The Expansion of Community-Based Tuberculosis Programming:

Critical Program Design Issues for New Partners

To help new partners get involved, experienced organizations describe nine critical elements of community-based TB program design.

CORE Group
Working Together in Health for Mothers, Children, and Communities

USAID
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Abstract

The Tuberculosis Working Group of the CORE Group met with global partners and colleague agencies over two days in Washington, D.C., in early 2007. The meeting, "Lessons Learned Exchange: TB Programming from the Community-Based Perspective," sought to gather and exchange lessons learned in community-based treatment of tuberculosis (TB). This paper reflects participant discussions and lessons learned that were articulated throughout the event.

This document outlines nine project-design challenges most likely to face those working at the community level. This document should be used as a primer for gaining a better understanding of the challenges community-based programs and providers face, as well as some of the ways nongovernmental organizations (NGOs) are currently addressing these challenges. This document is not intended to outline a comprehensive community-based TB effort. There is no right way to respond to the challenges outlined here. The best way to answer them will depend on the nature of your organization and in the setting in which you seek to do this work.

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Introduction

Tuberculosis (TB) kills 1.5 million people each year. It is the greatest curable infectious killer worldwide. One-third of the world's population is infected with the TB bacterium and nearly 9 million people become sick with active TB each year. It is the number one killer of people living with HIV/AIDS. Multidrug-resistant TB (MDR TB) and high-mortality extensively drug-resistant TB (XDR TB) are on the rise, especially in countries with high TB-HIV co-infection rates. Most TB occurs in the developing world, with the marginalized, the poor and other hard-to-reach people facing the greatest barriers to diagnosis, treatment and cure.

"The STOP TB Strategy reflects a paradigm shift to actively engage patients and local communities."

    —Irene Koek
    Chief, Infectious Disease Division
    Global Health Bureau, USAID

These harsh realities have catalyzed the international health world to create new partnerships and approaches to curb this epidemic and ultimately rid the world of TB. In 2000, the STOP TB Partnership, a network of international organizations, countries and donors from the public and private sectors, governmental and nongovernmental organizations (NGOs) and individuals was developed to foster momentum and offer technical leadership toward these goals.

The release of the community involvement guidelines from the Advocacy, Communications and Social Mobilization Working Group of the STOP TB partnership offers explicit guidance to national TB programs (NTPs) and Ministries of Health—and potential new NGO partners—to fill in the community piece of the TB programming puzzle.

CORE Group's Tuberculosis Working Group Weighs In

Many of CORE Group's TB Working Group members (consisting of CORE Group members and partner organizations) have been implementing community-based TB efforts for years, even decades. Some of these NGOs added TB programming to their community-based health portfolios in response to the needs of local populations, and others did so in response to donor or government concerns. Nevertheless, widespread use of community-based interventions to stop TB has not been the norm. Historically, interventions to reduce and treat TB have been centered within public health service facilities, based on a medical model that focused solely on TB, electing not to integrate TB diagnosis and care with other health services or programs.

The Tuberculosis Working Group of the CORE Group met with global partners and colleague agencies[1] over two days in Washington, D.C., in early 2007. The meeting, "Lessons Learned Exchange: TB Programming from the Community-Based Perspective," sought to gather and exchange lessons learned in community-based treatment of TB. This paper reflects participant discussions and lessons learned that were articulated throughout the event.[2]

Dr. McEwan's testimony quoted below emphasizes the need for sustainable and long-term approaches to social development that can keep progress going as international project staff and resources come and go. Community empowerment is the "grandmother" of sustainability. It entails investing time and sincere effort to partner with communities and give community members concepts and tools to sort through and address their situation. Although difficult to define and measure, community empowerment lays the foundation for all progress, not just for curbing TB, but for whatever else communities want to change.

In order to sustain TB prevention and treatment efforts, then, the community must be included in all facets of program design. "Empowering" projects start with partnerships: with civil society organizations and associations, current and former TB patients, religious leaders, health providers including village doctors and traditional healers, local officials, and other people with influence. Project design should include short-term concrete outcomes that can generate excitement and validation to fuel ongoing empowerment and development efforts.

Community-based NGOs know that "the devil is in the details" when it comes to implementing health programs that make a difference. Thus, the "Lessons Learned Exchange" participants generated and elaborated on nine "hot topics" in community-based TB care. These are programming issues that need to be thoughtfully addressed—starting with program design and continuing throughout monitored and evaluated implementation—in order to successfully identify and cure people with TB and prevent new cases.

"Infections and global health conditions like TB and HIV do not often lend themselves to four or five year annually renewable funding cycles nor to silo funding of specific interventions."
— Dr. Elena McEwan, Catholic Relief Services Testimony to the U.S. Congress, March 21, 2007

Critical Program Design Issues in Community-Based TB Programming

1. Safety First: Prevent Infection of Staff, Volunteers and Other Persons

2. Create Behavior Change & Mobilization Campaigns to increase case finding & treatment rates

3. Take the Sting out of Stigma

4. Link TB and HIV/AIDS Programs at the Community Level, where applicable

5. Develop Human Resources: NTP, Health System and NGO Staff, Health Care Providers, Volunteers and Other Community Stakeholders and Influencers

6. Access and Work with Marginalized Populations

7. Improve Adherence through Patient Support

8. Act Locally, Think Nationally

9. Mobilize and Promote the Improved Use of Resources for Community-Based TB Control

1. See Appendix 1
2. Presentations, posters and more about this meeting can be found at http://www.coregroup.org/resources/tb_les-lrn _mtg_rpt.cfm

Challenge 1.

Safety First: Prevent Infection of NGO Staff, Volunteers and Others

Why it matters	What NGOs can/should do
Mechanisms for the spread of TB are not fully understood, but it is known that key transmission locations ranging from waiting rooms to patients' homes need to be carefully managed.	Meeting with patients outside and opening a window are two examples of simple practices that can help prevent the spread of TB.

Lessons Learned and Recommendations
1. Follow recommended protocols for infection control in the community. For example, proper ventilation can help reduce the local concentration of infectious particles in a room. The use of fans and the proper design in waiting areas (e.g., open windows and doors) can prevent the spread of TB.

2. People living with HIV/AIDS are dangerously vulnerable to TB infection. NGO staff and volunteers who are HIV positive (and may not know it) should not be exposed to people with known or suspected active cases of TB.

3. Train staff and volunteers in how TB is spread, when a person is infectious and what actions to take. Regularly assess their understanding. |

What Is Directional Airflow?

NGO staff and volunteers may need to work with TB patients in small rooms: in clinics, community locations and in homes. It is key to have a basic understanding of how to protect staff and others from infection. One way to do this is through the use of directional airflow. Ventilation can help reduce the local concentration of infectious particles in a room. This is done by matching the location of people in a room to the airflow. Simply stated, locate the people you are trying to protect from TB exposure near an air supply. Locate people who may be infectious near a place where air is exhausted from the space.

How Directional Airflow Helps Reduce the Risk

In the clinic setting, this principle can help protect staff from an unidentified TB patient. For example, use of directional airflow can help reduce the risk that TB will spread from a client to a staff member doing intake interviews. If the air direction is known, the staff member should sit near the fresh air source, and the clients should sit near the exhaust location.

In a room in which large numbers of people may congregate, such as a waiting room, anyone could be a source of TB, and TB could spread to others in the room. Therefore, the direction of air movement is less critical. It is more important to achieve good air mixing in all locations so that particles are more quickly diluted and removed.

Directional Airflow and Staff Location

If placed in or near a wall opening, propeller fans can also move air into and out of a room. For example, fans installed in the windows on the back wall of a building exhaust air to the outside. If doors and windows in the front of the building are kept open, the overall effect should be to draw in fresh air through the front of the building and exhaust air through the rear. With this arrangement, the risk that TB will be spread is greater near the back of the building.

