. Community-based surveys on knowledge, attitudes, and practices (KAP) can be used to assess impact of ACSM activities, and measure changes. ACSM activities can be linked to specific gaps in case detection or treatment outcome targets, and appropriate indicators identified to measure impact of these activities. Data and knowledge gained by OR should be shared with the NTP and other groups to strengthen health systems. Monitoring and evaluation are important OR components. Creation and implementation of an M&E system should involve local staff, and ideally enable ongoing monitoring and analysis of data, after the project ends.

V. Conclusion

LESSONS LEARNED: AVOID THESE COMMON PITFALLS

As our collective experience in community-based responses to TB increases, so grows our understanding of **common mistakes** that can be avoided.

1. **Performing TB activities in isolation**. NGOs should not try to run TB activities completely independently, that is, without identifying existing partners and coordinating project efforts with the NTP, MOH, donors, and other implementing partners to ensure the appropriate selection, timing, and implementation of activities.

2. **Creating parallel TB programs that compete with NTPs**. NTPs should be central to TB programs and remain the reporting agency. Ideally, they should be supplying TB drugs. Creating structures that compete with the NTP will undermine their authority and will not be sustainable in the long run.

3. **Not planning for sustainability when developing human resources.** NGOs may rely heavily on community-based volunteers during the life of their project—but what will happen once the project is over? NGOs should consider how the salaries of staff will be supported after the project is completed, or consider training with skills that can be transferred to other programs, such as integrated training in HIV. Volunteers or treatment supporters are sometimes promoted to CHWs or other personnel who can then take part in national TB programs.

4. **Not paying enough attention to local beliefs and practices**. Careful attention to beliefs and practices, including misinformation and sources of stigma, will be needed when embarking on TB activities. Understanding the community where you are working will also help maintain sustainability. If the interventions are embedded within the community and are aligned with local cultural practices, this will increase the chances of deep and lasting change.

5. **Improving knowledge, attitudes, and practices without planning for increased demand.** Advocacy can increase resources and place TB as a higher priority on national health agendas. However, it will also increase demand for services, and plans should account for the demand to be created. Even if resources are not yet available for the demand, NGOs should anticipate how to maintain partnerships with other TB care providers and also work together for more political commitment to improve resources.

6. **Reinventing the wheel.** Whatever tool or material that is needed—ranging from mobile phone software to M&E frameworks to patient education materials—chances are, it already exists. And whoever made it will be happy to share. Before starting from scratch, do research. Many networks and resource hubs exist for the sole purpose of sharing.

JOIN THE EFFORT TO STOP TB

TB is preventable and curable—but only when we band together to make it so. The tools we use now have been available for decades but have not reached enough people. Never before have international health organizations, large donors, and health experts so loudly and actively called out to civil society organizations to help get these resources to more people and help stop TB.

Civil society is thriving around the world—in scale, in scope and in quality. Many, many organizations have key elements needed for successful TB care programs: partnership skills, an understanding of participation, communication and advocacy strengths, and the ability to work from the ground up to design patient-center care, increased efficiencies, and integrated services. NGOs are skilled in telling patient stories, defusing stigma, and responding to needs as they arise. TB patients, and people at risk of TB, desperately need this treasure trove of skills and experience. They are entitled to live in dignity and have access to basic resources, including information, care, and medicine. The global team that is conquering TB includes governments, advocates, donors, international organizations, health systems, and others—but not enough of civil society. We have the tools and means to make TB a disease of the past, which is its rightful place in human history—please join us to make this vision a reality. We can't do it without you!

USAID FROM THE AMERICAN PEOPLE

MCHIP Maternal and Child Health Integrated Program

coregroup Advancing community health worldwide.

GUIDANCE: HOW TO DEVELOP HIGH-QUALITY TB EFFORTS

A wide range of disciplines have come together to contribute to the vision of the well-rounded, properly grounded TB effort. As your organization crafts your own unique response to the challenge of TB, we recommend that you…

1. Forge Values-Based, Close-Knit Partnerships

Beginning or expanding an existing community-based TB effort requires a strong team that can work together to provide for people with TB, people with TB symptoms, and their communities. This team strategy should be built on a foundation of health equity (reaching everyone, even people who are poor or difficult to find), and respect and dignity for patients and communities, staff, and volunteers at all levels. Designing and running a team-based approach should emphasize active and effective communication among all participants.

