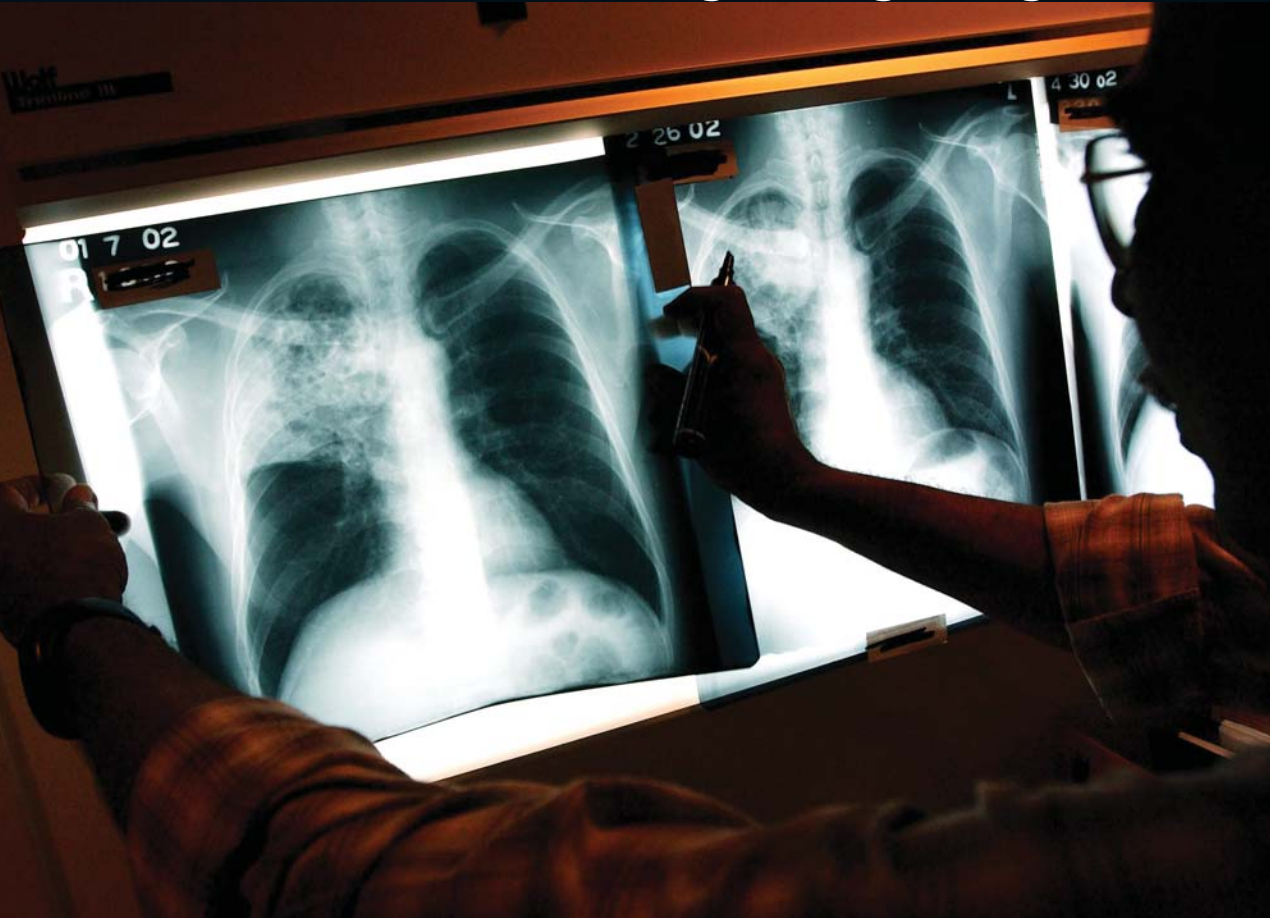


TB POLICY IN

# Tanzania



## A Civil Society Perspective

*A series of reports on TB policy in  
Bangladesh, Brazil, Nigeria, Tanzania, and Thailand*

**PUBLIC HEALTH WATCH**

 **OPEN SOCIETY INSTITUTE**  
Public Health Program



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ISBN: 1-891385-57-7

978-1-891385-57-5

Published by

Open Society Institute

400 West 59th Street

New York, New York 10019 USA

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Design by Jeanne Criscola | Criscola Design

Layout by Judit Kovács | Createch Ltd.

Printed in Hungary by Createch Ltd.

Cover Photograph by Spencer Platt | Getty Images

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# Preface

On the first World TB Day of the new millennium, ministerial representatives of the 20 countries carrying 80 percent of the global tuberculosis (TB) burden adopted the Amsterdam Declaration to Stop TB. By adopting the Declaration, these governments pledged to take bold new steps in addressing the TB epidemic in their countries and affirmed their commitment to “implement, monitor and evaluate” their national TB programs according to the TB control strategy recommended by the World Health Organization (WHO).

In the Declaration, the governments also expressed their will to “promot[e] the development of . . . partnerships to stop tuberculosis with all stakeholders in society, including government departments and organizations, the private health sector, industry, *non-governmental organizations and the community*” (emphasis added).

Public Health Watch supports independent monitoring of governmental compliance with the Amsterdam Declaration as part of its mandate to promote informed civil society engagement in policymaking on tuberculosis and HIV/AIDS—two closely linked diseases that lead to millions of preventable deaths annually. Established by the Open Society Institute’s Public Health Program in 2004, Public Health Watch also supports civil society monitoring of governmental HIV/AIDS and TB/HIV policies, examining compliance with the United Nations Declaration of Commitment on HIV/AIDS and the WHO Interim Policy on Collaborative TB/HIV Activities.

For the TB Monitoring Project, Public Health Watch civil society partners in Bangladesh, Brazil, Nigeria, Tanzania, and Thailand have prepared assessments of national TB policies based on a standardized questionnaire, which facilitates structured review of governmental compliance with key elements of the Amsterdam Declaration and the WHO TB control strategy. Public Health Watch researchers come from a range of backgrounds, including academia, development, journalism, and independent activism, and from both large and small nongovernmental organizations (NGOs).

The Public Health Watch monitoring methodology incorporates multiple opportunities for dialogue and exchange with a range of policy actors during report preparation. Researchers convene an advisory group of national TB experts, activists, and policy actors. They prepare draft reports on the basis of input from the advisory group, desktop and field research, interviews, and site visits. Researchers then organize in-country roundtable meetings to invite feedback and critique from policymakers, academics, government officials, representatives of affected communities, and other key stakeholders. Finally, Public Health

Watch supports researchers in conducting targeted advocacy at the domestic and international levels around their report findings and recommendations.

To access all five country reports of the TB Monitoring Project or to learn more about Public Health Watch, including the HIV/AIDS Monitoring Project and the TB/HIV Monitoring and Advocacy Project, please see: [www.publichealthwatch.info](http://www.publichealthwatch.info).

## Acknowledgments

*TB Policy in Tanzania: A Civil Society Perspective* was researched and drafted by Jamillah Mwanjisi in collaboration with Media Bank and Mangi Ezekiel Muhimbili of the University College of Health Sciences. The staff of Public Health Watch prepared the overview and provided editing and administrative assistance. Additional editing and production assistance was provided by the Communications Office of the Open Society Institute.

Public Health Watch would like to acknowledge the significant contributions of the Tanzanian Advisory Group, both in helping to conceptualize and review the report and plan advocacy efforts around its key findings and recommendations.

On November 8, 2005, Media Bank hosted a roundtable meeting in Dar es Salaam to invite feedback and critique of a draft of this report from approximately 16 participants from the government, nongovernmental organizations, and international agencies. The final report has undergone revisions, with additional input from other health experts. Public Health Watch would also like to thank the following individuals and organizations for their invaluable contribution to the report by making themselves available for interviews, by providing access to data, research, and documentation, or by reviewing and critiquing earlier drafts: Innocent Semali, Comprehensive Community Based Rehabilitation Tanzania, WAMATA, TANOPHA, and Service, Health, Development and Education for People Living with HIV/AIDS (SHIDEPHA).

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## Public Health Program

The Open Society Institute's Public Health Program promotes health policies based on social inclusion, human rights, justice, and scientific evidence. The program works with local, national, and international civil society organizations to foster greater civil society engagement in public health policy and practice, to combat the social marginalization and stigma that lead to poor health, and to facilitate access to health information.

## Open Society Institute

The Open Society Institute works to build vibrant and tolerant democracies whose governments are accountable to their citizens. To achieve its mission, OSI seeks to shape public policies that assure greater fairness in political, legal, and economic systems and safeguard fundamental rights. On a local level, OSI implements a range of initiatives to advance justice, education, public health, and independent media. At the same time, OSI builds alliances across borders and continents on issues such as corruption and freedom of information. OSI places a high priority on protecting and improving the lives of marginalized people and communities.

Investor and philanthropist George Soros in 1993 created OSI as a private operating and grantmaking foundation to support his foundations in Central and Eastern Europe and the former Soviet Union. Those foundations were established, starting in 1984, to help countries make the transition from communism. OSI has expanded the activities of the Soros foundations network to encompass the United States and more than 60 countries in Europe, Asia, Africa, and Latin America. Each Soros foundation relies on the expertise of boards composed of eminent citizens who determine individual agendas based on local priorities.

[www.soros.org](http://www.soros.org)

## Abbreviations

ARV	Antiretroviral drug
CB-DOTS	Community-based DOTS
CDC	U.S. Centers for Disease Control and Prevention
CIDA	Canadian International Development Agency
DCT	Diagnostic counseling and testing
DOT	Directly observed treatment
DOTS	The internationally recommended strategy for TB control
DRS	Drug Resistance Surveillance
DTLC	District TB and leprosy coordinator
GDP	Gross Domestic Product
GLC	Green Light Committee
GLRA	German Leprosy and TB Relief Association
HMIS	Health Management Information System
HSSP	Health Sector Strategic Plan
IRIN	Integrated Regional Information Network
IUATLD	International Union Against Tuberculosis and Lung Disease
KABP	Knowledge, Attitudes, Beliefs and Practices
KITUPA	Kilombero Tuberculosis Research Project
KNCV	Royal Netherlands Tuberculosis Association
MDR-TB	Multidrug-resistant TB
MoH	Ministry of Health
MTDP	Medium Term Development Plan
NACP	National AIDS Control Program
NGO	Nongovernmental organization
NIMR	National Institute of Medical Research
NSGRP	National Strategy for Growth and Reduction of Poverty
NTLP	National Tuberculosis and Leprosy Programme
PASADA	Pastoral Activities and Services for PLWHA and the Dar es Salaam Archdiocese
RTL	Regional TB and leprosy coordinator
SDC	Swiss Agency for Development and Cooperation
SWAp	Sector-wide approach
TACAIDS	Tanzania Commission for AIDS
TDR	Special Programme for Research and Training in Tropical Diseases
TPHA	Tanzania Public Health Association

TZS	Tanzanian shilling
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children’s Fund
USAID	United States Agency for International Development
VCT	Voluntary counseling and testing for HIV infection
WHO	World Health Organization

**I.**

**PUBLIC HEALTH WATCH**

**Overview**

## Estimated Global TB Burden Among High-Burden Countries, 2004

		Population 1,000s	TB Incidence (all forms) number 1,000s*	TB Incidence (all forms) per 100,000 population	TB Mortality (all forms) per 100,000 population	HIV Prevalence in Incident TB Cases %
1	India	1,087,124	1,824	168	30	5.2
2	China	1,307,989	1,325	101	17	0.9
3	Indonesia	220,077	539	245	46	0.9
4	Nigeria	128,709	374	290	82	27
5	South Africa	47,208	339	718	135	60
6	Bangladesh	139,215	319	229	51	0.1
7	Pakistan	154,794	281	181	40	0.6
8	Ethiopia	75,600	267	353	79	21
9	Philippines	81,617	239	293	48	0.1
10	Kenya	33,467	207	619	133	29
11	DR Congo	55,853	204	366	79	21
12	Russian Federation	143,899	166	115	21	6.8
13	Viet Nam	83,123	147	176	22	3.0
14	Tanzania	37,627	131	347	78	36
15	Uganda	27,821	112	402	92	19
16	Brazil	183,913	110	60	7.8	17
17	Afghanistan	28,574	95	333	92	0.0
18	Thailand	63,694	91	142	19	8.5
19	Mozambique	19,424	89	460	129	48
20	Zimbabwe	12,936	87	674	151	68
21	Myanmar	50,004	85	171	21	7.1
22	Cambodia	13,798	70	510	94	13

\* The WHO ranks the high-burden countries by the absolute number of new TB cases in each country and is not adjusted due to population size.