> —Adapted from: Tuberculosis Infection Control: A Practical Manual for Preventing TB. Francis J. Curry National Tuberculosis Center. 2007.

Resources

TO LEARN MORE ABOUT TB INFECTION CONTROL:

Francis J. Curry National Tuberculosis Center. *Tuberculosis Infection Control: A Practical Manual for Preventing TB. 2007*. Available online at: http://www.nationaltbcenter.edu/products/product_details. cfm?productID=WPT-12CD; accessed December 2007.

U.S. Agency for International Development Tuberculosis Team. TB Virtual Resource Center. 2007 *Infection Control Documents*. Available online at: http://www.tbvrc.org/TBVRC_Resource.cfm?click_action=yes&m_id=50; accessed December 2007.

World Health Organization. *TB Infection Control Guidelines* (to include guidance on creating a national plan). Pending.

Challenge 2.

Use Behavior-Change and Mobilization Interventions to Increase Case Findings and Treatment Rates

Why it matters	What NGOs can/should do
Behavior-change and communications interventions and social mobilization efforts recognize the power of the social environment within which individuals act and seek to understand and influence that context accordingly. For example, individuals may understand that they have TB and that the health facility will provide free drugs to cure it, but they may choose instead to visit a traditional healer secretly at night. Why? A visit to a publicly prominent facility could result in job loss, shunning by and of the family or other forms of community rejection.	Tap into global and local behavior-change and community-mobilization experience and resources to address this critical facet of community-based TB programming. The goal is to ensure that communities, including health-system staff, key stakeholders, people with TB, their families and others are knowledgeable about, motivated to address, have relevant skills about and are in the habit of detecting, preventing and curing TB.

Lessons Learned and Recommendations

1. Partner with community entities and individuals in order to change the norms that dictate what is and what is not socially acceptable. Engage the entire community in TB advocacy and messaging. This could include anyone who lives in the community—local politicians, leaders, teachers and health-system staff. It can also include nontraditional partners such as university students, Rotary Club members, beauty shop owners and police officers.

2. Consider the health system as part of the community. This "system" however, is often more like a puzzle with many pieces and includes informal, Western and traditional, as well as public and private entities.

3. Work to empower the community by considering the following, recommended by Save the Children[3]:

– Recognize community history and social, economic and political changes as influences on behavior
– Encourage and enhance critical consciousness and the ability to reflect on underlying assumptions affecting a person's actions
– Increase the ability of community leadership to facilitate the following processes in the community: conflict resolution, collection and analysis of data, problem-solving, program planning, resource mobilization and policy advocacy (Goodman et al., 1998)
– Recognize local/community authority to make and implement decisions (who has the power to make decisions or can confer authority for decision-making)
– Promote community power and its ability to create or resist change and turn decision-making power to local social actors
– Develop strong social and inter-organizational networks

3. Save the Children, *Taking Community Empowerment to Scale: Lessons Learned from Three Successful Experiences,* 2007.

Case Study in Community Mobilization
Catholic Relief Services Project in Angola Succeeds in
Getting TB Patients Registered

The Angola TB program of Catholic Relief Services (CRS) is part of a larger
HIV/AIDS program that is being implemented by resident partner Caritas
Benguela. Over the course of one year in Benguela province, the project con-
tributed to the prevention of HIV and TB incidence through a two-pronged
approach that included health-system improvements and community involve-
ment. The program was a multifaceted, locally-based effort involving many
local channels, including participatory education, mass media and capacity
building of staff.

Community-Mobilization Efforts

In order to change social norms, improve community competence and ulti-
mately change behavior, the program worked to improve knowledge of key
health issues among health-system staff and the general public. Project staff
and partners implemented a variety of participatory education and mass media
activities, such as posters, pamphlets and billboards, oral presentations and
development of World AIDS Day campaigns. Project staff trained and carried
out outreach activities with target groups (such as religious leaders of faith-
based organizations) and provided basic health and management training to
other local partners.

Community theater presentations were especially popular. The Twayavoka
Theater Group made 26 theater presentations in three communities using
Umbundu, the local language of the province. Twayavoka presentations were
well received in communities, which responded enthusiastically to the format
of the real-life situations familiar to villagers. This entailed presenting a prob-
lem in a play and showing a "bad" ending. The audience was then asked to
provide an alternative "good" ending, using information presented during the
play. The play would then be reenacted following the audience script.

Health-System Improvements

In addition to working with the public, many key players in the local TB sys-
tem were included in this effort to improve demand for and quality of services.
The TB component of the project provided training to nurses, technicians,
doctors and public health workers in many areas, some of which included: HIV
Rapid Test training, voluntary testing and counseling training, TB diagnostics
and treatment, biosecurity for labs and clinical management of TB/HIV/AIDS
and opportunistic infections.

By the end of the year nearly 30,000 registered TB patients were reached with
communication and education activities. Over 4,000 community members par-
ticipated in theater activities including members of 13 schools, churches and
community groups. More than 8,000 people were tested for HIV, and 6,000

were tested for TB. The health-system's capacity to deal with this influx was improved through the training of more than 50 health-system staffers. Monitoring and evaluation activities showed improvement in service quality and successful uptake of training content. At the TB Center in Balombo, irregularities in the TB patient registry were noted early in the project, attributable to nurse and technician errors. By the project's end, these irregularities had largely disappeared.

—Catholic Relief Services

Resources

TO LEARN MORE ABOUT BEHAVIOR CHANGE COMMUNICATION AND TB:

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CORE Group. *The Social and Behavioral Change Working Group.* 2007. Provides a variety of publications and materials on social behavioral interventions. Available online at: http://www.coregroup.org/working_groups/behavior.cfm; accessed December 2007.

Health Communications Partnership. *Tuberculosis Information.* 2007. Available online at: http://www.hcpartnership.org/Topics/tuberculosis.php; accessed December 2007.

International Union against Tuberculosis and Lung Disease. *Social Mobilisation of Nongovernmental Organisations in TB Control: Report of the Bangkok Workshop, September 2004 and Recommendations of the Brazil Workshop, July 2004.* August 2005. Available online at: http://www.iuatld.org/upload/home_news/social_ mobilisation_uk_143.pdf; accessed December 2007.

Johns Hopkins University, Center for Communications Programs. *Media and Materials Clearing House.* 2007. A searchable database of communications materials—including tuberculosis related materials—from around the world available online at: http://www.m-mc.org/; accessed December 2007.

Stop TB Partnership, Advocacy, Communication and Social Mobilization Working Group. *Advocacy, Communication and Social Mobilization at the Country Level.* 2007. Provides a host of materials and publications, including community-based guidance and tools for monitoring and evaluation. Available online at: http:// www.stoptb.org/wg/advocacy_communication/acsmcl/; accessed December 2007.

Challenge 3.

Take the Sting out of Stigma

Why it matters	What NGOs can/should do
Stigma presents a major barrier to identifying and successfully treating people with TB. For example, the fear of ruining marriage prospects keeps some unmarried woman from seeking care. In many cultures, people with TB can face other societal rejections such as loss of their jobs, or being forced by their own families to live outside and eat in the dirt.	Use community programming expertise and established field presence to dismantle stigma and foster knowledge, attitudes and practices supportive of patient rights and responsibilities. Stigma is a psychologically and socially complex issue, so programmatic efforts to address it must be based on respectful, in-depth cultural inquiries and carefully framed responses to each society's unique context.

Lessons Learned and Recommendations

1. Getting patients to come forward is often difficult, especially in areas of high coexistence of TB and HIV. People with TB are often viewed as "having a death sentence" or are marked as the most impoverished in a community. In turn, people with HIV are often associated with immoral behavior and thought to have a virulent, lethal contagion, all of which prevents some TB patients from getting tested or treated for HIV.