2. Focus on Participation

Engaging communities in all aspects of TB—from prevention to diagnosis to care, and from design to implementation to monitoring and evaluation—can empower communities, foster local ownership, and improve impact and sustainability. From the start, an ongoing dialogue between the National Tuberculosis Program (NTP), NGO/CSOs and the communities is central to help everyone understand the complexities of TB prevention, diagnosis, and treatment, the needs of affected communities, and what might be the most effective ways forward.

3. Invest in Advocacy, Communication and Social Mobilization (ACSM)

ACSM is a comprehensive TB strategy to advocate for better services and funding, to ensure materials are available, and to directly involve communities. Social mobilization can empower communities and individuals to better understand TB as an illness, feel motivated that they and their communities can be cured of TB, and provide them the skills needed to take effective action. This mobilization and work on behaviors can prevent the spread of TB, identify and support people who may have it, and ensure that they get better. Success in these arenas is heavily dependent on awareness, education, attitudes, skills, and practices. Many excellent materials to assist with this work have been developed and are freely available.

4. Ensure a Strong Referral System

A referral system is the mechanism for connecting community-based efforts and people with TB symptoms to relevant services, which may include government services and private providers. All TB efforts should be knowledgeable about of the role of services of the National Tuberculosis Program (NTP) and/or its local affiliates. This knowledge is required not only to firmly link any TB program with the NTP, but also so local TB efforts understand systems for prevention, diagnosis, and treatment, and can meet patient needs. Referrals should be two-way: 1) community care programs should be able to refer people with TB symptoms to NTPs and formal health facilities; and 2) the NTP and health facilities should refer patients to community-based care whenever possible.

5. Integrate Programs into Existing Health Systems and Services

Many NGOs run a variety of development and health programs, including sanitation, micro-credit programs, HIV, immunization, family planning, antenatal care, nutrition, and many others. Integrating or linking these efforts with TB services can maximize resources and provide holistic services to TB patients and their communities.

6. Never Give Up!

TB is a significant health problem and, even though TB has been with mankind for a long time, not enough people know about it, and not enough is being done. The communities that TB affects the most are the ones least likely to have the correct information about TB prevention, diagnosis, and treatment, and are often the ones that feel powerless to do something about it. Lend your spirit and energy to changing these realities, as we all work together to stop TB.

"We do not accept the deaths of countless adults and children who die of TB in the 21st century, from a disease that has been preventable and curable since the late 1940's. Ending this pandemic and providing the health care needs of those affected by TB and TB/HIV is a core responsibility of governments, bilateral and multilateral donors, non-governmental organizations and civil society representatives.

-The Kuala Lumpur Civil Society Declaration on Tuberculosis, November 16, 2012

APPENDIX: Recommended Resources

THE STOP TB STRATEGY AND GLOBAL PLAN

The Stop TB Strategy. http://www.who.int/tb/strategy/en/
"WHO's six point Stop TB Strategy builds on the successes of DOTS while also explicitly addressing the key challenges facing TB. Its goal is to dramatically reduce the global burden of tuberculosis by 2015 by ensuring all TB patients, including, for example, those co-infected with HIV and those with drug-resistant TB, benefit from universal access to high-quality diagnosis and patient-centered treatment. The strategy also supports the development of new and effective tools to prevent, detect and treat TB. The Stop TB Strategy underpins the Stop TB Partnership's Global Plan to Stop TB 2006-2015."

The Global Plan to Stop TB 2011–2015. http://www.stoptb.org/global/plan/
"The Global Plan to Stop TB is a comprehensive assessment of the action and resources needed to implement the Stop TB strategy and make an impact on the global TB burden."

KEY RESOURCES

Advocacy, Communication and Social Mobilization: Library of publications
http://www.stoptb.org/resources/publications/acsm_docs.asp

International Standards for Tuberculosis Care (ISTC)
"The purpose of the International Standards for Tuberculosis Care (ISTC), developed by the Tuberculosis Coalition for Technical Assistance (TBCTA), is to describe a widely accepted level of care that all practitioners, public and private, should seek to achieve in managing patients who have, or are suspected of having, tuberculosis." http://www.who.int/tb/publications/2006/istc/en/index.html

National Tuberculosis Program / Ministry of Health of your country
Connecting with these may call for some detective work, as you seach out key representatives of these organizations who are willing to share information and ideas, and collaborate. They may be staff of a nearby facility or may be located quite a distance away.