Source: "Table 6: Estimated TB burden, 2004," in WHO, *Global Tuberculosis Control: Surveillance, Planning, Financing*, WHO, Geneva 2005, p. 28.

The Public Health Watch TB Monitoring Project partners with civil society researchers in Bangladesh, Brazil, Nigeria, Tanzania, and Thailand, all of which are WHO-designated TB high-burden countries, to monitor and advocate for improved governmental policies and services to control TB. The five reports that have resulted from their monitoring efforts reveal a number of overarching themes regarding TB and TB/HIV.

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. Media coverage of TB is limited, and national TB programs (NTPs) generally lack strong communications strategies and staff with the experience and skills to interact effectively with the press.

Reports from all five countries highlight a number of other issues as well.

First, inadequate attention to the linkages between TB and poverty has resulted in a paucity of government measures to address the hidden costs of treatment that burden the poor and other vulnerable groups, including women.

Second, the fact that TB patients often rely on private service providers leads to inequitable access to quality services, constrains government capacity to monitor the course of the epidemic, and raises concerns about the potential of increasing resistance to first-line TB drugs.

Third, context-specific approaches to TB control that integrate community participation are showing positive results but require additional support and funding from domestic and international sources.

Finally, Public Health Watch 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. At present, there are few structured mechanisms to encourage broad public participation in the design, implementation, and evaluation of TB policy at the domestic or international level.

In addition to the common themes and findings outlined in this overview, country-specific recommendations can be found at the end of each national report.<sup>1</sup>

## High-level political commitment?

The adoption of the Amsterdam Declaration to Stop TB in 2000 marked an important milestone in the attempt to muster high-level political commitment to a reinigorated global TB control effort. Governments of the countries with the highest burden of TB pledged to expand access to the WHO-recommended DOTS framework for TB control in their countries;<sup>2</sup> to ensure sufficient human and financial resources to support implementation; to monitor and evaluate their national TB programs in line with WHO standards; to ensure “quality, access, transparency and timely supply” of TB drugs; and to support partnerships with NGOs and the community.<sup>3</sup>

However, rhetorical commitment to the Declaration has not been reflected in adequate budgetary allocations at the national and subnational levels. Without strong national leadership, state and local officials are less likely to give budgetary priority to either TB control, particularly in highly decentralized political systems as in **Brazil** and **Nigeria**, or health care reforms, as in **Tanzania** and **Thailand**, where cost-cutting measures have had a dramatic impact on the capacity of national TB programs, particularly with regard to monitoring and evaluation, staffing, and training.

Underfunding of the health sector in general has compromised capacity to treat TB within existing public health systems in **Bangladesh**, **Nigeria**, and **Tanzania**. The executive director of Nigeria’s National Primary Health Care Development Agency commented that “where [primary health care] services are available, the quality is such that people prefer to go elsewhere for the services.”<sup>4</sup> Public Health Watch researchers from all five countries judged that government spending on TB was inadequate to ensure the effective implementation of national TB policies. For example, only about two-thirds of all Bangladeshi laboratories have the capacity to perform high-quality smear tests,<sup>5</sup> and laboratory rooms in some subdistricts are small and poorly ventilated, creating health risks for staff. As researcher Afsan Chowdhury noted, “If you measure political commitment [in Bangladesh] in terms of resource mobilization—if you see this as a measure of the extent to which TB is on the political agenda—it’s low, there’s not much.”<sup>6</sup> TB workers are underpaid and overworked, leading to high turnover, sagging morale, and low recruitment. As funding for TB control has declined in Brazil over the past few decades, so has the prestige of TB work, even as increased investment in HIV/AIDS since the early 1990s has helped enhance the status of HIV/AIDS workers.

In **Brazil**, **Nigeria**, **Tanzania**, and **Thailand**, the HIV/AIDS epidemic has fueled a dramatic resurgence in TB rates and put an additional strain on health infrastructures, yet governments have been slow to respond with corresponding increases in TB budgets and personnel. In **Tanzania**, the resurgence in TB rates—a six-fold increase in the number of cases between 1983 and 2003—has largely been attributed to the HIV epidemic. HIV preva-

lence among TB patients in **Nigeria** increased more than four-fold over the period between 1991 and 2001.<sup>7</sup> In **Thailand**, the resurgence of TB and the number of patients coinfecting with TB/HIV has been similarly dramatic, yet the integration of the TB control program into the more powerful and better funded National AIDS Control Programme—intended to promote collaborative TB and HIV policies and services—has instead dissipated the authority and resources of the TB program.

International donors cover a large share of TB control budgets in **Bangladesh**, **Nigeria**, and **Tanzania**. For instance, the Tanzanian government in 2003 contributed 10 percent of the National TB and Leprosy Programme’s total annual budget.<sup>8</sup> As one Nigerian health care provider noted, “remove the donor, and everything would crash.”<sup>9</sup> Public Health Watch researchers unanimously recommend that donors should take greater care to ensure that assistance programs strengthen long-term capacity to conduct TB control activities without external support. “Most international cooperation is project-based,” researcher Akramul Islam of Bangladesh said. “But we’re trying to do long-term thinking. Many international organizations think they will come here and transfer knowledge—but how can you just transfer knowledge and then wash your hands?”<sup>10</sup>

Even in countries such as **Brazil** and **Thailand**, where domestic spending accounts for the greater part of the health budget, donor resources are playing an increasingly significant role in TB control. In 2005, 45 percent of the Thai National TB Programme budget came from the Global Fund to Fight AIDS, Tuberculosis and Malaria. In recent years, bilateral agencies such as the US Agency for International Development (USAID) and other external public and private funding sources have provided most of the investment in clinical and operational research in Brazil. Access to global funding streams is making a clear contribution to national TB control efforts in all five countries. Yet Public Health Watch researchers all expressed concern about the potential for displacement of government responsibility and the impact on the capacity of governments to sustain TB control efforts in the long term.

There has been minimal public mobilization around the need to hold governments accountable for their commitments to reach Amsterdam Declaration targets. Without effective pressure from domestic constituencies, governments have had little incentive to improve their performance on TB control. Researcher Ezio T. Santos Filho believes that the position of a middle-income country such as **Brazil** on the list of TB high-burden countries can only be explained by the absence of mechanisms to ensure that critical scrutiny of government TB control efforts includes the participation of people from communities most directly affected by TB. And **Bangladeshi** researcher Afsan Chowdhury insists that the involvement of dedicated National TB Programme officials is not enough; other sectors must lend their support as well. “We need a broad cross-section of actors involved to have an effective TB control policy,” Chowdhury said. “We need advocates *around* the minister of health—we need to make TB activists out of politicians. And TB needs to be pushed onto

the political agenda, not only of the health ministry, but also of the ministries of finance and planning.”<sup>11</sup>

The marginality of the Declaration at the country level is symptomatic of a broader issue: insufficient public awareness of the scope and seriousness of the TB epidemic. Global incidence of TB has increased over the past 10 years.<sup>12</sup> TB kills approximately 2 million people a year<sup>13</sup> and is a leading cause of death by infectious disease for people living with HIV/AIDS. Yet when contrasted with the extent of social mobilization around health issues such as HIV/AIDS, the general lack of awareness that TB is a serious health threat is striking.

## Lack of awareness

*There is nothing more than a poster on the wall in health facilities to promote awareness.*

—Ezio T. Santos Filho, *Public Health Watch* researcher, Brazil<sup>14</sup>

Public Health Watch researchers from all five countries identified lack of awareness about TB at all levels as a critical issue—one that has multiple adverse consequences and implications for the effectiveness of TB control efforts.

In the high-burden countries under study, many people do not know the basic facts about TB: how the disease is transmitted; that it can be treated and cured; and where to access free treatment. In **Bangladesh**, where over half of the population is infected with the TB bacillus, a recent study found that some women believed they could get TB by wearing torn slippers.<sup>15</sup> According to one Nigerian doctor, “most people [in Imo State] still think that TB patients have been poisoned. Some think it is a curse from the gods—especially when many family members get infected—and go to fortune tellers and prayer houses for deliverance.”<sup>16</sup> Even groups at an elevated risk of TB infection, including people living with HIV/AIDS, appear to lack information about TB. For example, a recent series of social mobilization workshops among HIV/AIDS activists in **Brazil**—where TB is one of the leading causes of death by infectious disease for people with HIV/AIDS—revealed that few participants knew even the basic facts about TB transmission and treatment.<sup>17</sup>

Lack of information can lead to delays in accessing treatment, increasing the potential for transmission of the disease. One recent study in Tanzania found that only 42 percent of TB patients visited a health facility within three months of the onset of symptoms; the median duration between onset of TB symptoms and visiting a health facility was about eight months.<sup>18</sup>

The low level of awareness extends to high-level political officials as well. The leader of one faith-based organization in **Thailand** remarked that “the general perception among political leaders as well as in Thai society is that TB has been completely eradicated.”<sup>19</sup>

In **Tanzania**, where over 50 percent of people living with HIV/AIDS are coinfecting with TB, many politicians and local government leaders believe that TB is a “disease of the past” that affects relatively few people and therefore do not consider TB a priority.

The scarcity of information and educational resources adapted for use at the community level is an obstacle to the initiation of awareness-raising efforts. And patients who do not understand the requirements of treatment are more likely to default, raising the risk of multidrug-resistant TB (MDR-TB), which few high-burden countries, including **Bangladesh**, **Nigeria**, **Tanzania**, and **Thailand**, have the capacity to detect and treat. **Brazil** has a strong system in place for treating its relatively few cases of MDR-TB but has undertaken a national investigation to determine whether high treatment default rates could be affecting national rates of drug resistance. A prominent TB doctor in Bangladesh expressed frustration that so little effort has been made to produce and disseminate culturally sensitive materials in the local language: “We are producing documents in English—for whom? For the donors! [We need TB materials] in Bangla, Bangla and more Bangla. And we have to remember that only one in three people can even read Bangla.”<sup>20</sup> Researcher Jamillah Mwanjisi reported that available information on TB in **Tanzania** is overly technical and jargonistic, especially in comparison to resources on HIV/AIDS, and that TB officials make little attempt to communicate the basic, essential information that people need in language they can understand. “There is quite a lot of room for social mobilization around TB—for activists to get involved,” she said. “The problem is that TB is so closed to [everyone except] the experts.”<sup>21</sup>

People from the communities most affected by TB and TB/HIV must be involved in the creation of materials about TB that are accurate and sensitive to local social and cultural contexts. Direct support to community activists and leaders would help them develop and use such materials to promote TB awareness in their communities.

## Media involvement

*[World TB Day is like] a flash of the camera, and then it's gone.*  
—Somsak Akksilp, director, Office of Disease Prevention and Control, Thailand<sup>22</sup>

Except for official statements on World TB Day, the NTPs in all five countries have made little attempt to communicate important information about TB through newspapers, television or radio outlets on a systematic and continuous basis. NTPs generally lack strong communication strategies and staff has little experience working with the media.

Mirroring the situation within the general population, most journalists know little about TB. **Nigerian** researcher Olayide Akanni—a journalist herself—found that journalists are reluctant to report on TB because they are not sufficiently aware of the issues. “The majority of journalists,” she said, “do not even know that TB is an issue.”<sup>23</sup> At one recent

meeting organized by Akanni’s organization, Journalists Against AIDS, a group of health correspondents from major Nigerian media outlets acknowledged that they had limited knowledge about the seriousness of the TB epidemic, how TB is spread, the linkage between TB and HIV, and other related issues.<sup>24</sup> “Journalists are not able to write articles about [TB], because we lack information,” a **Bangladeshi** journalist said. “We don’t receive information from TB experts and programs in a way that we can use it.”<sup>25</sup> Editors and media owners in **Nigeria**, **Tanzania**, and **Thailand** are reportedly reluctant to cover TB and other health topics because they do not believe these “softer” issues will generate enough public interest. Few government or donor-supported media training programs have focused on TB and TB/HIV.