2. Understand that stigma can be especially powerful in rural communities where outside influences (which are often the source of critical information concerning symptoms and treatment) are limited, and traditional social norms (often perpetuating misinformation about causes and curability) are the unquestioned backbone of everyday social relations.

3. Programs can begin to address stigma with the staff of a community-based project through regular trainings and dialogue. Staff and volunteers often personify the old adage: "You are either a part of the problem or a part of the solution." Health-facility staff can be a prime source of insight into local stigmas and are often ripe for and receptive to learning ways to address it.

Case Study: The Complexity of Stigma in Senegal

Many people in Senegal see the physiological symptoms of disease in an individual body as signs of disorder in their relationship with their family, their community, or the spirits of the ancestors. Between the invisible realm of the spirits of ancestors and the physical world, there is no difference of reality, only one of visibility. This view leads people to try to restore health by restoring these relationships, via a traditional healer.

As the tuberculosis progresses, physical deterioration caused by the illness fosters social exclusion, supporting the interpretation that the disease represents a disruption of key relationships, thus muddling cause and consequence.

In some villages, when a person dies from tuberculosis, the family performs rituals that express a total break with the dead person to symbolically exclude her or him from the family, including the symbolic cutting of a thick cord. In other villages, families deny a tuberculosis victim the right to normal funeral ceremonies, which would prevent him or her from entering the realm of the spirits of the ancestors. The belongings of the victim, especially clothes, are burned.

For people with TB to turn to medical services using a Western or "modern" approach would require that they accept a very different concept of health and disease.

    —Christian Children's Fund

Resources

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TO LEARN MORE ABOUT TB AND STIGMA:

World Health Organization. The Patients' Charter for Tuberculosis Care. 2006. This document can be a strong starting point for addressing stigma. Available online at: http://www.who.int/tb/publications/2006/istc_charter.pdf; accessed December 2007.

Challenge 4.

Link TB and HIV/AIDS Programs

A HEAD NURSE OUTSIDE OF ACCRA, GHANA, WITHDRAWS BLOOD FROM A WOMAN FOR AN HIV TEST.   © 2006 ADAM SCOTTI, COURTESY OF PHOTOSHARE

Why it matters	What NGOs can/should do
The deadly impact of HIV and TB co-infection cannot be overstated. HIV is the most powerful risk factor known for the conversion of latent TB into active TB. In turn, TB is a leading cause of death for people with HIV. As HIV infection progresses, the immune system becomes less able to prevent the growth and local spread of opportunistic infections, including TB.	Combine state-of-the-art technical knowledge with the perspective of patients and communities to develop thoughtful approaches to this life-and-death issue. Advocate for funding and resources that eliminate barriers to integrated services.

Lessons Learned and Recommendations

In areas of substantial HIV incidence, TB and HIV/AIDS treatment efforts must connect to reduce the burden on patients of having to deal with two separate health-care systems and to reduce the morbidity and mortality of both diseases. While national tuberculosis programs and Ministries of Health are gradually designing and implementing integrated protocols, generally, gaps between TB and HIV detection, care and prevention efforts are more common than program linkages.

Suggestions for building TB/HIV linkages into program design:

– Get TB and HIV service organizations, providers, advocates and patients in the same room—possibly in the form of a coalition. Map communities in terms of who is providing HIV services and TB services and decide how they can be connected.
– Co-locate and co-schedule TB and HIV services (with careful consideration of infection control procedures: see Challenge 1).
– Incorporate screening, testing and contact tracing for TB and HIV into community health worker systems.
– Whenever possible, ensure that direct observed treatment (DOT) providers are addressing adherence issues for both TB and HIV medications—or at least are coordinating with other providers.
– See that nutrition and food security is addressed in a coordinated way in support of TB/HIV co-infected patients.
– Explore barriers and solutions related to home-based care providers taking on both HIV and TB (stigma, fears, misconceptions, overload, etc.).
– Ensure that capacity-building and awareness-raising addresses co-infection issues, via curricula, behavior-change and communication efforts, health fairs, job aides, etc.
– Seek clarity on challenges and opportunities related to gender, such as integrating TB testing into maternal HIV services.
– Do not overburden existing programs with more than can be realistically handled or push integration prematurely.

Case Study: Integrating HIV and TB Services
Catholic Relief Services in Rwanda
An Integrated HIV/TB Service Model
AIDSRelief Project in Rwanda

CRS's AIDSRelief project is a five-member consortium of NGOs that works through a network of local partner treatment facilities to provide HIV care and medications in nine countries. In Rwanda, AIDSRelief relies on a capacity-building model to improve the quality of care through integration of TB and HIV services.

The capacity-building model includes using group learning about TB and HIV illness and treatment that aims to educate the community about how each disease is spread as well as about the associated symptoms and treatments. To improve demand for services and effective treatment, each local facility develops a plan—in collaboration with local government—for community-mobilization activities. The AIDSRelief program also conducts on-site mentoring in program performance for all staff, which aims to support quality services.

People living with HIV in the HIV program are screened for TB on enrollment into an HIV care and/or treatment program. Screening is conducted at least every six months using the screening tool of the National Integrated Program for the Fight against Tuberculosis. All local-facility health providers are trained in job-specific aspects of TB. Community health volunteers, trained to use a screening tool and provided with basic TB education, work in their home areas to identify and refer possible TB cases to the local facility.

AIDSRelief project managers have described some of their lessons learned in community-based TB/HIV integration:

– National standards, protocols and reporting mechanisms for TB and HIV must be in place to support hospital, facility and community interventions.

– HIV counseling and testing presents an opportunity for TB screening.

– Quality training can equip community health volunteers to address TB, HIV and other health issues.

– Regular home visits by community volunteers addressing HIV can offer extensive community penetration in the effort to detect possible cases of TB.

– Comprehensive training of local-facility staff improves identification of active TB.

– The mentoring model is an appropriate tool to address the complexity of successful HIV/TB treatment.

– Each local facility's HIV and TB care and treatment plans must include a strong, integrated plan for community mobilization.

– Nurse-based models of care allow services to reach far into remote areas.

– In an era of extensively drug resistant TB (XDR TB), strong adherence programs are needed. AIDSRelief's successful model for antiretroviral therapy (ART) adherence can be used as a model for TB adherence.

– Adequate resources for TB are necessary. If they are not available, advocacy efforts are called for.

> —Catholic Relief Services

Resources

TO LEARN MORE ABOUT TB AND HIV:

CORE Group and Health Alliance International. *Integrating TB and HIV Care in Mozambique: Lessons from an HIV Clinic in Beira.* September 2005. Available online at: http://www.coregroup.org/working_groups/HAI_Mozambique_TB-HIV_case_study.pdf; accessed December 2007.

Mass, John Michael, Darby Communications. *Winstone Zulu Stop TB Video.* 2007. Created for the World Health Organization, STOP TB Partnership and USAID. A six-minute movie on TB/HIV, starring activist Winstone Zulu. Available online at: http://www.macloo.com/video/TB_HIV_video_from_WHO/stopTB_Winstone.htm; accessed December 2007.

STOP TB Partnership. *TB/HIV Working Group.* 2007. Offers news, publications and more. Available online at: http://www.stoptb.org/wg/tb_hiv/; accessed December 2007.

Tuberculosis Virtual Resource Center. TB/HIV fact sheets, manuals, guidelines and technical materials. 2007. Available online at: http://www.tbvrc.org/TBVRC_Resource.cfm?click_action=yes&m_id=14; accessed December 2007.

World Health Organization. *Tuberculosis Infection Control in the Era of Expanding HIV Care and Treatment.* 2006. Available online at: http://www.who.int/tb/publications/2006/tbhiv_infectioncontrol_addendum.pdf; accessed December 2007.

Challenge 5.