Patients' Charter for Tuberculosis Care.
"The Patients' Charter outlines the rights and responsibilities of people with tuberculosis. It empowers people with the disease and their communities through this knowledge. Initiated and developed by patients from around the world, the Charter makes the relationship with health care providers a mutually beneficial one." http://www.who.int/tb/people_and_communities/patients_charter/en/index.html

CIVIL SOCIETY AND COMMUNITIES

Consultation meeting to strengthen the active engagement of civil society organizations in the global TB prevention, care and control efforts. "Critical areas and practical suggestions to strengthen the collaboration of civil society organizations with WHO at all levels in order to facilitate the implementation of evidence-based policies were identified." http://www.who.int/tb/people_and_communities/civil_society_meeting30sep_01oct2010/en/index.html

The Expansion of Community-Based Tuberculosis Programming: Critical Program Design Issues for New Partners. "This easy-to-read, 40-page paper from CORE Group outlines nine program design challenges for NGOs interested in working on community-based TB programming. The challenges were the result of the two-day Lessons Learned Exchange convened by CORE Group." http://www.coregroup.org/storage/documents/Workingpapers/CORE_TB_web.pdf

Promising Practices for Community Engagement in Tuberculosis Activities
"This 2009 publication from Catholic Relief Services highlights promising practices in increasing case detection and treatment rates as documented in the Maguindanao TB Control Project. It chronicles how community groups—Microscopy on Wheels (MOW), TB Clubs, Muslim Religious Leaders (MRLs) and Barangay Health Workers (BHWs)—have contributed to addressing the problem of TB."
http://www.crsprogramquality.org/storage/pubs/health/Promising%20practices%20for%20Community%20Engagement%20in%20Tuberculosis%20Activities.pdf

SPECIAL POPULATIONS

Children and TB. This webpage contains a host of resources and links.
http://www.coregroup.org/our-technical-work/working-groups/tuberculosis/pediatrictb

TB and HIV. This webpage of the International HIV/AIDS Alliance contains practical tools, news, and other useful resources. http://www.aidsalliance.org/TechnicalThemeDetails.aspx?Id=9

Women and Tuberculosis: Taking a Look at a Neglected Problem. This seven-page booklet from ACTION provides a clear overview of the issue.
http://c1280432.cdn.cloudfiles.rackspacecloud.com/Women__Tuberculosis.pdf

ORGANIZATIONS

ACTION (TB Advocacy)	www.action.org
CORE Group's Community Health Network	www.coregroup.org
International Union Against Tuberculosis and Lung Disease	www.theunion.org
Treatment Action Group (TB and HIV advocacy)	www.treatmentactiongroup.org
The Stop TB Partnership	www.stoptb.
The World Health Organization	www.who.int/topics/tuberculosis/