In the absence of a well-articulated NTP communications strategy, few government TB officials have received media training or support in obtaining the necessary skills for working with the press. Journalists in **Nigeria** and **Tanzania** have found that the primary sources of information on TB—public health officials and health care workers—are reluctant to grant interviews. According to Akanni, to reach Nigerian public health officials, “there are bureaucracies you have to overcome, and you have to book an interview about two weeks in advance.”<sup>26</sup> Mwanjisi added that in Tanzania, “When you go to interview [TB officials], they’ll tell you a string of expert jargon, and when you ask, ‘Can you please explain it to me?’ they say, ‘Oh, you would not be able to understand it.’ That kind of attitude puts off a lot of journalists.”<sup>27</sup>

The fact that few civil society organizations are dealing with TB further limits potential sources of information for journalists. Mwanjisi commented that “even HIV support groups, who are referring people living with HIV to TB services, do not know anything about what is happening with the national TB program.”<sup>28</sup>

## Stigma and discrimination

*Stigma is frustrating access to TB treatment especially for people living with HIV . . . [and] the hostile attitude of health care officials . . . is responsible for this. Nobody would want to go to a place where he or she is likely going to be treated like an outcast. No matter how effective the treatment becomes, at the end of the day, you will simply avoid such places. If that is the only place where such treatment exists, so be it; some individuals would rather die than go there.*

—Yinka Jegede-Ekpe, coordinator, Nigerian Community of Women  
Living with HIV<sup>29</sup>

Lack of public awareness contributes to an environment in which people living with TB are more likely to feel shame and to face stigmatization and discrimination, even from health care workers, reinforcing their reluctance to seek treatment and care. Women, migrants, and members of other at-risk groups are particularly stigmatized. In areas of high HIV prevalence, people with TB are often assumed to have HIV as well, intensifying the level of stigmatization they experience.

Without an understanding of how TB is spread and that it can be cured, an atmosphere of suspicion, fear, and hostility toward people with TB can easily develop. In **Bangladesh**, BRAC research has shown that “common people would not like to associate with TB patients [for] fear of transmission,” making people with TB reluctant to seek diagnosis and care.<sup>30</sup> Though TB prevalence is reportedly quite high in factories (particularly among garment workers and in Export Processing Zones) and on tea plantations in Bangladesh, BRAC reports that factory owners are reluctant to allow access to TB service providers, and workers are reluctant to be tested for fear of losing their jobs if they test positive for TB.<sup>31</sup> A **Nigerian** TB patient reported that many TB patients abandon their jobs due to stigmatization from fellow workers who fear infection as well as more blatant forms of discrimination, including being fired by their employers.<sup>32</sup>

Mwanjisi sees a direct link between lack of reliable information about TB and TB/HIV coinfection and the high level of stigma attached to TB in **Tanzania**: “As soon as it is suspected that someone might have TB, everybody thinks that he or she also has HIV. . . [and t]his is because there is very limited information about TB—almost nothing—especially at the community level.”<sup>33</sup> The fears and prejudices of some health workers also add to the stigmatization of people living with both diseases.

Public Health Watch research strongly suggests that women are particularly vulnerable to stigmatization and discrimination and may be more hesitant to seek diagnostic and treatment services as a result. For example, research in Kanchanburi, **Thailand**, uncovered a common belief that TB is a “male” disease, associated with a high-risk lifestyle and “unfeminine” behaviors, so for women the onset of TB symptoms is accompanied by intense feelings of shame and loss of esteem.<sup>34</sup> In many communities in **Bangladesh**, women with TB face social disapproval for displaying physical symptoms such as coughing in public as well as a greater prospect of rejection by their husbands (or by prospective husbands if they are unmarried). As a result, Bangladeshi women are more likely than men to attempt to hide or deny TB infection, trying home and traditional remedies first and seeking professional services only as a last resort.<sup>35</sup>

Gender-related stigma is exacerbated by the fact that women typically face greater barriers in accessing health care than men. Women often have more restricted access to private income to cover the hidden costs of treatment such as nutritional supplements and transportation. In both **Bangladesh** and **Tanzania**, women cited cost as a significant

barrier; reportedly, **Tanzanian** women often have to “choose between traveling [to a clinic] and getting their medications or buying food for the family”<sup>36</sup>—and often opt against accessing TB care.

There are strong indications that TB is a serious health threat among migrants to **Thailand** from neighboring Burma, Laos, and Cambodia. Unable to read or speak Thai, lacking official documentation, and fearing deportation if they come into contact with public authorities, many are hesitant to seek treatment. Those who do seek treatment move so frequently that their treatment is often interrupted, raising serious concerns about MDR-TB.

TB is having a devastating impact on other vulnerable groups as well, including prisoners, refugees, and minority groups. Yet some NTPs have failed either to conduct the necessary monitoring and data analysis themselves or to support the collaborative research with academic institutions and NGOs that would allow them to identify vulnerabilities and to develop appropriately targeted programs and services. For example, in **Brazil**, since Brazilians of African descent are overrepresented among the poor, it seems likely that Afro-Brazilians—and particularly Afro-Brazilian women—also suffer higher rates of TB, yet there has been little research on this issue.<sup>37</sup> Where such data exists, as with regard to prisoners in **Thailand**, the government has been able to design and implement effective outreach programs.

## **TB and poverty**

There is abundant evidence that poverty increases vulnerability to TB. The malnutrition, overcrowding, poor air circulation, and unhygienic sanitation facilities commonly experienced by the poor all increase the probability of TB infection. People living in poor communities are also harder hit by the hidden costs of diagnosis and treatment and are therefore less likely to access TB services. One recent government study in Bangladesh found that 70 percent of patients at DOTS centers were below the poverty line.<sup>38</sup> TB prevalence and mortality rates in Brazil reflect broader socioeconomic patterns, with poor and disadvantaged communities suffering most.

TB, in turn, can make patients more vulnerable to poverty. TB treatment and associated costs are relatively higher for poor people. TB decreases an individual's mental and physical capacity to work, further adding to the financial burden of treatment and multiplying the extent and impact of poverty. As 90 percent of **Bangladeshi** TB patients are in the most economically productive age group (15–54 years), the economic and social burden to their families is massive. According to a document prepared by the Bangladeshi government, the economic impact associated with TB and TB coping strategies is credited with pushing 30 percent of nonpoor patients below the poverty line.<sup>39</sup>

## The hidden costs of treatment

*It is true that we receive free diagnosis and treatment, but [TB] drugs are very powerful, and they need to be taken with sufficient food. A majority of us [patients] are from poor families and we have only one meal per day. So sometimes we are forced to skip the drugs.*

—TB patient, Dar es Salaam, Tanzania<sup>40</sup>

Adhering to the six-month TB treatment regimen is a challenge, particularly for patients who are malnourished, taking antiretroviral drugs, grappling with other illnesses, or poor. Strict compliance with treatment requires a serious investment of patients' time, energy, and household resources. Reports from all five countries revealed that even though TB treatment is free, patients are often confronted with significant "hidden costs," including outlays for diagnostic tests, transportation to health facilities, nutritional supplements (since patients require an adequate diet to take their medications), and time away from work. In Tanzania, patients from rural areas in particular may spend several hours traveling to and from health facilities and one to six hours in the clinic waiting to receive medications—every day for the first two months of treatment. Similarly, in Nigeria, research revealed that states in the north, which are typically poorer, have far fewer TB centers available per capita, meaning that patients have to travel much farther for treatment. For example, as of January 2005, Zamfara State in the north had only 10 DOTS centers for a population of 3.6 million people, while Ogun State in the south had 116 DOTS centers for 2.3 million people.<sup>41</sup> For many patients, who also have to think about earning a livelihood and familial responsibilities, traveling such a long distance for TB care is simply untenable.

Yet despite the clear connection between TB and socioeconomic factors, governments continue to deal with the disease primarily as a public health problem rather than as a broader development issue. TB is usually left to the "experts," a small circle of medical and health professionals working within or connected to the Ministry of Health. For example, while maternal and child health, infant mortality, and HIV/AIDS are highlighted in **Thai** poverty reduction schemes, TB is not mentioned. The **Brazilian** government has long acknowledged that providing "incentives" such as nutritional supplements and transportation subsidies to TB patients is necessary to ensure treatment adherence. Yet under Brazil's decentralized system, individual states and municipalities have the responsibility to budget for the incentives, and thus their availability in practice varies greatly from state to state and within states.

Patterns of TB prevalence and the crippling hidden costs of treatment may help to explain why there has not been more civil society involvement around TB. People living in poverty, women, and members of other vulnerable groups are not generally well

represented in policymaking processes; these groups are most likely to lack higher education, political access, and allies in policymaking circles. People struggling to stick to a demanding treatment regimen are more likely to be focused on survival (while they are ill) and putting the experience behind them (after they are cured) rather than policy debates. Yet involving people living in the communities most affected by TB—especially those who have successfully completed treatment—is crucial to the development of more effective public outreach programs and to improving the quality and accessibility of services overall. Given the marginalization often faced by the people and communities most affected by TB, governments and international donors must take an active role in encouraging and supporting partnerships with community-based organizations to reach these groups more effectively.

## Public-private collaboration

*Management of TB patients in private practice is not of acceptable quality.*

*. . . [D]ifferent anti-TB regimens are prescribed depending on the experience of the private provider and on the patient's purchasing power.*

*—Report of Third Joint International TB DOTS/ HIV/AIDS Monitoring Mission to Nigeria<sup>42</sup>*

Many people with TB symptoms turn first to private practitioners in their communities, even in areas theoretically “covered” by governmental DOTS programs. People seek services from private providers because they lack knowledge about or sufficient access to free treatment, or because they are looking for better service than they expect to receive at publicly managed clinics. TB treatment regimens in private facilities are often based upon an individual’s purchasing power rather than on national guidelines for TB treatment. In Nigeria, for example, rather than relying solely on smear tests, private providers use chest x-rays to diagnose TB in people who can pay for this service. Widespread reliance on private providers who are not collaborating with the government also has a negative impact on the accuracy of official TB case recording and reporting and the likelihood of treatment default.

While those who can afford it often seek treatment from licensed private medical doctors, large numbers of TB patients seek treatment from a range of other, less qualified private providers, including traditional healers, pharmacists, and unlicensed doctors, few of whom can be counted on to follow NTP guidelines. A recent study in **Bangladesh** found that up to 70 percent of poor TB patients had consulted traditional healers, homeopathic providers, or allopathic doctors before seeking out DOTS services;<sup>43</sup> because these private providers charge fees for TB services, patients are more likely to appear for treatment only when they have enough money to buy drugs, or drop out entirely when their money runs out. Defaulting on treatment increases patients’ risk of developing (and spreading) MDR-TB.

Few private providers in **Bangladesh, Nigeria, Tanzania, and Thailand** systematically refer TB patients to public health clinics or report on the outcomes of the cases they treat. In **Brazil**, although most public health care providers also “moonlight” as private doctors to compensate for low public sector salaries, most TB patients access free treatment through the public health system. Private and public providers alike often view official case recording and reporting requirements as complicated and time-consuming, especially if no incentives to encourage compliance are in place.

Building incentives into public-private partnership agreements can have a positive impact. TB reporting from private hospitals in Bangkok, **Thailand**, improved significantly when the city’s Metropolitan Authority introduced a user-friendly computerized case recording and reporting system as well as concrete incentives such as free x-ray and sputum testing services, training, and TB education materials.<sup>44</sup> By contrast, similar public-private pilot projects have yielded less promising results in **Bangladesh** and **Nigeria**. As one Bangladeshi expert noted, “It’s very easy to say ‘public-private partnership,’ but it’s very hard to implement. . . . We have no dearth of policies; the question is how to implement them—that is the real challenge.”<sup>45</sup> Careful study is needed to assess why some pilot projects have succeeded and others have failed.