Develop Human Resources

Why it matters	What NGOs can/should do
Staff and volunteers play a major role in determining the extent to which patients avail themselves of services, and whether treatment is successful. Inadequately trained or overworked program staff and volunteers can derail project success in many ways, including: treating patients in a negative, judgmental or curt manner; creating treatment regimens that are based on unrealistic expectations of patients to present for medication; and failing to follow up properly with patients who do not show up for medication.	Invest time and resources necessary to develop staff, volunteer and health-provider capacities and workloads to manage the effort and deliver quality services, based on a meaningful understanding of the patient's perspectives. During this ongoing process, be as consultative as possible with existing health-care stakeholders in the communities.

Lessons Learned and Recommendations

1. Partner with medical clinics, national tuberculosis program (NTP) efforts and/or the Ministry of Health's systems to ensure the best care for a community. Health-care providers are a diverse group, encompassing home-based caregivers, volunteers, public- and private-sector nurses, doctors and lab technicians, traditional healers, pharmacists and others. Some address only TB, others only HIV and AIDS and others a gamut of health issues. They work in clinics, hospitals, laboratories, offices and homes, and in rural, village and urban settings. Ensuring effective TB care and control among such a diverse set of people, jobs and settings means NGOs will often have to partner with others.

2. Ensure quality human-resource development by using performance measuring and monitoring techniques. For example, MCDI uses its own district rapid assessment tool (DRAT) to measure elements of program quality in its Ndwedewe-based integrated TB, HIV and AIDS project. Types of quality measured by the DRAT: how well clinic staff perform on sputum turnaround time, smear conversion rates, cure rates, direct observed treatment (DOT) support, TB-HIV integration and community education.

4. NGOs that partner with NTPs can enrich human resources and TB programs by:

– Ensuring institutionalization of best practices in skill building (for both technical and interpersonal/communications skills)
– Educating NTP leadership and staff on quality of care from individual, community, and health perspectives
– Advocating for NTP norms and guidelines that effectively define roles and responsibilities at all levels

Case Study in Using Volunteers:
Bridging the Gap between Community and Clinic

NGOs often address understaffing by using trained community volunteers, sometimes called *promotoras*. Project Concern International (PCI), Mexico, is strengthening DOT through an innovative effort that expands the community-based health worker system to become a fully integrated component of the larger TB program. The project is working to overcome historical and ingrained tensions between facility-based and community-based approaches.

By working collaboratively with ISESALUD—the state health service—PCI maximizes the potential for sustainability and expansion of the program. PCI and ISESALUD have developed a two-level system of DOT provision: via *promotoras* and DOT *workers*.

Promotoras provide day-to-day DOT, while workers can be both supervisors and DOT providers. Promotoras receive incentives based on patient load. Workers receive a monthly salary and health benefits. The goal is for each staff person to cover a minimum of five patients. Promotoras who are assigned to health centers may see up 20 patients per day and are in charge of following up on defaulters.

Women who fulfill both of these community-based roles are supported with technical training and resources, collaboration with project and facility staff, regular communication and coordination, quality services to which patients may be referred and incentives and transportation reimbursement. These strategies ensure that caseloads remain manageable, service quality is high, and appropriate community coverage is available.

Assessment and Outcomes: Project achievements measured at midpoint included a treatment success rate of 78% as compared with a baseline of 58%. An external evaluator noted several achievements related to community-based DOT:

"The model of specialized community-level TB outreach staff appears on target to improve treatment success. . . . the DOT personnel have become integral members of the TB health-care team and consensus was that, without them, treatment of TB patients would revert back to the less successful medical-model approaches of the past.

"In the health centers where DOT personnel are assigned, key relationships exist between the medical staff and the DOT workers. . . . medical staff, physicians and nurses appreciate the support of the outreach staff in providing special focus on treatment adherence for TB patients. . . . a supportive attitude of the medical director was noted as important to the overall quality of patient care."

"Be as consultative as possible with existing healthcare stakeholders in the communities, who community members already know and have relationships with, especially in designated TB-Emergency countries.

In South Africa, once we make efforts to reach out to and train traditional healers, who the community turn to more than us or the Department of Health services, they are pleased to be respected and included and do make efforts to cooperate, such as referring TB suspects to clinics for testing and not prescribing enemas and other treatment that counteract TB care."

— Martha Benezet, MCDI, South Africa

Lessons Learned:

– Significant time and energy must be devoted to building bridges between community and facility-based health workers, understanding barriers to collaboration, strengthening lines of communication, improving levels of trust and addressing fears and threats that may or may not be real.

– Different "languages" (interpretations of words and concepts) and "cultures" (perspectives, priorities, points of view) must be regularly addressed. Health workers and promotoras may define "DOT," "community," "support" and "care" differently.

– Working to illustrate the value of each component (facility and community, medical/clinical and programmatic) to all stakeholders helps lead to mutual respect, improved communication and greater collaboration.

—Project Concern International

Resources

TO LEARN MORE ABOUT TB AND HUMAN–RESOURCE DEVELOPMENT:

American Lung Association. *Mr. TB Germ.* 2007. This two-part flash movie (about five minutes total) is a good tool for educating newcomers to TB including staff, community members and others. Available online at: http://www.lungusa.org/site/apps/s/content.asp?c=dvLUK9O0E&b=34706&ct =67361; accessed December 2007.

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WHO, Stop-TB Partnership. *Engaging All Health Care Providers in TB Control: Guidance on Implementing Public-Private Mix Approaches.* 2006. Available online at: http://www.stoptb.org/resource_center/assets/documents/PPM%20 Guidance.pdf; accessed December 2007.

WHO. *Task Analysis: The Basis for Development of Training in Management of Tuberculosis.* 2005. Available online at: http://whqlibdoc.who.int/hq/2005/ WHO_HTM_TB_2005.354_eng.pdf; accessed December 2007.

**The Tuberculosis Coalition for Technical Assistance (TBCTA) website has several additional tools, including WHO-authored reports, relating to human resource development for TB programs. http://www.tbcta.org/Library/.

Challenge 6.

Access and Work with Marginalized Populations

Why it matters	What NGOs can/should do
Marginalized populations face the double burden of increased risk of TB combined with decreased likelihood of proper diagnosis and successful treatment. They have a right to diagnosis and care. In order to halt the TB epidemic, they must be reached.	Use expertise and established presences to reach these vulnerable populations with access to education and services. Advocate on their behalf at all levels.

Lessons Learned and Recommendations

Many international and local development NGOs not currently working in TB care are perfectly poised to do so because they have been working with marginalized groups at the community level for many years. Some groups work regularly with the most marginalized people of all, including drug addicts, alcoholics, commercial sex workers, prisoners and recently released prisoners—all populations that can play an unwitting but powerful role in fostering the epidemic of multidrug-resistant TB.

These NGOs understand the level of commitment and hard work that such efforts entail, including overcoming cultural barriers and deconstructing prejudices (see Challenge 4). For many NGO workers, their hearts are "in the field" and their skills can be brought to work in a TB prevention program. Dozens of creative tools and approaches have been devised and well tested and staff skills honed in order to find and successfully work with marginalized groups. Sample approaches include positive deviance, rapid rural assessment, participatory research and implementation, appropriate technology and community self-analysis.

Reaching neglected, shunned, isolated, poor or otherwise marginalized populations often requires strong local partnerships with key stakeholders, such as officials, associations, volunteers and religious and civic leaders. During the project design phase NGOs need to begin to identify and engage partners who are best positioned to reach these "invisible citizens," who may not get services due to factors including poverty, gender, age, sexual orientation, caste, ethnicity, homelessness and health status. These partners may include cultural associations, small NGOs, HIV support groups, activist groups, medical students, poverty alleviation NGOs, women's groups, microlending programs, faith-based organizations and churches and private clinics.