REFERENCES

1. WorldVision. World Vision. 2012 [cited 2012 23 May]; Available from: http://www.worldvision.org.
2. CARE. 2012 [cited 2012]; Available from: http://www.care.org.
3. World Health Organization. Community Involvement in Tuberculosis Care and Prevention: Towards Partnerships for Health : Guiding Principles and Recommendations Based on a WHO Review, 2008, Geneva: World Health Organization. 83 p.
4. World Care Council and World Health Organization. The Patients' Charter for Tuberculosis Care : Patients' Rights and Responsibilities 2006, [France]: World Care Council. [4] p.
5. Transitions in tuberculosis, in Respiratory Epidemiology in Europe, Gulsvik A and Annesi-Maesano I (eds). European Respiratory Monograph. 2000, European Respiratory Society.
6. World Health Organization, Stop TB Dept. Treatment of Tuberculosis: Guidelines, 4th edition, 2010, Geneva: World Health Organization. x, 147 p.
7. Tuberculosis Coalition for Technical Assistance and World Health Organization. International Standards for Tuberculosis Care: Diagnosis, Treatment, Public Health, 2006, [The Hague]: Tuberculosis Coalition for Technical Assistance. 57 p.
8. Zignol, M., et al. Surveillance of anti-tuberculosis drug resistance in the world: An updated analysis, 2007–2010. Bull World Health Organ, 2012. 90(2): p. 111–119D.
9. World Health Organization. Tuberculosis Fact Sheet N 104, 2012 [cited 2012 23 May]; Available from: http://www.who.int/mediacentre/factsheets/fs104/en/.
10. World Health Organization. Global Tuberculosis Control: WHO Report 2011, 2011, Geneva: World Health Organization. viii, 246 p.
11. World Health Organization. Multidrug and Extensively Drug-Resistant TB (M/XDR-TB) : 2010 Global Report on Surveillance and Response,2010, Geneva: World Health Organization. x, 58 p.
12. Stop TB Partnership. No More Crying, No More Dying: Toward Zero Death in Children, 2012. World Health Organization.
13. Arnadottir, T. and International Union Against Tuberculosis and Lung Disease. Tuberculosis and Public Health: Policy and Principles in Tuberculosis Control, 2009, Paris, France: International Union Against Tuberculosis and Lung Disease.
14. Murray, J.F.. A century of tuberculosis. Am J Respir Crit Care Med, 2004. 169(11): p. 1181–6.
15. Stop TB Partnership. End of Year Message from Dr. Lucica Ditiu, 2011 [cited 2012 May 2012]; Available from: http://www.stoptb.org/news/stories/2011/ns11_078.asp.
16. Uplekar, M., Stop TB Partnership, and World Health Organization. The Stop TB Strategy: Building on and Enhancing DOTS to Meet the TB-Related Millennium Development Goals, 2006, Geneva: World Health Organization. 20 p.
17. U.S. Government, Lantos-Hyde United States Government Tuberculosis Strategy, 2010.
18. World Health Organization. Report of a WHO Consultation on Strengthening the Active Engagement of Civil Society Organizations in the Global TB Prevention, Care and Control Efforts, September 30–1 October 2010, Geneva, Switzerland, 2010, Geneva: World Health Organization. 7 p.
19. Maher, D. and Stop TB Initiative. Community Contribution to TB Care: Practice and Policy 2003, Geneva: World Health Organization. 166 p.
20. Stop TB Partnership. Good Practice: Stop TB Partnership Challenge Facility for Civil Society, 2011.

World Health Organization.

21. CORE Group. Partnering with Grandmothers and Healers to Eliminate the "Disease of Dust" in Senegal: A Case Study in Community-Based Tuberculosis Control, 2008.
22. U.S. Centersfor Disease Control and Prevention. Core Curriculum on Tuberculosis: What the Clinician Should Know, 2011.
23. World Health Organization. WHO Policy on TB Infection Control in Health-CareFacilities, Congregate Settings and Households, 2009, Geneva: World Health Organization. 40 p + annexes.
24. Granich, R., et al. Guidelines for the Prevention of Tuberculosis in Health Care Facilities in Resource-Limited Settings, 1999, Geneva: World Health Organization. 51 p. + addendum (85 p.).
25. Deane, J., et al. Advocacy, Communication and Social Mobilization to Fight TB: A 10-Year Framework for Action, 2006, Geneva: World Health Organization.
26. Partners in Health. Community-Based Care for Drug-Resistant Tuberculosis: A Guide for Implementers, K. Seung, Editor, 2011, USAID TB CARE II.
27. CORE Group. The Expansion of Community-Based Tuberculosis Programming: Critical Program Design Issues for New Partners, H.R. Karen LeBan, Editor, 2008, CORE Group: Washington, DC.
28. CORE Group. The Designing for Behavior Change Curriculum, 2008.
29. World Health Organization, Stop TB Dept. Compendium of Indicators for Monitoring and Evaluating National Tuberculosis Programs, 2004, Geneva: World Health Organization. 166 p.
30. World Health Organization, Stop TB Dept. Implementing the WHO Stop TB Strategy: A Handbook for National Tuberculosis Control Programmes, 2008, Geneva: World Health Organization. 184 p.
31. World Health Organization and Stop TB Partnership. The Global Plan to Stop TB 2011–2015: Transforming the Fight towards Elimination of Tuberculosis 2010, Geneva: World Health Organization. 96 p.
32. Trebucq, A., et al. Xpert(R) MTB/RIF for national tuberculosis programmes in low-income countries: When, where and how? Int J Tuberc Lung Dis, 2011. 15(12): p. 1567–72.
33. World Health Organization. Molecular Line Probe Assays for Rapid Screening ff Patients at Risk of Multidrug-Resistant Tuberculosis (MDR-TB), 2008: Geneva, Switzerland.
34. World Health Organization. Automated Real-Time Nucleic Acid Amplification Technology for Rapid and Simultaneous Detection of Tuberculosis and Rifampicin Resistance: Xpert MTB/RIF System : Policy Statement 2011, Geneva: World Health Organization. 36 p.
35. World Health Organization. Electronic Recording and Reporting for Tuberculosis Care and Control, 2012, Geneva: World Health Organization. vii, 76 p.
36. Stop TB Initiative. Falling Short: Ensuring Access to Simple, Safe and Effective First-Line Medicines for Tuberculosis, 2010.
37. World Health Organization. Advocacy, Communication and Social Mobilization for TB Control: Collection of Country-Level Good Practices (in press), Geneva: World Health Organization.
38. Floyd, K., et al. Cost and cost-effectiveness of increased community and primary care facility involvement in tuberculosis care in Lilongwe District, Malawi. Int J Tuberc Lung Dis, 2003. 7(9 Suppl 1): p. S29–37.
39. Nganda, B., et al. Cost and cost-effectiveness of increased community and primary care facility involvement in tuberculosis care in Machakos District, Kenya. Int J Tuberc Lung Dis, 2003. 7(9 Suppl 1): p. S14–20.