## The practicability of DOTS

*People living with HIV/AIDS become actively involved [in their own treatment]; they do home visit projects; they join committees at hospitals; they have a role in encouraging and supporting their fellow people living with HIV/AIDS to stick to treatment. This is the crucial role local communities have played in making AIDS programs successful [and] this . . . story could be replicated for TB patients.*

—Rev. Sanan Wutti, *The Church of Christ in Thailand*<sup>46</sup>

Quality-assured TB sputum microscopy and access to “directly observed treatment” (DOT) are two of the principal components of the WHO-recommended DOTS TB control strategy. Public Health Watch research suggests that financial and human resource constraints pose serious obstacles to guaranteeing DOT by public health care workers in many high-burden countries, and that ensuring strong community participation in TB control efforts can both help fill this gap and enhance public awareness and engagement around TB and TB/HIV. The emergence of the HIV/AIDS epidemic has highlighted the inadequacy of current TB diagnostic tools, even where these are available.

In many parts of the world, NTPs have interpreted DOT to mean that trained health care workers should supervise and observe patients on a daily basis in taking their

daily medication. This is one response to the acknowledged challenge of assuring treatment completion. However, in **Thailand** and **Bangladesh**, TB programs have recognized that it is simply not feasible for health care workers to observe all TB patients on a daily basis. For example, statistics from one TB treatment center in Chiang Mai, Thailand, indicate that fully 42 percent of patients self-administer treatment.<sup>47</sup> According to the director of a health facility in Bangkok, “The government and . . . the international community . . . say that people must receive DOT in every single case, . . . [but] . . . we can’t do this 100 percent. . . . Nurses have a lot of duties and many diseases to take care of—so no, they don’t get to everyone. We try to utilize community workers. . . . But [without] financial support, this won’t be sustainable.”<sup>48</sup> TB clinics in the **Brazilian** city of Rio de Janeiro offer patients the option of traveling back and forth to the clinic every day (or three times a week) to receive DOT, but many decline and choose to take responsibility for treatment themselves, often due to work responsibilities or a wish to avoid being identified publicly as a TB patient.<sup>49</sup>

In fact, a shortage of trained health care personnel and, particularly, of dedicated TB staff, affects the practicability of offering DOT in all five countries. In **Nigeria**, national debt and restrictions on public spending imposed by the World Bank and the International Monetary Fund (IMF) have historically placed major limitations on health sector allocations and spending, including on securing and retaining personnel.

The challenges for TB control are even greater in areas of high HIV prevalence, as many TB clinics are not equipped to meet the added challenge of diagnosing coinfecting patients. According to reports from **Brazil**, **Nigeria**, **Tanzania**, and **Thailand**, many HIV-positive patients die from TB without ever being diagnosed or treated. As a staff member from the National Reference Laboratory in **Nigeria** said, “Sputum tests alone [often do] not give the right diagnoses of TB, especially if the patient is HIV-positive. . . . We no longer refer TB patients to DOTS centers because they are often lost [seldom diagnosed or treated].”<sup>50</sup>

Though the WHO has issued an Interim Policy on Collaborative TB/HIV Activities<sup>51</sup> to help countries frame a coordinated response to the challenges of diagnosing and treating coinfecting patients, few countries—even those with high HIV prevalence such as **Nigeria** and **Tanzania**—have progressed beyond the planning and “pilot project” phase.

Though the importance of close supervision of TB treatment by trained medical experts is not debated, “top-down” efforts to ensure compliance need to be balanced with consideration for the importance of patient autonomy and the value of enlisting community-based support, as the WHO has increasingly recognized.<sup>52</sup> Still, Abdul-Mayeed Chowdhury, the executive director of BRAC, noted that within the current TB control paradigm, “Ordinary people are treated as the recipients of the services that are being delivered to them, rather than as equal partners in their treatment.”<sup>53</sup> Many TB advocates urge TB policymakers to draw upon examples of community-based ARV distribution among people living with HIV/AIDS as a useful model for developing community-based DOTS programs.

## Community-based DOTS

*TB should not be seen as an ‘experts-only’ disease; it affects everyone and everyone has a role to play.*

—Jamillah Mwanjisi, Public Health Watch researcher and director of Media Bank, Tanzania<sup>54</sup>

National TB programs in Bangladesh, Tanzania, and Thailand have sought to make TB treatment more accessible and affordable by initiating community-based TB programs, often in collaboration with NGOs. Though many of these programs have shown impressive results at relatively low cost, few have attracted sufficient investment and support for scale-up, either from domestic sources or international donors.

In response to lack of government capacity to administer DOT through health care workers in every community, BRAC and other NGOs provide community-based TB services in over two-thirds of **Bangladesh**. The BRAC approach—the most widely used model of its kind in the country—revolves around the *shastho shebika*, or female community health worker. *Shastho shebikas* are trained to identify TB symptoms and refer patients to TB diagnostic centers in the communities in which they live. Once a community member is diagnosed with TB, *shastho shebikas* obtain free TB drugs, administer DOT at the household level, and record and report relevant data to BRAC and to the NTP. *Shastho shebikas* receive significant support from BRAC in the form of regular training and refresher courses as well as the opportunity to earn income: they are permitted to sell pharmaceutical supplies in their communities, and for each TB patient cured, they receive a small fee of Tk 125 (approximately \$1.90). Many reportedly gain personal satisfaction and prestige from their jobs as well. As one *shastho shebika* noted in a recent interview, “I enjoy my work because it has gained me respect in my community.”<sup>55</sup>

The BRAC model of community-based care has achieved impressive results: treatment success rates at or above the global target of 85 percent,<sup>56</sup> at a cost of 50 percent less than the equivalent services in areas covered by the NTP.<sup>57</sup> BRAC’s community-based DOTS program has also reaped impressive social dividends. *Shastho shebikas* distribute information and raise awareness not only about TB, but about a range of health issues, and not just to people with TB symptoms, but to the entire community, thus defusing stigma. *Shastho shebikas* report that people who have recovered from TB are often their greatest allies in encouraging others to report symptoms and seek treatment. And the fact that BRAC’s TB services are implemented in collaboration with the Bangladeshi government, which provides free drugs, monitoring, and supervision, reinforces governmental capacity and leadership on TB control.

Pilot community-based DOTS programs have also demonstrated positive treatment outcomes at relatively low cost in the Kilombero and Temeke districts of **Tanzania**.

Following the initiation of the program, the cure rate in Kilombero jumped from 48 to 78 percent.<sup>58</sup> One district representative commented that the program was able to maintain a high quality of treatment services at a fraction of the cost to patients because travel costs had been eliminated.<sup>59</sup> One patient from the Temeke district of Dar es Salaam described the program as a “savior,” especially for communities far from health facilities or where roads are impassable during rainy seasons.<sup>60</sup> In Temeke, too, the program both maintained quality of services and improved cost effectiveness by 37 percent.<sup>61</sup> However, both pilot projects have now been terminated due to lack of funding. Community health workers continue to implement some community-based TB services on an ad hoc basis,<sup>62</sup> but without financial support for transportation or training from district health management teams these efforts have remained limited in scope.

In **Thailand**, village health volunteers and family members assist health workers in the provision of health services, including the distribution of TB drugs and the administration of DOT. However, there are some indications that the government has not devoted sufficient attention and resources to providing training and support for these volunteers. In addition to administering DOT, village health volunteers provide a wide range of primary health services, including TB education, in return for free medical care. Family volunteers do not receive even this level of compensation. Some village health volunteers report that they find their jobs are unappealing,<sup>63</sup> and others report that the responsibility of providing community and patient education is too great to be left to volunteers.<sup>64</sup> Many Thai health administrators agree that volunteer workers “need to be supported and salaried. We can’t make them work for free all the time.”<sup>65</sup>

Community-based DOTS programs provide a promising model for extending the capacity of government TB programs and engaging affected communities and individuals in becoming actively engaged in TB control efforts. However, Public Health Watch research suggests that NTP participation and leadership, particularly in providing infrastructural and technical support and training, may be important if the “scaling-up” and long-term sustainability of such programs is to be considered.

## Civil society engagement in TB policymaking

*Public pressure is still not felt by the National TB Programme; it's still a specialist program, and we're still telling the public what to do—that we know best. We need to show that the right belongs to the people [and the] provision of TB services has . . . to be seen as an obligation. Until we do this, [TB control] is not sustainable, and we won't reach the targets.*

—Afsan Chowdhury, Public Health Watch researcher and director of advocacy, BRAC, Bangladesh<sup>66</sup>

Civil society engagement in the design, implementation, and evaluation of TB policies at the national and international levels has been minimal. Though the importance of community involvement in addressing many of the issues raised in Public Health Watch reports is increasingly acknowledged at the rhetorical level, there are still far too few mechanisms and opportunities for meaningful participation. NGOs working in the field of health are still seen primarily as service providers; their role in promoting and demanding greater governmental accountability for delivering effective TB policies and services is not widely recognized.

At the national level, TB officials are not accustomed to receiving scrutiny from civil society actors. In **Nigeria** and **Tanzania**, Public Health Watch researchers found that TB officials were resistant to the idea that “nonexperts” could have a role to play in assessing quality of services or in helping to design and implement community-based and patient-centered programs. “The attitudes of some government health workers—maybe they have to change,” a health activist in **Thailand** said. “It seems like [TB experts] think they know everything. They are very knowledgeable, but they don't trust that NGOs can work on these issues . . . because we have not been formally trained.”<sup>67</sup> In other countries, there are initial signs of increasing support for civil society engagement in TB policymaking. For example, BRAC's impact on the development and implementation of TB policy in **Bangladesh** and beyond is widely acknowledged. And since 2003 the **Brazilian** NTP has indicated greater receptivity to community sector involvement in monitoring implementation of its policies; in 2004, the Ministry of Health announced its support for a new “Brazilian Partnership Against TB,” a visible sign of renewed support for a multisectoral TB control effort.

At the same time, civil society engagement at the international TB policymaking level has been minimal, though there are signs that this situation too may be changing with the increasing involvement of experienced HIV/AIDS activists and former TB patients in the Stop TB Partnership and other international bodies. To date, WHO officials have insisted that the primarily statistical and epidemiological nature of its annual *Global Tuberculosis Control* report must be preserved. As such, NGOs have not generally been invited to

participate in the preparation or review of government reports submitted to the WHO. There is currently no mechanism for civil society groups to provide independent assessments or recommendations during preparation of the *Global Tuberculosis Control* report on what could be done to improve the effectiveness of TB policies and services.

While the WHO's international case detection and treatment success targets are seen as helpful in motivating governments to demonstrate progress from year to year, without a transparent data collection and reporting system that allows for public review and feedback there is a strong incentive for governments to report greater progress than is actually being achieved. For example, a number of **Brazilian** officials and researchers have asserted that data gathered for WHO reports are not widely available at the national level;<sup>68</sup> that Brazilian experts are unaware of the methodology by which data are collected; and that there are significant discrepancies between the information reported to the WHO and national data with regard to DOTS coverage in particular, creating an inaccurate picture of the situation on the ground.<sup>69</sup> As long as governments see the Amsterdam Declaration and other regional and international commitments as a useful way of attracting international funding without incurring domestic responsibility, these commitments will not spur the desired broad public mobilization that is widely acknowledged to be a prerequisite for an effective, sustained TB control effort.