Case Study in Working with Marginalized Populations
Locally Tailored, Nationally Connected
Doctors of the World, Kosovo

In 2000, Doctors of the World (DOW) initiated programs for TB health care for marginalized minority communities of Kosovo, as an integrated extension of the DOW program in majority areas. Many in the minority communities of Kosovo did not feel safe accessing the new health-care institutions in majority areas. DOW introduced a comprehensive and innovative set of interventions, including setting up TB facilities in two minority enclaves, training doctors and nurses in directly observed treatment (DOT), and including minority communities in the Kosovo-wide health education program.

The TB facilities were established through coordination with local medical staff, which was instrumental in designing the facilities to meet community needs. Medical staff also began to build trust with the minority community by establishing personal relationships with members of the community, and then expanding these relationships into a network of local staff that trusted the DOW model. International consultants, perceived by community members as being more neutral, carried out technical training.

Nurses were trained to carry out TB patient contact tracing, treatment monitoring, DOT provision, and patient health education, often during home visits to patients. These nurses served as key implementers of the general public-education component as well. Community-based education efforts created TV and radio spots, newspaper advertisements, posters, peer programming and campaigns. Teachers were trained to educate their students about TB.

These efforts led to several successful outcomes, including:

– Increased cooperation between majority and minority health-care systems

– Lower TB incidence rates in certain minority areas

– Improved TB-related treatment seeking

– Greater equality of access to treatment as measured by improved case finding and successful treatment

– Reduced TB stigma among the Kosovar population

The intervention was also followed by a 16% improvement in case notification rates over one year and an 18% increase in treatment success rates for minority areas.

DOW's close working partnership with the Institute of Public Health was an indispensable aspect of the program. Another critical element was the building of trust between the DOW doctors and their minority counterparts. An

emphasis on health education, particularly with the patients themselves, also had powerful effects. Although the establishment of TB clinics in certain areas had impact directly in that region, links with other nearby minority communities did not occur automatically without a great deal of conscious effort and deliberate programming.

Major elements of this program could be replicated in other countries and regions. The model of working with minority communities on a local level—with local staff providing services individually tailored to the community but maintaining international standards and ensuring integration into national health structures—is one that can be used elsewhere.

> —Excerpted from CORE Group Case Study: Implementation of a National TB Control Program in Minority Communities

Resources

TO LEARN MORE ABOUT REACHING MARGINALIZED POPULATIONS:

CORE Group. *Implementation of a National TB Control Program in Minority Communities.* 2004. Available online at: http://www.coregroup.org/working_groups/DOW_Kosovo_TB_study.pdf ; accessed December 2007.

Burns, A., R. Lovich, J. Maxwell, and K. Shapiro. *Where Women Have No Doctor: A Health Guide for Women.* 1997. Chapter 25 provides an overview of women and TB. Clear and simple, suitable for sharing with staff and literate volunteers and patients. Available online at: http://www.hesperian.info/assets/wwhnd/wwhnd_ch25_tb.pdf; accessed December 2007.

Kartashova, L., R. Northrup, A. Toktobayanov, A. Trusov, and Z. Zhandauletova. CORE Group. *Tuberculosis Control in Karaganda Prison through DOTS: Lessons from Kazakhstan.* 2005. Available online at: http://www.coregroup.org/working_groups/Proj_Hope_Kazakstan_TB_case_study.pdf ; accessed December 2007.

World Health Organization, Stop TB Partnership. *Guidelines for Social Mobilization: A Human Rights Approach to TB.* 2001. This guide makes the case for using a human rights framework for reaching vulnerable groups with TB care, specifically the poor, children, women, migrants, refugee, prisoners, substance abusers and people living with HIV. Available online at: http://www.stoptb.org/events/world_tb_day/2001/H.RightsReport2001.pdf ; accessed December 2007.

World Health Organization. *Addressing Poverty in TB Control: Options for National TB Control Programmes.* 2005. Available online at http://whqlibdoc.who.int/hq/2005/WHO_HTM_TB_2005.352.pdf ; accessed December 2007.

World Health Organization. *STOP TB's Poverty Subgroup.* 2007. Offers a host of publications and resources. Available online at: http://www.stoptb.org/tbandpoverty/news.asp; accessed December 2007.

World Health Organization. *TB in Prisons.* 2007. Publications and guidance available online at: http://www.who.int/tb/challenges/prisons/en/index.html; accessed December 2007.

Challenge 7.

Improve Drug Treatment Adherence through Patient Support

A DOTS (DIRECTLY OBSERVED TREATMENT, SHORT-TERM) AWARENESS PRO-MOTIONAL LOGO IN INDIA, WHERE THE REVISED NATIONAL TUBERCULOSIS CONTROL PROGRAMME IS CHANGING THE LIVES OF TB PATIENTS.

Why it matters	What NGOs can/should do
Many people with TB do not complete their six-month course of TB medications, thereby putting themselves as risk of relapse and themselves and their communities at risk of multidrug-resistant and extensively drug-resistant forms of TB.	Poor adherence is often attributable to lack of information, as well as to economic, social and/or physical barriers presented by a regimen that may entail publicly visiting a clinic every day (raising fears of stigma or requiring patients to bear the cost and time needed to make a round trip to the facility). Unpleasant side effects of the medications can also hamper treatment adherence. NGOs should try to respond to these patient realities with community-based staff and volunteers who can provide convenient and confidential social support, education and services.

Lessons Learned and Recommendations

Around the world, neighbors, friends, volunteers, community health workers and paid community members have been enlisted to provide DOT—direct daily observation and recording of drug taking—for TB patients. The community-based DOT model is, by necessity, as flexible as the world's living conditions. In India, tea-stall operators store and dispense daily medication. In Cambodia, pharmacists provide the same services. In Haiti, accompaniers visit the homes of people with TB to ensure proper and consistent adherence. As community-based TB services expand, so does the use of volunteers as DOT supporters, community educators, and community liaisons.

Using volunteers to link to the community is vital for getting information, services and support to people with TB, who are often spread out in a region's least accessible places. Like regular staff, volunteers need periodic, consistent training and supervision in order to ensure quality services. Also like paid employees, they need support and recognition of the value of their contribution to keep them motivated.

Reaching neglected, shunned, isolated, poor or otherwise marginalized populations often requires strong local partnerships with key stakeholders, such as officials, associations, volunteers and religious and civic leaders. During the project design phase NGOs need to begin to identify and engage partners who are best positioned to reach these "invisible citizens," who may not get services due to factors including poverty, gender, age, sexual orientation, caste, ethnicity, homelessness and health status. These partners may include cultural associations, small NGOs, HIV support groups, activist groups, medical students, poverty alleviation NGOs, women's groups, microlending programs, faith-based organizations and churches and private clinics.

Providing material incentives to volunteers and/or patients is a controversial practice in the health community because some feel it is not sustainable. That is, once programs offer incentives—which can range from umbrellas and boots to formal recognition or training—all subsequent programs must do the same or the volunteers or patients will quit. Others feel incentives are necessary for success. Most agree, however, that when incentives are used, they should factor in a cultural, economic, and long-term vision that considers these issues. An ideal sustainable approach is one in which the government supports the project model and covers the cost of the incentives. Some projects have established a program that enables volunteers to graduate from volunteer to counselor to social worker, or that provides enhanced nursing credentials. This helps to reduce the turnover of trained volunteers.

Case Studies in Using Volunteers to Improve Drug Treatment Adherence
Volunteer Patient Liaisons—
Community Support in the Facility Setting
Medical Care Development International, South Africa

To improve adherence to TB treatment, increase cure rates and to reduce cases of multidrug-resistant and extensively drug-resistant TB, Medical Care Development International (MCDI) has trained and placed home-based care volunteers in each government health facility in its project area to act as "TB patient liaisons."

TB patients interact with the health system more successfully with the help of TB patient liaisons, who are perceived as peers, who sit with patients and their family members to explain treatment. The liaisons may offer to train a family member as a DOT supporter (essential in a rural area where homes are often remote and transport is expensive and limited) or encourage the patient to cross-test for HIV, thus providing the psychosocial support and trust-building that overworked nurses are often unable to give.