40. Stop TB Initiative and Stop TB Partnership. The Global Plan to Stop Tuberculosis : Stop TB Partnership, 2002, Geneva: World Health Organization. 189 p.

41. Van den Boogaard, J., et al. Community vs. facility-based directly observed treatment for tuberculosis in Tanzania's Kilimanjaro Region. Int J Tuberc Lung Dis, 2009. 13(12): p. 1524–9.

42. Health Care Improvement Project. CHW Central, 2012 [cited 23 May 2012]; An online resource for information and dialogue about Community Health Workers (CHWs). CHWs play an important role in increasing access to health services in poor and underserved communities around the world. CHW Central supports community health workers and strengthens CHW programs by connecting experts, practitioners, and supporters in interactive discussion forums and sharing the latest developments in CHW research, practice, and policy.]. Available from: http://www.hciproject.org/chw-central.

43. Rural Assisance Center. Community Health Workers Toolkit. 2002–2012 [cited 23 May 2012]; Designed to help evaluate opportunities for developing a CHW program and provide resources and best practices developed by successful CHW programs.]. Available from: http://www.raconline.org/communityhealth/chw/.

44. Population Council. APHIA II OR Operations Research Project in Kenya Policy Brief 2, 2011.

45. Results Educational Fund. Women and Tuberculosis: Taking a Look at a Neglected Issue, 2010: Washington, DC.

46. WaterAid. Join Up, Scale Up: How Integration Can Defeat Disease and Poverty, 2011.

47. CORE Group. Getting the Knack of NACS: SOTA Meeting on Nutrition, Assessment, Counseling and Support (NACS), 2012: Washington, DC.

48. Getahun, H., et al. Prevention, diagnosis, and treatment of tuberculosis in children and mothers: Evidence for action for maternal, neonatal, and child health services. J Infect Dis, 2012. 205 Suppl 2: p. S216–27.

49. Partapuri, T., Steinglass, R., and Sequeira J.. Integrated delivery of health services during outreach visits: A literature review of program experience through a routine immunization lens. J Infect Dis, 2012. 205 Suppl 1: p. S20–7.

50. World Health Organization, Stop TB Dept. and Dept. of Chronic Diseases and Health Promotion. Practical Approach to Lung Health: Manual Initiating PAL Implementation, 2008, Geneva: World Health Organization. 125 p.

51. World Health Organization. Integrated Health Services – What and Why?, 2008: Geneva, Switzerland.

52. World Health Organization and Stop TB Partnership. Advocacy, Communication and Social Mobilization (ACSM) for Tuberculosis Control : A Handbook for Country Programmes, 2007, Geneva: World Health Organization.

53. International Union Against Tuberculosis and Lung Disease. Project Axysha, 2011; Project Axshya (meaning "TB-Free") adds a new dimension to TB control in India through community "ownership" and civil society-led public health programming.]. Available from: http://www.axshya-theunion.org/.

54. PATH. Overcoming Barriers to TB Control The Role of Advocacy, Communication, and Social Mobilization (ACSM), 2011.

55. Child Survival and Health Grants Program. Technial Reference Materials: Behavior Change Interventions, 2010, Washington, DC: USAID.