TB policymakers have noted the importance—and the absence—of a strong social mobilization component in TB control efforts to date.<sup>70</sup> There have been some incipient attempts to stimulate greater activity in this area. For example, in 2004 the Stop TB Partnership formed the Advocacy, Communications and Social Mobilization Working Group. The WHO Stop TB Department has begun to collect information on advocacy efforts in high-burden countries and has promised to establish a working group that includes community participation to develop indicators for more detailed reporting on communications and social mobilization activities as well. The Stop TB Partnership has also welcomed several community-led initiatives such as the creation of a community task force to ensure representation of people living with HIV/AIDS and/or TB in all of its decision-making structures.<sup>71</sup> In Round Five, the Global Fund awarded substantial grants to support TB advocacy, communications, and social mobilization activities in a number of high-burden countries. Perhaps most significantly, the new *Global Plan to Stop TB* (2006–2015), published in March 2006, identifies the following as one of its six key elements: “Engage people with TB and affected communities to demand, and contribute to, effective care, [involving] scaling up community TB care, creating demand through context-specific advocacy, communication and social mobilization; and supporting development of a patient’s charter for the tuberculosis community.”<sup>72</sup> However, the promise of these nascent structures and declarations of intent has yet to be fulfilled; the level of social mobilization around TB and community participation in TB policymaking processes is still inadequate.

Community mobilization and participation have proven essential in advocating for research, development of new tools, and the increased resources for the fight against HIV/AIDS. But many of those directly affected by TB lack resources and opportunities to engage in policy processes. Others may wish to distance themselves from the disease—and the stigma attached to it—once they have been cured. Ezio T. Santos Filho, a long-time HIV/AIDS activist in **Brazil**, asserts that waiting for the kind of “bottom-up” engagement and activism that was undertaken by the well-educated and politically connected constituencies first affected by AIDS in countries such as Brazil and the United States may not be realistic when so many of those affected by TB are from the poorest and most marginalized communities in their countries.<sup>73</sup> Greater social mobilization around TB and TB/HIV will be necessary to eradicate TB, but this will not occur without a concerted and sustained effort on the part of donors, policymakers, and community activists.

–Public Health Watch

# Notes

1. For all five national reports please see [www.publichealthwatch.info](http://www.publichealthwatch.info) or contact Public Health Watch at: [phwinfo@sorosny.org](mailto:phwinfo@sorosny.org).
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8. “Table 1: NTLF funding and expenditure for 2003,” in MoH, *NTLP Annual Report* (Dar es Salaam, 2003), p. 4.
9. Interview with health care provider, Ogun State, February 16, 2005.
10. Comment by Akramul Islam, Public Health Watch researcher and manager of the health and nutrition program, BRAC, December 14, 2005.
11. Comment by Afsan Chowdhury, director of advocacy, BRAC, Dhaka, December 11, 2005.
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15. Fazlul Karim, Insana Begum, Akramul Islam, and AMR Chowdhury, “Gender barriers to TB Control: Fade-out or in?” BRAC Research and Evaluation Division, September 2003, p. 6.
16. Interview with C.O. Nwakonobi, Imo State TB and leprosy coordinating officer, Imo State, April 11, 2005.
17. Ezio T. Santos Filho, Public Health Watch researcher, observations from social mobilization workshops, Rio de Janeiro, 2003.
18. Study by Healthscope Tanzania and the NTLF, reported in MoH, *NTLP Annual Report* (Dar es Salaam, 2003), p. 5.
19. Comments by Rev. Sanan Wutti, The Church of Christ in Thailand, Public Health Watch roundtable meeting, Chiang Mai, December 9, 2005.
20. Comment by Zafrullah Chowdhury, project coordinator, Gono Shahsthya Nagar Hospital (GK), *Daily Star* roundtable meeting, Dhaka, December 13, 2005.
21. Presentation by Jamillah Mwanjisi, Public Health Watch researcher and director of Media Bank, Global Health Council panel discussion, Washington, D.C., March 2006.
22. Comment by Somsak Akksilp, director, Office of Disease Prevention and Control Region Seven, Public Health Watch roundtable meeting, Bangkok, December 6, 2005.

23. Presentation by Olayide Akanni, Public Health watch researcher and senior programme officer, Journalists Against AIDS (JAAIDS), Global Health Council panel discussion, Washington D.C., March 2006.
24. JAAIDS, "TB/HIV, Confronting a Dual Epidemic," JAAIDS media roundtable meeting, Lagos, March 16, 2005.
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61. E. Wandwalo, B. Robberstad, and O. Morkve, “Cost and cost-effectiveness of community-based and health facility based directly observed treatment of tuberculosis in Dar es Salaam, Tanzania,” *Cost Effectiveness and Resource Allocation*, 2005.
62. Interview with health workers, Ifakara, February 2005.
63. Interview with NTP consultant to the Bureau of AIDS, TB and STIs, October 3, 2005.
64. Group discussion with village health volunteers in Mae Sod District, Tak province, January 26, 2005.
65. Comment by Sumalee Amarinsangpen, Office of Disease Prevention and Control Region 10, Public Health Watch roundtable meeting, Chiang Mai, December 9, 2006.
66. Comment by Afsan Chowdhury, Public Health Watch researcher and director of advocacy, BRAC/ Public Health Watch roundtable meeting, December 12, 2005.
67. Comment by Jutatip Chaisakul, Health Development Networks, roundtable meeting, Chiang Mai, December 9, 2005.
68. Comments by participants in Public Health Watch roundtable meetings, Rio de Janeiro, São Paulo, and Brasilia, March 28, 30, and 31, 2006.

69. According to the most recent statistics released by the WHO, 52 percent of the Brazilian population was covered by the DOTS strategy in 2004, a figure many Brazilian experts believe to be significantly overestimated. See WHO, *Global Tuberculosis Control: Surveillance, Planning Financing*, (Geneva: WHO, 2006), p. 79.
70. See, e.g. Stop TB Partnership, *Report on the Meeting of the second ad hoc Committee on the TB epidemic: Recommendations to Stop TB Partners*, WHO, 2004, p. 15.
71. See “Call To Action for TB and HIV Community Activists and Advocates To Stop Tuberculosis (TB),” at [www.aidsinfonyc.org/tag/tbhiv/wtbd2005.html](http://www.aidsinfonyc.org/tag/tbhiv/wtbd2005.html) (accessed June 19, 2006).
72. Stop TB Partnership, *Global Plan to Stop TB 2006–2015*, Geneva: World Health Organization, 2006. See [www.stoptb.org/globalplan/assets/documents/GlobalPlanFinal.pdf](http://www.stoptb.org/globalplan/assets/documents/GlobalPlanFinal.pdf) (accessed May 25, 2006).
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**II.**

**Report on TB Policy  
in Tanzania**

# Executive Summary

Two decades ago, the Tanzanian National Tuberculosis and Leprosy Programme (NTLP) was regarded as one of the best performing disease-control programs in the world. However, HIV/AIDS has contributed to a marked resurgence of tuberculosis (TB) in recent years and placed a severe strain on the national health system, compromising the delivery of even basic services. The number of TB cases has increased six-fold since 1983, placing Tanzania 14th on the World Health Organization's (WHO's) list of high-burden countries. TB is now the leading cause of death among HIV-positive people. Yet public and political awareness of TB as one of Tanzania's most critical health problems is low.

The NTLP has affirmed its commitment to the WHO-recommended DOTS strategy and global TB targets of 70 percent case detection and 85 percent treatment success. Despite significant challenges, the NTLP has maintained a relatively high rate of treatment success (81 percent). However, the case detection rate is only 47 percent, largely due to a sharp increase in the number of smear-negative and extrapulmonary cases, which often result from TB/HIV coinfection and are harder to detect.

Lack of basic knowledge about TB and the interaction of TB and HIV is an issue among both policymakers and the broader public, and this contributes to the high levels of stigma surrounding the disease. Low levels of awareness that TB is a current threat and not a "disease of the past" have led to a low level of political commitment to TB control at the district as well as the national level, which stands in sharp contrast to the level of attention accorded to the HIV/AIDS epidemic. Political leaders should speak about TB whenever they speak of HIV/AIDS, since a coordinated response to these "twin diseases" is necessary to control both epidemics successfully. There is a clear need for the NTLP to undertake a sustained communications and awareness-raising initiative, which should target not just the general public, but also decision makers at the district and community levels.

There is little coordination between HIV/AIDS and TB programs. The NTLP, National AIDS Control Program (NACP), and Tanzania Commission for AIDS (TACAIDS) have reportedly drawn up initial plans to improve collaboration on TB/HIV policies at the national level. These plans should be shared widely before proceeding to implementation in order to draw upon the input and experience of nongovernmental organizations (especially faith-based groups) and private providers already delivering integrated TB and HIV/AIDS services. The NTLP should make further expansion of pilot TB/HIV programs a priority.

Similarly, there is limited coordination of TB control activities between public and private health providers. For the most part, the government remains almost the sole TB service provider, with little involvement in DOTS implementation from the private sector or

from nongovernmental organizations. By contrast, the government's partnership with the private sector in HIV/AIDS service provision is extensive and better defined.

Insufficient government funding for the health sector in general and for combating TB in particular has also led to insufficient budgetary allocations. The resulting deterioration in the quality of basic health care services across the country has created additional challenges for TB control programs, including drug shortages and a dearth of well-trained managers and health care workers.

TB is having a devastating impact on vulnerable groups, including people living in poverty (particularly in urban areas), prisoners, refugees, and mine workers, but the NTLP's progress in developing targeted programs and services for these groups has been slow. For example, though TB drugs are available free of charge, poor patients often find associated costs (including fees for consultation, initial costs for diagnostic services, and the cost of transportation to and from health clinics) a significant barrier to accessing treatment. To improve its overall performance, the NTLP will need to take steps to make treatment more affordable and accessible to the poor and to other vulnerable groups. Community-based DOTS programs have demonstrated positive treatment outcomes at relatively low cost and have made TB services more accessible and affordable to patients by bringing treatment closer to patients' homes. This model should be examined closely as a potentially sound basis for expanding access to TB services throughout the country.

International funding is making a major contribution to domestic TB and TB/HIV programming. For example, with support from the Global Fund to Fight AIDS, Tuberculosis and Malaria, the NTLP plans to expand its pilot TB/HIV program from 3 to 34 districts. However, the fact that external sources cover at least 65 percent of the NTLP's budget has raised concerns among program officials about "donor-dependence" and long-term sustainability. Greater political commitment to TB control must be reflected in increased allocation of domestic resources to core TB control activities; donors should take care to ensure that assistance programs reinforce NTLP leadership and contribute to strengthening the Tanzanian health system.

# Background

Between 1977 and 1984, the National Tuberculosis and Leprosy Programme (NTLP) cut the number of tuberculosis (TB) cases by two-thirds, earning a reputation as one of the best performing disease-control programs in the world.<sup>1</sup> However, the emergence of the HIV/AIDS pandemic reversed this successful trend. Between 1983 and 2003, the number of TB cases increased by almost six-fold, from approximately 12,000 cases to 64,500;<sup>2</sup> in 2004, the government registered a total of 65,665 cases.

Today, TB is responsible for 17.5 percent of the total disease burden for people five years of age and older, ranking behind AIDS (approximately 50 percent) and AIDS-related conditions (32 percent). Most persons affected by TB are of reproductive age, which negatively affects economic growth and presents a barrier to poverty-reduction efforts. Many Tanzanian experts believe that multidrug-resistant TB (MDR-TB) is a growing problem and that government statistics on MDR-TB may underestimate the actual scale of the problem.

## Baseline statistics

Tanzania has a notably young population:<sup>3</sup> Infants and children under five years of age constitute about 5 percent and 17 percent of the total population, respectively, and about 47 percent of the population is below 15 years of age. TB and HIV/AIDS are expected to have a dramatic demographic impact in coming years, as both diseases have the biggest impact on persons of working age (between 15 and 65 years old).<sup>4</sup>

The surge of TB and HIV/AIDS has occurred within a context of overall macroeconomic improvement during the past decade, although a recent World Bank study indicated that without policy actions, Gross Domestic Product (GDP) could be 15–20 percent lower by 2015 than it would be without the HIV/AIDS pandemic.<sup>5</sup> Poverty is still widespread. The number of people living below the national poverty line (on less than one U.S. dollar a day) has decreased since 1991,<sup>6</sup> but still stands at more than 35 percent of the population.<sup>7</sup> Urban-rural disparities exist, with a higher concentration of poverty among rural households, particularly those dependent on agriculture. Although approximately 77 percent of the mainland population still lives in rural areas, urbanization has increased over the past 25 years.<sup>8</sup> TB is especially prevalent in congested, urban areas like the capital city, Dar es Salaam, where 25 percent of the nation's TB cases were recorded in 2003<sup>9</sup> and where HIV/AIDS and TB are the leading causes of death for adults.<sup>10</sup>

Government statistics on the number of TB cases detected underestimate the severity of the epidemic in Tanzania. Although the number of TB diagnostic centers has increased in some cities such as Dar es Salaam and Mwanza, the NTLP's extremely low case-detection rate has declined even further in recent years.<sup>11</sup> The government detects only 47 percent of TB cases.<sup>12</sup> The NTLP acknowledges that the national prevalence estimate of 479 TB cases per 100,000 people<sup>13</sup> may be inaccurate and plans to conduct a new TB prevalence survey between 2006 and 2007.