The liaisons also identify TB suspects in facility outpatient departments and encourage testing, trace treatment defaulters, and facilitates meetings between community-based home-based community volunteers and nurses to improve continuity and quality of patient care.

> —MCDI, South Africa

Patient Incentives in Kazakhstan: Cost Effective?
American Red Cross and Red Crescent Society
of Kazakhstan

Getting TB patients to show up at their appointed facility to take drugs can be difficult. Often patients do not have time due to work obligations, they may be feeling better because the drugs are beginning to take effect or they may be unhappy with the way they are spoken to by facility staff. The burden of following up with these no-show patients often falls on overworked health-care providers. Thoughtful program design that uses incentives such as a hot meal or money can get TB patients to show up to take their drugs.

The American Red Cross's *Tuberculosis Incentives Study* (conducted in 2003–5 and consisting of a prospective nonblinded cluster randomized controlled trial of patient-oriented incentives) measured the effect of incentives on treatment adherence and treatment success. Four hundred and forty-nine subjects were assigned to four groups:

1. Control (no incentive/usual care)

2. Money given for each visit (50 KZT, or US$0.33, enough for transport)

3. Hot meal, served each visit

4. Visiting nurse assignment (to give social support and trace potential default-ers as needed)

Outcomes

Patients in all three incentive groups missed fewer doses than control patients:

1. Mean number of missed doses: 0.9–1.8 (incentives) vs. 4.2 (control)

2. Missed at least one dose: 25–45% (incentives) vs. 49% (control)

3. Missed more than 5% doses: 7–15% (incentive) vs. 30% (control)

The order of incentive effectiveness for this outcome was, from most effective to least effective: hot meal > visiting nurse > money > control group. Analysis, including statistical significance, indicates that all three incentives are better than the control, but no distinction can be made between them.

Other Factors Affecting Adherence

– Negative attitudes were expressed toward outpatient DOT by both providers and patients.

– Many patients and their families would prefer inpatient therapy and seek it when they can.

– There is still a powerful stigma that may be related to the strongly held belief that one "always has TB," or at least that one is always susceptible once diagnosed, even after successful treatment.

– Strong preference was expressed for food parcels. The International Federa-tion of the Red Crescent Central Asia regional study also showed preference for food parcels and visiting nurses.

– Many expressed inconvenience and stigma associated with the hot meal incentive.

– The money incentive was not a strong motivator and was perceived to be insufficient to cover many expenses.

– No negative and many positive comments were expressed about visiting nurses.

Costs and Cost Effectiveness

The costs of the incentives were not great per patient visit but, when summed up over an entire treatment course of 54 continuation phase doses, the costs are not negligible.

– Providers and patients have similar negative attitudes toward TB outpatient therapy and would prefer either home delivery of medications (patients) or inpatient care for the entire six-month course of therapy (patients and health providers).

– Incentives can raise an already high baseline success rate among new patients, but incentives are perhaps better allocated to re-treatment or chronic patients where the baseline success rate is much lower.

Summary of Results for Each Incentive				
	Effectiveness	Cost Effectiveness	Satisfaction	Feasibility
Hot Meal	++	++	+	+
Money	++	+++	++	++
Visiting Nurse	+++	++	+++	+++

—American Red Cross and Red Crescent Society of Kazakhstan

Resources

TO LEARN MORE ABOUT REACHING MARGINALIZED POPULATIONS:

TB Virtual Resource Center. 2007. Various community-based TB care documents are available online at: http://www.tbvrc.org/TBVRC_Resource. cfm?click_action=yes&m_id=48; accessed December 2007.

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WHO. *Empowerment and Involvement of Tuberculosis Patients in Tuberculosis Control.* 2007. Available online at: http://whqlibdoc.who.int/hq/2007/WHO_HTM_STB_2007.39_eng.pdf; accessed December 2007.

WHO, Stop-TB Partnership. *Community Involvement in TB Care and Prevention: Toward Partnerships for Health* (working title). STOP TB Partnership. Pending.

Challenge 8.

Act Locally, Think Nationally

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Why it matters	What NGOs can/should do
Too often, well-designed community-based TB control programs work in relative isolation, missing opportunities to contribute data or findings to national-level control efforts or to have a larger-scale impact in the country where they are based.	Build relationships with key stakeholders, including the national tuberculosis program (NTP) or the Ministry of Health in order to support the flow of technical wisdom and data to bring quality services to more people.

Lessons Learned and Recommendations

NTPs have historically implemented programs focused on government facilities. This is a critical time for NGOs to offer program expertise and pro-actively connect and build partnerships with NTPs. Some current examples of these types of connections include:

– Project Concern International (PCI) introduced asset mapping, positive deviance and appreciative inquiry to NTP officials at various levels.
– Population Services International (PSI) has trained NTP officials in basic research techniques for developing appropriate behavior-change communication (BCC) materials.
– NGOs have presented data on innovative approaches at the community level to NTPs to advocate for their adoption and scale-up nationwide.

Community-based efforts can create lasting change through a sophisticated understanding of the cultural, economic and micropolitical context of a community. Unfortunately, staff members involved in these efforts are often so focused on their daily work that their successes—and the challenges and reasons behind them—are relatively unknown in the very country where they are working. Community-based programmers can foster high quality community-based efforts that reach more people—directly or indirectly—in a variety of ways, including:

– Sharing technical experience and strategies with the NTP and the Ministry of Health
– Linking with other TB, HIV and health organizations to share technical knowledge, energy and data
– Piloting projects as the first step, before expanding efforts
–Thinking about the criteria that would make your program scalable (i.e., relevance, compatibility, simplicity, testability and credibility)
– Gathering compelling monitoring and evaluation data that shows how a project successfully stops TB, is cost effective and/or addresses other issues that resonate with Ministries of Health and Finance to make a strong case for scale-up or replication

Case Study in Thinking Nationally
Mobilizing the Private Sector to Reduce the Burden of TB
Population Services International, Myanmar

In Myanmar, Population Services International (PSI) has creatively linked private community-level medical services into the national health system and supported it with a national scale communication campaign to increase program quality and reach.

PSI introduced the directly observed treatment short course (DOTS) to low-income communities through the Sun Quality Health (SQH) franchise network of private doctors in 2004. Rather than confine project activities to a limited location or small population, PSI chose to work with the SQH network so as to have extensive reach to low-income patients through a large-scale network of providers.

Network members are licensed general practitioners with clinics serving low-income populations. They work full-time in their clinics and demonstrate interest in quality and equitable health care. The TB social franchise intervention is targeted at low-income TB patients in the community at large, as well as those living among population subgroups in Myanmar, such as migrants, people living with HIV and ethnic and religious minorities.

The providers are trained in groups, via training courses in accordance with national and international guidelines. These workshops are participatory and interactive, with staff of the national TB program participating as resource persons. PSI works with the providers to appoint local outreach workers (typically cured TB patients) to assist with follow-up of the TB interrupters, case detection, contact tracing and service demand creation.

Once trained, participating providers receive training manuals, certificates, monthly client-record forms and a substantial supply of counseling, educational and promotional materials relating to TB. PSI's franchise officers conduct quality-monitoring visits to the clinics, in which they give on-site training and technical support to doctors.

Using Branding and Mass Media to Increase Reach

The TB providers received a branded DOTS signboard, which identifies their clinic as a site for free TB treatment. Behavior-change communications are critical to significantly improve of the health-seeking behaviors of the program's target group. The intervention implements a comprehensive TB communications strategy, developed to reflect themes identified during a marketing plan process that works to get patients to take a full course of TB treatment. The TB DOTS brand, developed by the intervention for the private sector, has been adopted by the public sector.