56. Davis, T.P. Barrier Analysis Facilitator's Guide: A Tool for Improving Behavior Change Communication in Child Survival and Community Development Programs, 2004: Washington, DC.

57. De Negri, B., et al. Empowering Communities: Participatory Techniques For Community-Based Program Development 2012 [cited 23 May 2012]; This training curriculum focuses on participatory learning and action (PLA) techniques for community-based programs. The curriculum uses experiential learning methods to teach the participatory program development approach; attitudes, behaviors, and skills necessary to be a successful PLA facilitator; and specific techniques that can be used.]. Available from: http://www.globalhealthcommunication.org/tools/36/.

58. Courtwright, A. and Turner, A.N. Tuberculosis and stigmatization: Pathways and interventions. Public Health Rep, 2010. 125 Suppl 4: p. 34–42.

59. World Health Organization and Stop TB Partnership. Advocacy, Communication and Social Mobilization for TB Control: A Guide to Developing Knowledge, Attitude and Practice Surveys, Geneva: World Health Organization.

60. Beyers N., Claassens, M., Enarson, D.A., Naidoo, P., Rusen I.D., and Smuts, B. Operational Research to Improve Health Services: A Guide for Proposal Development, 2001, Paris, France: International Union Against Tuberculosis and Lung Disease (The Union).

61. Treat TB. A Guide to Country-Level Implementation and Programme Support, 2011, Paris, France: International Union Against Tuberculosis and Lung Disease.

62. Marais, B.J., et al. Tuberculosis in women and children. Lancet, 2010. 375(9731): p. 2057–9.

63. Stop TB Partnership. Women and TB, 2009.

64. Karim, F., et al. Community perceptions of tuberculosis: A qualitative exploration from a gender perspective. Public Health, 2011. 125(2): p. 84–9.

65. FHI. Lessons Learned in Scaling Up TB/HIV Collaborative Activities, 2009.

66. FHI. Engaging Community-Based Organizations in TB/HIV Collaborative Activities: A Case Study in Nigeria, 2008.

67. World Health Organization. WHO Policy on Collaborative TB/HIV Activities : Guidelines for National Programmes and Other Stakeholders, 2012, Geneva: World Health Organization. 36 p.

68. World Health Organization, Stop TB Dept. and Dept. of HIV/AIDS. Guidelines for Intensified Tuberculosis Case-Finding and Isoniazid Preventive Therapy for People Living with HIV in Resource-Constrained Settings, 2011, Geneva: World Health Organization. vii, 39 p + Annexes.

69. CORE Group. Webinar: Childhood TB: An MSF Field Perspective, 2012.

70. World Health Organization. Guidance for National Tuberculosis Programmes on the Management of Tuberculosis in Children, 2006, Geneva: World Health Organization. vi, 41 p.

71. World Health Organization. Rapid Advice : Treatment of Tuberculosis in Children, 2010, Geneva: World Health Organization. iv, 19 p.

72. Donald, P.R. Childhood tuberculosis: the hidden epidemic. Int J Tuberc Lung Dis, 2004. 8(5): p. 627–9.

73. Graham, S.M. Desk-Guide for Diagnosis and Management of TB in Children, 2010, Paris, France: International Union Against Tuberculosis and Lung Disease.

74. Cruz, A.T. and Starke, J.R. Pediatric tuberculosis. Pediatr Rev, 2010. 31(1): p. 13–25; quiz 25-6.

75. Action/Advocacy to Control TB Internationally. Children and Tuberculosis: Exposing a Hidden Epidemic, 2011.

76. World Health Organization. Combating Tuberculosis in Children: Information Sheet, 2012.

77. CORE Group. Webinar: Pediatric TB: The Basics, 2012.

78. Kuehne J. and Finch K. Tuberculosis: Voices in the Fight against the European Epidemic, 2011. RESULTS UK.

79. Getahun, H. and Raviglione, M.Transforming the global tuberculosis response through effective engagement of civil society organizations: The role of the World Health Organization. Bull World Health Organ, 2011. 89(8): p. 616–8.

80. Mwanza AIDS Support Organization. Narrative Report on Stop TB Project in Mwanza, Malawi for a Period of 3 Months, 2011.

CORE Group
(202) 380-3400
www.coregroup.org