Many people with TB symptoms go undiagnosed due to a lack of public awareness and the inaccessibility of diagnostic services in some areas of the country. In addition, the NTLP's low case-detection rate stems from an increase in smear-negative and extrapulmonary cases, which are harder to diagnose and therefore less likely to be treated. TB/HIV coinfection is largely responsible for the increase in these types of cases; the share of smear-negative and extrapulmonary cases has risen dramatically over the last 22 years, from 33 percent in 1979 to 54 percent in 2001.<sup>14</sup>

## **TB/HIV**

As noted above, HIV is the most significant cause for the resurgence of TB. According to the NTLP, "60 percent of the increase in the incidence of TB in Tanzania can be attributed to HIV."<sup>15</sup> Fifty percent of all TB patients are estimated to be coinfecting with HIV; this figure has been rising steadily in recent years.<sup>16</sup> TB is also the leading infectious cause of death among HIV-positive people. Individuals who are coinfecting with TB and HIV are 20 to 30 times more at risk of developing active TB disease than those who are HIV-negative.<sup>17</sup> In Tanzania, HIV/AIDS and TB are referred to as "twin diseases."

## **Health sector reform**

In 1985, a combination of domestic resolve and external donor pressure prompted the government to initiate a set of broad-ranging institutional and policy reforms to improve the efficiency and accessibility of health care services. In 1994, the government formally entrenched equity as the guiding principle in the provision of health services—a principle that has endured through subsequent phases of policy development and revision.<sup>18</sup>

These reforms have included the introduction of cost-sharing, the establishment of Community Health Funds, and the adoption of the sector-wide approach (SWAp) to finance health programs, which entails pooling government and donor resources into "common baskets" of funding for specific issues and a decentralization of health services and program management.<sup>19</sup> Reforms have also led to the formation of participatory structures such as

district-level Council Health Management Teams and Community Health Funds. These structures are designed to bring together various health professionals, including government health officers, civil society and faith-based organizations, as well as the private sector, to set priorities and plan health interventions at the community and district levels.<sup>20</sup>

As part of the health sector reforms, the NTLF is gradually attempting to “horizontalize” TB services by integrating them into the general health care delivery system. This effort—which has been largely influenced by donors—is intended to minimize duplication of efforts and promote a more rational distribution of scarce resources. However, in practice, reforms have resulted in the loss of the TB-specific focus that more traditional “vertical” programs provide and serious gaps in TB funding and services, particularly at the district level. Moreover, limited NTLF funding has meant that dedicated TB services available through other initiatives, such as the community-based DOTS program, have been limited in scope. Ongoing efforts to integrate TB treatment into the general health care delivery system should be more carefully planned to identify and minimize the impact of unintended consequences and to better serve health needs at the community level.

The establishment of a “common funding basket” for all health interventions, controlled by the Ministry of Finance, was intended to ensure that the Ministry of Health (MoH) would have sufficient resources to implement the activities identified in its strategic plan. However, the system has led to increased competition for limited resources between the NTLF and other MoH programs. When the NTLF’s proposed programming and activities are not reflected in the MoH’s list of priorities, as is currently the case, funding for TB control suffers.<sup>21</sup> In the early years of its existence, the NTLF received dedicated funding. Under the shared “basket” system, however, the NTLF has increasingly had to compete with other national priorities and health emergencies.

Decentralization of health services and program management has produced mixed results with regard to TB programming in particular. Ideally, decentralization can empower local authorities to make informed decisions on resource allocation for TB treatment, imparting a sense of ownership for TB control at the district and local levels. In some regions, decentralization has encouraged greater community involvement in setting health priorities and plans through district Council Health Management Teams. However, decentralization of authority has also raised a challenge for district health management teams because it has required increased resource mobilization at the local level and reallocation of essential TB staff.<sup>22</sup> There is already a serious shortage of health workers and an increased workload due to HIV/AIDS in most of the country’s health facilities.

To counteract funding shortages at the local level, some communities have established Community Health Funds. Households may enroll in the fund by making an annual contribution of TZS 10,000 (or \$10); the fund is then used to finance participants’ primary health care. This scheme has been supported by some experts as an important complemen-

tary form of health care financing, especially for low-income and rural households.<sup>23</sup> In some districts, the Community Health Fund has been used to expand the number of trained DOTS staff and to purchase laboratory equipment for TB diagnostic services.<sup>24</sup> However, on a national scale, the lack of adequate human and financial resources still presents a major challenge for the NTLF, limiting its potential to expand programmatic services, including diagnostic and DOTS centers.

## Political commitment

In 1995, Tanzania's former president, Benjamin Mkapa, designated HIV/AIDS as a "national disaster" and encouraged other political leaders to speak out about HIV/AIDS. But the increase in political will to control HIV/AIDS in recent years stands in sharp contrast to the relatively low level of political commitment for TB. Political leaders should raise the issue of TB whenever they talk about HIV/AIDS since these are "twin diseases" and dealing with them separately is ineffective.

Since the inception of the NTLF, one governmental action stands out as a landmark in the history of TB control in Tanzania. Since 1977, the government has ensured the provision of first-line drugs for TB treatment free of charge. Both health care workers and TB patients interviewed during this study viewed this policy as a clear manifestation of political will to eradicate TB. As further evidence of political will, the NTLF program officer highlighted the government's "substantial funding" for NTLF activities and provision of professional staff for TB control.<sup>25</sup> Other experts have pointed to the fact that TB and HIV have been included in the 2005 *National Strategy for Growth and Reduction of Poverty* (NSGRP) report, which, they suggest, is a sign of broad government commitment.<sup>26</sup>

But the current level of political commitment is not adequate. While the government provides treatment free of charge, consultation fees and initial costs for TB diagnostic tests are not always free, presenting a serious financial obstacle for many patients. The government's financial commitment to TB control is also insufficient. For instance, in 2003, the government contributed only TZS 1.1 billion (\$983,943), or approximately 10 percent of the total annual NTLF budget. The rest of the NTLF budget came from external donors.<sup>27</sup>

Political commitment for national TB control activities has been compromised by competing health priorities, which have been heavily influenced by donor preferences. Most TB patients, activists, and some medical personnel interviewed for this report believe that the government and donors prioritize HIV/AIDS and malaria over TB.<sup>28</sup> Political commitment for national TB control activities has also been compromised by the strong focus on health sector reforms. Health workers interviewed believe that the large amount of funding

devoted to antiretroviral drugs (ARVs) and infrastructure for HIV/AIDS programs has displaced funding available for other health priorities, including non-ARV drugs and salaries for medical personnel working on other issues.<sup>29</sup>

Decentralization has meant that priority-setting has devolved to district-level health management teams; as a result, these teams' commitment to and capacity for implementing strong TB control programs have become more important. However, these teams are often not equipped with sufficient training, support, or resources to manage the increasing demand for TB services effectively. This may be due to the lack of clear, easily understood information about the immediate issues and concerns associated with TB diagnosis, treatment, and interaction with HIV at the community and district level. Even when district governments prioritize TB control, they often lack sufficient funding or delay disbursement of funds to health facilities.

Finally, the lack of political commitment stems to a great extent from many policymakers' lack of basic knowledge about TB and from stigma associated with the disease. Many politicians and local government leaders do not consider TB a priority because they still believe that TB is a disease of the past that affects relatively few people. Others find it politically risky to mention TB due to sensitivities surrounding TB's growing association with the HIV/AIDS epidemic; despite increased political commitment to HIV/AIDS control, HIV/AIDS is still a sensitive issue for some politicians. Therefore, public awareness campaigns should target not just the general public, but also decision makers at every level.

## **Public mobilization and public awareness**

The media gives little coverage to TB in comparison to the attention given to HIV/AIDS. Similarly, domestic and international NGOs are relatively less mobilized to encourage greater public awareness and more extensive and substantive media coverage of TB. As a result, public awareness of the threat posed by the resurgence of TB is low. Policymakers and the broader public both lack basic knowledge about TB and the interaction between TB and HIV, which contributes to stigmatization of people living with the disease.

## Media coverage

Media coverage of TB is generally limited to a story on World TB Day. In 2003, for instance, the United Nations Integrated Regional Information Network (IRIN) quoted the following statement from the minister of health, Anna Abdallah: “I know that many of my fellow Tanzanians are now afraid just to know that they have TB because they automatically assume that they also have HIV/AIDS. TB is curable, and we have proved this here in Tanzania. I want the press to tell people that, while there is a link between HIV/AIDS and TB, people should not be afraid to come forward. It is not true that every TB patient is HIV positive.”<sup>30</sup>

Aside from World TB Day, a one-year review of media stories revealed that TB made major headlines only in December 2004, when the board of the Global Fund to Fight AIDS, Tuberculosis and Malaria held a high-level meeting in Arusha. At that time, there was also a special program on the Independent TV Network (ITV) focusing on TB. In general, however, there is far more television,<sup>31</sup> radio, and print coverage about the risks of HIV/AIDS than about TB.

The lack of media coverage about TB may be related to the absence of training and other forms of support for journalists. Professional institutes for journalism do not cover public health issues such as HIV/AIDS and TB as part of their standard curricula. To encourage quality coverage of HIV/AIDS, the National AIDS Control Program, Tanzania Commission for AIDS (TACAIDS), and domestic and international NGOs have supported a wide range of seminars and training sessions for journalists to publicize basic facts about HIV/AIDS transmission and how to avoid stigmatizing language in covering HIV/AIDS.<sup>32</sup> These efforts have produced results: Journalists are now increasingly including HIV/AIDS in their reporting agendas.

In contrast, most journalists lack proper information and training on TB, including MDR-TB and TB/HIV coinfection.<sup>33</sup> In recent years, the NTLP has not supported any workshops to train journalists on TB-related issues, although media workshops have been tentatively included in the NTLP’s 2006 communications strategy.<sup>34</sup> Moreover, few NGOs or faith-based organizations have stepped up to fill this gap. More broadly, NGO engagement in community education campaigns on TB and on the relationship between HIV/AIDS and TB is extremely limited. No human rights organizations, traditional healers’ associations, or patients’ associations are working exclusively on TB information campaigns, although a few HIV/AIDS support groups are working to raise awareness about TB.

There is an urgent need for specialized training for journalists on TB, MDR-TB, and TB/HIV coinfection. At the same time, HIV/AIDS advocates should also be trained on diagnostic and treatment issues for coinfecting individuals and encouraged to incorporate consideration of TB into their training curricula on HIV/AIDS.

## Public awareness about TB

In light of the above, it is perhaps not surprising that most health care workers and patients interviewed for this report expressed the need for greater efforts to address the low level of public awareness about TB and TB/HIV.<sup>35</sup> Many people in the general population are unable to identify the symptoms of TB, or know where and how to access TB diagnostic and treatment services. Low levels of public awareness that TB is a current threat rather than a “disease of the past” also contribute to the lack of political commitment to TB control at the district as well as the national level. This, again, is in sharp contrast to the broad level of general awareness about and subsequent political commitment to the HIV/AIDS epidemic.

Low levels of public awareness and stigma have serious consequences. Lack of information results in delays in diagnosis and lower rates of treatment compliance, which increase the risk of MDR-TB and death. Lack of public awareness has also negatively affected public mobilization and activism around TB.