HIV diagnosis and treatment via DOTS is available in PSI's four existing voluntary, confidential counseling and testing centers. Via the project network, referral is offered to TB patients with symptoms and/or signs of HIV-related conditions, as well as to TB patients with a history that suggests a high risk of exposure to HIV.

The intervention has been designed to support the National Strategic Plan. PSI actively participates in TB-coordinating bodies in Myanmar, under the guidance of the NTP and the WHO, including participation in the TB Technical Support Group, the Drug-Resistant TB Committee, and a STOP TB Partnership. The intervention specifically links the private-sector doctors and laboratories to the NTP via establishment and enforcement of national quality standards, provision of free drugs to the private sector by the NTP, establishment of referral mechanisms between sectors and the routine reporting of private-sector data to the NTP.

To date, more than 415 private SQH doctors have been trained in more than 100 townships. To date, these doctors have tested 48,354 clients and registered more than 22,852 TB cases, of which 10,345 are smear-positive. They have achieved a treatment success rate of 83% among new smear-positive cases and 80% treatment success rates overall. Only 4% of clients have defaulted. Research has found that the project is indeed reaching the poor with quality TB services and increasing case-detection rates in areas where the project is active.

To view a Myanmar TB commercial starring a national celebrity singing about the project's DOT brand, visit http://www.psi.org/where_we_work/myanmar.html

—Population Services International

Resources

TO LEARN MORE ABOUT "THINKING BIG" IN COMMUNITY-BASED TB:

Management Systems International. *Scaling Up—From Vision to Large-Scale Change: A Management Framework for Practitioners.* 2006. Available online at: http://www.msiworldwide.com/documents/ScalingUp.pdf; accessed December 2007.

Save the Children. *Taking Community Empowerment to Scale: Lessons from Three Successful Experiences.* 2007. Available online at: http://www.savethechildren. org/publications/programs/health/Taking-Community-Empowerment-to-Scale.pdf; accessed December 2007.

Challenge 9.

Mobilize and Advocate for Improved Use of Resources for Community-Based TB Care

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Why it matters	What NGOs can/should do
The level of resources devoted to TB control lags behind the true scope of the problem. In addition, TB resources could be more effectively employed to combat TB through a sharper focus on—and more resources devoted to—community-level programming.	Foster activity at the community level to empower individuals and local groups to understand and advocate for quality TB and TB/HIV interventions and services. Advocate for the needs of people with TB by using NGO influence in global, national and regional forums. Make the case for more resources to fight TB and for improved national programs—which means ensuring that the community-level piece of the puzzle is effectively included.

Lessons Learned and Recommendations

TB control can be more costly per case detected than other health programs. TB strikes working adults in the prime of life, thereby affecting everything from the gross national product of countries to the well-being of the family members who depend on the patients. Policy makers, at all levels—from the community to the international arenas—often react strongly when they learn the true costs of TB at multiple levels.

NGOs are called on to advocate on many levels for more—and more effective use of—community-based TB resources. Different levels call for specific advocacy agendas:

At the district and community level, resources are needed for capacity building of staff and organizations, for staff time to properly manage cases, for volunteer support, and to fund badly needed community awareness and mobilization activities. NGOs can build the capacity of local counterparts by serving as an intelligence bridge to inform local-level players about global trends, national policies and resources, and to supply timely medical and social information. NGOs can also inform larger organizations and entities of the struggles and successes of communities, families and individuals.

At the national level, officials can be called on to improve hospitals, staffing, laboratories and drug quality and supply, and to develop local trials and support community-based approaches, especially scale-up. NGOs should serve as a bridge between communities (local and international) and the NTP. A good working relationship with the NTP is therefore critical.

"Many times it's the basics that people don't understand—that TB is treatable, curable. Nothing makes the donors happier to know, once they understand this, that their resources are saving lives from TB. It costs $10 for the medicine to save a life. A life for the cost of a pizza.

"Unless we make TB a political issue like HIV/AIDS is, we will not win the fight. . . . We are all connected by the air that we breathe. Thus it's everyone's responsibility to fight TB and TB/HIV collectively."

—Lucy Chesire, Kenyan TB-HIV advocate

The national level is also a strategic location for supporting and developing high profile advocates and media connections. These key partners, especially when connected with civil society coalitions, can reach out to top levels of government, donors, the general population and even to health-system managers and care providers through responsively improved policies and increased resources. Media and community-level partners can come together to put a face on TB through documentation, stories and contacts. When put together, well documented project outcomes, data, and stories can serve as an effective stategy for long-term change.

At the global level, donors and policymakers need to be informed about the potential of community-level activities, the urgency of the TB problem, and the need for new drugs and technologies. International NGOs can tell the stories of TB patients and communities to ensure that their perspectives are represented at the global level.

Case Study in Mobilizing for Resources
Building a Coalition to Get the Funds Flowing
RESULTS: Kenya

Problem Identified: In 2005, much TB programming momentum in Kenya was stalled due to systemic holdups of Global Fund TB grants. The resources were being delayed in government bureaucracies and at the level of the Country Coordinating Mechanism.

Proactive Strategy to Address the Problem: Concerned activists identified the Kenya AIDS NGO Consortium (KANCO) as a starting point for creating and organizing a broader coalition and advocacy effort to advance TB work in Kenya. The resulting group included more than 20 civil society organizations, a partnership called the United Civil Society Coalition against AIDS, TB and Malaria (UCC-ATM). The combined influence and reach of its members ensured that this powerful group was impossible to ignore as it took its message to the public as well as to national and international stakeholders, including politicians from Kenya and other countries, the head of Kenya's national tuberculosis program, other health and government officials, celebrities, public health champions and journalists.

Sample Activities: RESULTS UK supported the effort by bringing four U.K. members of parliament (MPs) to Kenya to learn about the scale of the TB problem and what the U.K. and Kenyan governments, as well as the Global Fund, were doing to address it. The MPs visited with patients, health

"United Civil Society Coalition at the country level in Kenya has made a big difference.

We have actually moved forward. I believe other countries can do it, too."

—Lucy Chesire, Kenyan TB-HIV advocate

workers, NGOs, donor representatives, and Ministry of Health officials. A well-attended news conference generated media messages as the MPs (as respected outsiders) were able to speak frankly about the key issues. A conference call including 60 grassroots activists in the U.K. further supported the efforts of the UCC-ATM.

Outcomes Achieved: Within months of creation, the UCC-ATM facilitated the processing of two grants that had been in limbo. Kenyan Global Fund governance was restructured in the Ministry of Health and the Country Coordinating Mechanism (including designated representation for TB patients). As a result, the logjam blocking the flow of Global Fund TB resources in Kenya was broken. KANCO and the UCC-ATM are continuing their monitoring of these and other resource flow issues and their advocacy with a unified voice for improved policies and increased resources for TB and other health issues.

> —Adapted from RESULTS Educational Fund, ACTION
> and Lucy Chesire

Resources

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TO LEARN MORE ABOUT ADVOCACY AND COMMUNITY-BASED TB:

Constella Futures and World Health Organization, Stop-TB Partnership. *Networking for Policy Change: TB/HIV Advocacy Training Manua, and Participant's Guide.* 2007. Available online at: http://www.stoptb.org/wg/tb_hiv/assets/documents/Final%20Manual_edited.pdf and http://www.stoptb.org/wg/tb_hiv/assets/documents/Participant%20Guide%20TB_HIV_edited.pdf; accessed December 2007.

Public Health Watch, Open Society Institute. *Civil Society Perspectives on TB Policy.* Public Health Watch, Open Society Institute. 2006. The Open Society Institute makes the case that government and civil society must work together to raise public awareness and engagement around TB and TB/HIV. The publication offers case studies from Bangladesh, Brazil, Nigeria, Tanzania and Thailand. Available online at: http://www.soros.org/initiatives/health/focus/phw/articles_publications/publications/civilsociety_20061101; accessed December 2007.