Those who do have access to information on TB tend to be people who have received TB treatment, although a study involving 296 TB patients in Mwanza indicated that basic knowledge was unexpectedly low even among TB patients.<sup>36</sup> Many participants in the study were illiterate and from a relatively low socioeconomic background compared to the general population. These factors must be taken into consideration in designing effective public education campaigns around TB. The study also revealed significant lack of treatment compliance among TB patients and posited that this was due to lack of knowledge about the importance of prolonged, uninterrupted treatment.<sup>37</sup>

Problems resulting from the lack of information are exacerbated by the existence of misinformation and stigma. Lacking knowledge about how TB is spread, individuals and communities are more likely to be swayed by superstition; according to one health care worker, some people believe that TB patients have been bewitched.<sup>38</sup> TB patients are often labeled as HIV-positive;<sup>39</sup> anyone with a dry cough is often jokingly advised to “go and visit ANGAZA” (the voluntary counseling and testing centers operated by the African Medical Research Foundation in many parts of the country). One study revealed that stigma and misconceptions about the cause of TB were major factors in widespread delays in seeking treatment. According to the study, less than 30 percent of people with TB visited a health facility within one month of the onset of symptoms and only 42 percent did so within three months; the median duration between onset of TB symptoms and visiting a health facility was about eight months.<sup>40</sup>

## Public awareness about NTLP activities

*The Ministry of Health is my nightmare. I remember there was a time I submitted my questions regarding malaria prevention. I went up and down the Ministry of Health for four weeks. My questions were not answered and I gave up.*

—Journalist, Independent Monitoring Group<sup>41</sup>

The NTLP's activities are not well publicized at the regional and national levels, as compared with TACAIDS' activities on HIV/AIDS, for example. As a result, public awareness about NTLP policies and services is low.

Access to information from government ministries, especially from the MoH, presents a challenge. When requesting an interview, journalists are required to submit their questions in writing well in advance and often spend several weeks waiting for a response from or an appointment to interview the ministry's spokesperson. Over the years, this has discouraged journalists from seeking information from the MoH unless they are invited for a press conference or given a press release.

In an attempt to provide more information on its TB control efforts and to increase public awareness, the NTLP has drafted a new communications strategy to guide publicity and advocacy campaigns.<sup>42</sup> Once approved, the communications strategy will reportedly guide NTLP use of media, including radio and television programs, to publicize its activities and raise TB awareness. The strategy also reportedly identifies the need for the MoH to employ an information and communications officer to serve as a link between the media and the MoH. However, implementation of the communications strategy has not yet begun and is not publicly available. There is a clear need for the NTLP to implement a sustained communications and awareness-raising initiative, which should target not just the general public, but also decision makers at the district and community levels.

# Government Program for TB and TB/HIV Control

## Program content

The NTLP's approach to TB is part of a wider MoH effort to control communicable diseases according to the country's "disease burden priorities," which are calculated by the number of lives lost to a disease as a proportion of the total population. The vision of the NTLP as stated in its Strategic Plan for 2005–2009 is to control TB and leprosy to the point where "they are no longer a public health problem in Tanzania" and to provide "quality and effective interventions to control TB and leprosy in Tanzania with a focus on gender mainstreaming, equity, accessibility and those most at risk." Specifically, the NTLP aims to reduce the incidence of TB through early diagnosis of as many TB patients as possible. To achieve these goals, the NTLP needs to address more aggressively the many barriers to treatment for TB patients living in poverty.

In the early years after its launch in 1977, the NTLP was hailed as one of the best performing TB control programs in Africa.<sup>43</sup> And despite the enormous challenge posed by the six-fold increase in TB prevalence between 1984 and 2001, the NTLP has made some progress. Through DOTS expansion, the government has increased the number of diagnostic and treatment centers and achieved an 81 percent treatment completion rate.<sup>44</sup> There are regional variations in treatment completion rates. For example, relatively low treatment rates (approximately 73 percent) were reported in the Kilimanjaro, Pwani, and Tabora regions, while Mtwara reached a cure rate of over 90 percent.<sup>45</sup> Regions with good geographical coverage of health facilities, such as Dar es Salaam, Kilimanjaro, and Arusha, do not always achieve higher treatment completion rates for reasons that include the high prevalence of HIV/AIDS and unmanageable caseloads in some DOTS clinics.

The low case-detection rate and high TB prevalence present serious challenges to the government's current TB control efforts. The national case-detection rate is only 47 percent, well below the 70 percent global target for 2005.<sup>46</sup> Through its DOTS expansion strategy, the NTLP aims to ensure that TB treatment is available in even the most rudimentary health clinics; but progress in reducing the epidemic in economically disadvantaged regions has been slow. The government's pilot community-based DOTS program represents one effort to ensure greater accessibility to TB treatment.

According to the NTLP, nationwide DOTS coverage was attained in 1986, in part facilitated by the integration of TB services into general health services. However, some TB

advocates point to the fact that patient demand for TB services exceeds the capacity of the DOTS facilities available. In the past few years, it appears that many health facilities have phased out their TB departments to devote more attention to HIV/AIDS.

People living in rural areas and those in poverty remain disadvantaged both in terms of service uptake and outcomes. As the National Strategy on Growth and Reduction of Poverty states, “Many poor people, children and women in particular, die without ever accessing a health facility.”<sup>47</sup> The strategy also recognizes that the health sector is central to poverty reduction. Similarly, the 2002 National Health Policy seeks to use a greater proportion of the health budget to ensure that TB and HIV/AIDS services are available to low-income communities, particularly in rural areas, since these communities are hardest hit by these and many other communicable diseases.<sup>48</sup> Despite this formal recognition of the linkage between poverty and TB, the government should take additional measures to make the full range of TB services more truly affordable and accessible for people living in poverty by reducing the “hidden” costs associated with DOTS, both in terms of patients’ time and money.

## **DOTS expansion**

As part of its DOTS expansion strategy, the NTLP is supporting integration of TB services into the general public health system and has, over the past few years, increased the number of diagnostic centers.<sup>49</sup> In recognition of population growth, the inadequate number of DOTS centers to meet demand for services, and barriers to treatment that have a negative impact on access to treatment and completion rates, the NTLP has promoted community-based DOTS (CB-DOTS) and a patient-centered approach in some districts. These programs have posted promising results, but lack of funding calls their sustainability into question.

## **Barriers to DOTS expansion**

*It is true that we receive free diagnosis and treatment, but [TB] drugs are very powerful, and they need to be taken with sufficient food. A majority of us [patients] are from poor families and we have only one meal per day. So sometimes we are forced to skip the drugs.*

—TB patient<sup>50</sup>

Efforts to expand DOTS to more health facilities have been hampered by scarce resources and understaffing.<sup>51</sup> As a result, many DOTS centers—especially those in urban areas—are overcrowded, and patients must spend hours waiting at the health facilities before receiving

care. In an article published in IRIN, a journalist noted that, at 7 a.m. on one day, at least 100 people were waiting in line at the Temeke District Hospital's TB clinic.<sup>52</sup> The implications are serious: Many of those affected by TB are not able to afford the time away from their jobs and families and forego or interrupt treatment as a result; some patients fail to initiate treatment following diagnosis; and, about 9 percent of those who initially seek treatment do not complete their treatment regimens.<sup>53</sup>

One patient who defaulted on TB treatment explained the difficulties associated with standard clinic-based TB services this way: "First of all, the treatment takes too long; eight months is too much. That's why when someone feels a little better they tend to stop the medication. Also, you need to come to the hospital to take medication for two months every day. You may be living far from the hospital, but also you need to do some other activities to get some money for the family and also for transport to the hospital."<sup>54</sup>

NTP policy stipulates that health workers should monitor provision of free drugs to all TB patients during the first two months to ensure treatment adherence; in the remaining six months of treatment, patients generally receive drugs to take home on a monthly basis. The NTP also emphasizes that patients who have previously received TB treatment must be under strict daily observation if possible during the entire period of treatment so as to prevent MDR-TB.<sup>55</sup>

Despite guaranteed access to free treatment, patients often shoulder a variety of extra costs associated with treatment, including consultation costs, initial costs for diagnostic tests and laboratory fees, and the cost of transportation to and from sometimes distant health facilities. One recent study in Dar es Salaam revealed that patients spent up to TZS 179,191 (or \$145) in additional costs, which is equivalent to more than three times a patient's average monthly salary.<sup>56</sup> These additional costs may include medications that are outside of the standard regimen for TB treatment. "The government should not announce that curing TB is free while people actually have to contribute to buy some medicine[s] to cure other diseases connected with TB," a health worker in Kilombero said. "When you tell people [that] they need to buy even panadol [a painkiller medication] or injections [to administer medication], people refuse because they know it is not for free."<sup>57</sup>

Food insecurity also affects DOTS compliance; TB drugs often upset one's stomach unless medication is accompanied by adequate nourishment. One DOTS provider noted, "We have some defaulters in our hospital, but it is not because they do not want to finish [the] dosage, but rather [because of] the unreliable availability of food during dosage administration."<sup>58</sup>

Given these considerable "hidden costs," many patients—especially those who live far from treatment centers<sup>59</sup>—are completely dependent on family members or friends for support, financial and psychosocial assistance, and care.<sup>60, 61</sup> Patients who lack this social network are much less likely to overcome these obstacles to treatment on their own; those

who do not have enough money for transportation or are simply too weak to travel the distance to the health facility are likely to forego or discontinue treatment.

The quality of care provided at DOTS clinics also affects treatment completion rates. Many patients noted a variety of complaints, including unfriendly staff behavior, long waiting periods, and insufficiently trained health care providers.<sup>62</sup> Many patients claim that clinicians and nurses do not provide adequate instructions on treatment regimens, including the duration and frequency of treatment.<sup>63</sup> Even when patients receive complete instructions from the provider, they may receive contradictory information from friends and family once they return to their communities.<sup>64</sup>

## **The NTLP response: community-based DOTS**

In general, the NTLP is trying to streamline a patient-centered approach to TB services into its larger strategy. With the patient-centered approach, a relative or friend observes the patient taking his or her medication every day; the goal of this approach is to reduce the number of visits patients must take to clinics, to make treatment easier for the patient, and, ultimately, to increase treatment compliance. In the CB-DOTS patient-centered model, TB outreach posts are established in communities that are far from large health facilities. From these community outreach posts (or “mobile clinics”), medical personnel train and provide support to community supervisors who are nominated by their communities. With this support, community supervisors are able to provide information, treatment, and support during scheduled visits to TB patients.

The NTLP piloted CB-DOTS in two districts—Kilombero (a rural setting) in 1995 and Temeke (an urban setting) in 2000—with the goal of increasing treatment compliance. In Kilombero, where the number of TB cases doubled between 1995 and 1999, the Kilombero Tuberculosis Research Project (KITUPA) worked with the district hospital to establish CB-DOTS. The project, cofunded by the NTLP and Spain’s international development agency, aimed to tackle identified TB control problems in the district, including overcrowding in the hospital wards and high treatment default rates. There was also a high level of stigma associated with TB because of high HIV rates; as a result, patients sought other remedies besides DOTS, such as going to traditional healers. Before the CB-DOTS project, the cure rate in Kilombero was only 48 percent;<sup>65</sup> with the project, the treatment success rate jumped to 78 percent. The NTLP district representative (DTLC) from Kilombero noted that the quality of treatment was on par with clinic-based DOTS services and that CB-DOTS is less expensive for patients because travel costs are eliminated.<sup>66</sup>

The NTLP later piloted a CB-DOTS program in the Temeke District of Dar es Salaam. The increase in the number of patients accessing and completing treatment was as

impressive as it had been in Kilombero. One patient described the program as a “savior,” especially for communities far from health facilities or where roads are impassable during rainy seasons.<sup>67</sup> A report on cost effectiveness of community-based versus health facility-based DOTS services also concluded that the CB-DOTS program both maintained quality of services and improved cost effectiveness by 37 percent.<sup>68</sup> Both the Kilombero and Temeke pilot projects have now terminated, although the community health workers in these and neighboring districts are implementing some community-based TB services on an ad hoc basis.<sup>69</sup> However, without financial support for transportation or added training from district health management teams, these efforts have remained limited in scope.