RESULTS International. *TB fact sheets, publications, and advocacy tools.* 2007. Available at: www.results.org; accessed December 2007.

World Health Organization. Tuberculosis Virtual Resource Center. *Advocacy and Partnership Materials.* 2007. Available at: http://www.tbvrc.org/TBVRC_RESOURCE2.cfm?sub_id=58&m_id=1; accessed December 2007.

Appendixes

Appendix 1: List of Attendees

Full Name	Title	Organization
Dipak Adhikari		Media Forum for Research and Development
Namita Agravat	Technical Advisor	U.S. Agency for International Development
Susan Bacheller	Tuberculosis Team Leader	U.S. Agency for International Development
Emily Bell	Project Officer	Open Society Institute
Martha Benezet	TB and HIV Program Coordinator	Medical Care Development Inc./ Int'l. Division
Amy Bloom	Senior TB/HIV Advisor	U.S. Agency for International Development
Katie Breese	Program Officer	University Research Co., LLC
Jean Capps	International Health Consultant	Independent
Dennis Cherian		World Vision International
Eunyong Chung	Senior Nutritional Advisor	U.S. Agency for International Development
Anusha Dahanayake	Co-Director	Global Health Action
Sandra Dalebout	TA, Infectious Diseases Unit	Project HOPE
Masoud Dara	E + E Project Director	KNCV Tuberculosis Foundation
Alka Dev	Program Manager	Doctors of the World–USA
Milan K. Dinda		People's Coalition against TB/HIV
Shannon England	Deputy Director, New Business Dev	Population Services International
Lauren Erickson-Mamane	Child Survival and Nutrition Programs Coordinator	Food for the Hungry International
William Oscar Fleming	HIV/AIDS Program Specialist	Christian Children's Fund
Dr. Giuliano Gargioni	Medical Officer	STOP TB, WHO
Stella Goings	Principal HIV/AIDS Advisor, Africa Bureau	U.S. Agency for International Development
Christy Hanson	TB Research Advisor	U.S. Agency for International Development
Mary Harvey	Health Officer	U.S. Agency for International Development
Ann Hendrix-Jenkins	Coordinator, Tuberculosis Working Group	CORE Group
Philip Hopewell		American Thoracic Society/University of California–San Francisco
Ineke Huitema	HRD Coordinator PMU TBCAP	KNCV Tuberculosis Foundation
Nobukatsu Ishikawa	Director	RIT/JATA
Stacy Kancijanic	Program Associate	University Research Co., LLC

Full Name	Title	Organization
Kristin King		CARE
Jeanne Koepsell	Senior Program Advisor	American Red Cross, International Services
David Kurth		Counterpart International
Karen LeBan	Executive Director	CORE Group
John Lwong	Executive Director	Fashoda Youth Forum
Inas Mahdi	Evaluation and Dissemination Specialist	Population Services International
Ruslan Malyuta		John Snow Inc.
Elena McEwan	Senior Health Technical Advisor	Catholic Relief Services
Jamie Mignano		Catholic Relief Services
Carrie Miller	HIV Technical Advisor	Catholic Relief Services
Sangeeta		Management Sciences for Health (MSH)
Mary Mugala	Office Manager	Partners for Development
Ya Diul Mukadi		Family Health International
Nirmal Kumar		World Vision INDIA
Jennifer Pearson	Executive Assistant	CORE Group
Areana Quinones	Malaria Program Coordinator	CORE Group
Jim Ricca	Capacity Development Advisor	Child Survival Technical Support
D'Arcy Richardson	Technical Director, TB Program	PATH
Khrist Roy	Technical Advisor	CARE
Leo Ryan	Director, CSTS+	Child Survival Technical Support
Janine Schooley	Vice President for Technical Services and Program	Project Concern International
Joel-Victor Semengue		GIC Maleo social marketing
Holly Shepherd		International Medical Corps
Srijana Shrestha		National TB Centre
Shanda Steimer		U.S. Agency for International Development
Vandana Tripathi	Program Director	Doctors of the World USA
George Tsilosani		A Call to Serve (ACTS) International
Laban Tsuma		PLAN International
Maarten van Cleeff	TB CAP Project Director	KNCV Tuberculosis Foundation
Cheri Vincent	Senior Public Health Advisor	U.S. Agency for International Development
Christine Whalen	Independent Consultant	Independent
Erin Wilson	HIV Policy Analyst	Association of State and Territorial Health Officials

Appendix 2: Resources for Getting Started in Community-Based TB Care

WHO. STOP-TB. 2007. Includes the Global Plan to Stop TB (2006-2015), advocacy materials, fact sheets, videos and event listings. Available at: http://www.stoptb.org; accessed December 2007.

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Other country-specific resources to consider:

Current NTP policy documents and press releases, if available. To keep abreast of available local government structures, supports and priorities for consistency and sustainability.

National/provincial Ministry of Health TB and ART protocols, if available.

Appendix 3: Fact Sheet on TB

The Disease

– TB kills approximately 1.5 million people each year, making it the greatest curable infectious killer worldwide.

– One-third of the world's population is infected with the TB bacterium.

– Nearly 9 million people become sick with active TB each year.

– Twenty-two countries carry 80% of the global TB burden (in order from highest burden of TB): India, China, Indonesia, Nigeria, South Africa, Bangladesh, Pakistan, Ethiopia, Philippines, Kenya, DR Congo, Russian Federation, Vietnam, Tanzania, Uganda, Brazil, Afghanistan, Thailand, Mozambique, Zimbabwe, Myanmar and Cambodia.

Infection and Transmission

TB is spread through the air when people inhale TB bacteria, most likely over the course of hours. TB bacteria are propelled into the air when infectious people cough, spit, talk or sneeze. Left untreated, a person with active TB can infect an average of 10–15 people every year.

Directly Observed Treatment, Short-Course (DOTS)

– DOTS (the standard strategy for detection and cure of standard TB) is one of the most cost-effective health interventions available today, costing just US$20–100 to save a life. A full six-month course of anti-TB drugs to treat a standard case of TB costs as little as US$15.

– Despite an affordable treatment, DOTS programs are detecting less than half (45%) of infectious TB cases worldwide.

Multidrug-Resistant (MDR) and Extensively Drug-Resistant (XDR) TB

– Four standard drugs, known as first-line drugs, can generally successfully treat TB. If these drugs are not prescribed or taken properly, MDR TB can develop.

– The drugs to treat MDR TB, known as second-line drugs, are more expensive and may have more problematic side effects.

– If second-line drugs are not prescribed or taken properly, XDR TB can develop.

– Treatment options for XDR TB have low levels of effectiveness.

– Like all forms of TB, XDR TB presents a serious danger to persons with HIV infection or an otherwise weakened immune system.

For more on TB Facts and FAQs, organizations, and the latest TB news updates, visit http://www.globalhealthreporting.org/tb.asp

Appendix 4: CORE Group's Tuberculosis Working Group

CORE Group, a membership association of international nongovernmental organizations (NGOs), promotes and improves the health and well-being of children and women in developing countries through collaborative NGO action and learning. As of December 2007, CORE Group's 47 member organizations work in more than 180 countries.

The TB Working Group of CORE Group enhances NGO capacity to design and implement quality TB programs by:

– Increasing linkages among NGOs that are currently implementing TB activities or planning to do so, as well as NTPs, the WHO, STOP-TB, the International Union against TB and Lung Disease and other international TB organizations.

– Providing forums for the exchange of experiences for improved design and implementation of TB programs.

– Representing NGO TB implementation issues, from the perspective of community-based programming, at international meetings and other relevant settings.

– Gathering and defining specific designs for cross–sectoral work to improve effective TB programming, with a focus on HIV/AIDS and TB synergies.

– Creating opportunities for research and implementation of innovations.

More at: http://www.coregroup.org/working_groups/tb.cfm