The NTLP is reportedly now working to scale up the CB-DOTS program across the country.<sup>70</sup> In its Strategic Plan for 2005–2009, the NTLP has included the introduction of CB-DOTS for districts with inadequate access to health facility-based DOTS services, and particularly for overcrowded squatter settlements in urban areas and isolated rural areas. The target is to implement CB-DOTS in 10 districts by 2009. Information was not available on how much government funding has been available for this purpose. Since inaccessibility of health care services has been identified repeatedly as one of the factors hindering TB treatment, many patients and health workers believe that scaling up CB-DOTS would be an effective and an important step towards achieving DOTS coverage targets.

This scale-up of CB-DOTS programs will require the MoH and the NTLP to allocate considerably more financial and human resources to ensure sustainability of current CB-DOTS programs as well as expansion to other areas.<sup>71</sup> To successfully expand CB-DOTS, the NTLP must also carefully consider additional implementation costs such as ongoing training and management of community supervisors and community mobilization. The above study found that these costs constituted approximately 53 percent of the provider costs. With the MoH’s present funding gap, adequate resources for CB-DOTS expansion may not be available to the NTLP, even though the savings are likely to outweigh the costs in the long term.

Greater civil society involvement—especially through community-based organizations and more partnerships with the private sector—is also necessary to achieve the desired expansion of the CB-DOTS program. Community-based organizations have proven to be effective partners for the care and support of people affected by and infected with HIV/AIDS; they have established extensive home-based care, counseling, and income-generating programs at the community level. The NTLP could facilitate a similar approach to TB control by increasing its collaboration with community-based organizations both in raising awareness about TB and in supporting community-based DOTS.

In addition to these two CB-DOTS projects, the government has encouraged a number of private health care initiatives to increase the integration of TB diagnostic and supervised treatment services into existing health programs at the community level. The

government provides free TB medication, training for community health workers, and supervision to private health facilities that work in partnership with the MoH. The government also provides subsidies to the faith-based hospitals that are providing health care services (including TB treatment) to nearly one-half of the Tanzanian population.

Perhaps the most successful example of public-private partnership for community-based DOTS is the NTLP's collaboration with the Pastoral Activities and Services for PLWHA and the Dar es Salaam Archdiocese (PASADA) to provide an integrated TB/HIV community-based care program, which relies heavily on volunteers. PASADA contacted the NTLP in 2003 after the organization realized that many of their HIV-positive patients were dying of TB. This program incorporates a model of home-based care and targets poor areas in Dar es Salaam, relying on about 150 volunteers, 75 of whom have been trained by the NTLP specifically in TB management.

To improve its overall performance, the NTLP will need to take steps to make TB treatment more affordable and accessible to the poor and to other vulnerable groups. Pilot community-based DOTS programs have demonstrated positive treatment outcomes at relatively low cost and have made DOTS more accessible and affordable to patients. The NTLP, NGOs, and international donors should examine this model closely as a potentially sound and sustainable basis for expanding access to DOTS services throughout the country.

## Controlling TB/HIV coinfection

*[In Dar es Salaam,] even though the two [government] departments [TB and HIV] are separate, there is a mixture of activities and in many cases, TB and HIV/AIDS activities do overlap. Usually, TB patients are encouraged to test for HIV as well, and counseling is done by staff from the HIV/AIDS department.*

—Health care worker, Dar es Salaam<sup>72</sup>

*NGOs should have their attention on curable diseases like TB and not concentrate only on HIV/AIDS. All those NGOs involved in poverty alleviation and HIV should include TB because it is part and parcel of the pandemic.*

—Acting district TB and leprosy coordinator, Kilombero<sup>73</sup>

The HIV/AIDS epidemic has created an enormous new challenge for TB control in Tanzania. Although the two diseases are inextricably linked, there is a lack of coordination between the government's TB and HIV/AIDS programs. The WHO has proposed a strategic framework of interventions to control TB and HIV/AIDS, including the establishment of coordinating

bodies for TB/HIV collaborative activities at all levels of government.<sup>74</sup> However, most of the health workers involved in provision of directly observed treatment (DOT) affirmed that the MoH has few TB/HIV policies in place.

The integrated TB/HIV programs that do exist have been implemented on an ad hoc basis. For example, the TB and HIV departments at the Temeke District Hospital are collaborating to treat coinfecting patients and to encourage VCT and screening among TB patients.

At the Abuja +5 Summit in May 2006, African heads of state agreed to new targets for TB and HIV/AIDS control, including ensuring access to VCT and ARV services for all TB patients who are living with HIV by 2010.<sup>75</sup> This may be difficult to achieve in Tanzania since VCT services are still scarce in many parts of the country. The NTLP has also started to train HIV counselors around the country to include TB issues in their outreach efforts, but it is not clear how many HIV counselors have been trained.

The NTLP has also been operating pilot TB/HIV programs in three districts—Temeke, Iringa, and Korogwe—since 2003. In these three districts, the government is recommending all TB patients be tested through clinic-based, routine Diagnostic Counseling and Testing for HIV (DCT), which is part of a WHO-recommended strategy to provide “one-stop” testing for HIV and TB to encourage people with HIV to be tested for TB as early as possible. With funding from the Global Fund, the NTLP expects to expand its TB/HIV program to 34 additional districts in collaboration with the Program for Appropriate Technology in Health (PATH), Clinton Foundation, WHO, Italian government, and U.S. Centers for Disease Control (CDC).<sup>76</sup> This TB/HIV coordination features very strongly in the NTLP’s Strategic Plan for 2005–2009, but these policies have yet to be implemented. According to the plan, the NTLP intends to establish collaborative mechanisms with the stakeholders involved in HIV/AIDS activities, including the National AIDS Control Program (NACP) and the Tanzania Commission for AIDS (TACAIDS). Reportedly, the policy will aim to reduce 1) the burden of HIV in TB patients by encouraging VCT services and 2) the burden of TB among people living with HIV/AIDS by screening for TB and by providing education on prevention and risk reduction strategies. It will also establish TB/HIV coordinating committees at the district, regional, and national levels. However, an official policy to manage the introduction of TB/HIV programs is still under development and the policy proposal has not yet been publicly released.

The absence of an official policy is an indication that few programs are actually offering integrated TB/HIV services beyond the ad hoc initiatives mentioned above. Some health workers believe it is critical for civil society organizations to incorporate TB into their existing activities and programs.

The government’s plans to manage TB/HIV programs should be shared widely before proceeding to implementation in order to draw upon the input and experience of

those nongovernmental organizations and private providers of integrated TB and HIV/AIDS services. The MoH plans to expand the pilot TB/HIV programs to three districts with support from the Global Fund; implementation of these programs should be monitored carefully and with civil society participation to provide a firm basis for expansion to the rest of the country.

In addition to establishing linkages between TB and HIV programs, a comprehensive TB/HIV strategy must also address the fact that HIV/AIDS makes TB harder to detect in coinfecting patients since coinfecting patients are more likely to have smear-negative and extrapulmonary cases of TB. Nationally, the overall percentage of these types of cases has increased.<sup>77</sup> In 2004, for instance, the number of smear-positive TB cases reported increased by 3.7 percent and extrapulmonary cases by 2.8 percent, compared to the previous year. Many laboratories lack the equipment to perform cultures, making proper diagnosis of TB among people living with HIV/AIDS extremely difficult. As early detection of TB is critical to health outcomes, the NTLP should ensure clear and broadly disseminated public information on TB/HIV coinfection.

“One-stop” testing and treatment centers for TB and HIV should be provided throughout the country. Through the Global Fund and other donors, VCT and ARV centers have expanded throughout the country. DOTS—or at least stronger referral mechanisms to DOTS clinics—should be incorporated into those VCT and ARV sites. “One-stop” services also help to reduce stigma since patients have already established trust with one provider.

Similarly, the WHO-recommended treatment regimen for coinfecting patients should be available to all ARV and DOTS providers. In February 2006, the NTLP introduced a new regimen for smear-negative and extrapulmonary TB patients, shortening the duration of treatment from eight to six months.<sup>78</sup> This policy could improve treatment adherence as a result of the significant reduction in the treatment duration *if* service providers are made aware of it and provided with proper training and support.<sup>79</sup>

## **MDR-TB**

The government has resolved to deliver the WHO-recommended standard of TB care to all patients, including the small number diagnosed with multidrug-resistant TB (MDR-TB). However, the NTLP has maintained its emphasis on the basic DOTS program; the DOTS Plus component for treatment of MDR-TB supplements the NTLP’s basic DOTS budget.<sup>80</sup>

According to available data, for the period from 1999 to 2003, the NTLP recorded an annual average of about 60 new cases of MDR-TB every year. Prior to 1999, an average of fewer than 30 MDR-TB cases had been treated per year. There is reason to believe the problem of MDR-TB is more pervasive, however. In 2003, for example, the NTLP recorded 378 cases of TB that failed to respond to treatment.

Poor management of MDR-TB was one of the critical issues mentioned in the review of the Medium Term Development Plan (MTDP) of 2001–2004. The new strategy for 2005–2009 notes: “Another dangerous prospect is the spread of multidrug-resistant TB, which threatens to reverse achievements so far gained in TB control in the country. . . . Despite the low prevalence, there are [a] substantial number of MDR-TB cases that are documented in different hospitals and among health care workers. The absence of a policy on follow-up of these cases or treatment regimen could easily increase transmission to the general population.”<sup>81</sup>

To support the government’s efforts in this area, WHO sponsored a visit by a DOTS-Plus consultant in 2003 and 2004 to assess the level of preparedness for DOTS Plus implementation as well as eligibility to apply to the international Green Light Committee for securing the appropriate drugs for treatment of MDR-TB. The consultant concluded that the introduction of DOTS-Plus would be feasible if several conditions could be met, including establishment of quality-assured laboratory capacity to conduct Drug Resistance Surveillance (DRS) and strengthening the systematic collection of specimens for culture and drug-susceptibility testing for new and re-treatment cases.<sup>82</sup>

In response, the NTLP has improved the quality of laboratory services, renovated the central laboratory, and procured new equipment.<sup>83</sup> The NTLP has also centralized the feedback mechanism to enable effective communication among the lower-level laboratories and has improved the registration system of MDR-TB cases throughout the country so that all MDR data are captured centrally.

The MoH plans to establish a DOTS-Plus component within the regular DOTS program at the Kibong’oto TB Hospital by 2009. The NTLP plans to apply to the WHO’s Green Light Committee to purchase second-line drugs and to seek technical assistance, including training for health personnel in MDR-TB management. With this assistance, the NTLP hopes to ensure treatment for all identified MDR-TB patients with a standardized second-line treatment regimen.

## **Case recording and reporting**

Although the NTLP is one of the few TB control programs in Eastern Africa with an electronic TB register, problems in data collection are evident. All TB facilities—public and private—are required to report to the NTLP on their TB-related activities. The government’s electronic TB register is designed to routinely record TB cases and treatment outcomes at the district level. Despite this reporting requirement, official NTLP data on TB are incomplete, delayed, and not easily accessible. Moreover, the NTLP does not include indicators for TB/HIV coinfection in its data collection system. These problems in data recording and

reporting hamper the free flow of information necessary for effective community involvement and civil society advocacy for improved TB policies.<sup>84</sup>

The NTLP is highly dependent on data gathered at the quarterly review meetings conducted at the district, regional, and national levels. These meetings are used to share quarterly data, discuss trends, and share issues that require attention. At the district level, DTLCs are equipped with motorbikes and are required to visit DOTS sites in their districts at least once per month to monitor progress and drug distribution.<sup>85</sup> However, the NTLP has noted problems related to regular and timely notification of TB data from service providers at the district level.<sup>86</sup> Some service providers reported difficulties in maintaining accurate records of patients who move to other locations.<sup>87</sup> The NTLP's delays in publishing updated annual reports also reflect larger, systemic problems with timely reporting of data. As of July 2005, the NTLP's 2004 report had still not been published.

There is a significant gap between the number of cases recorded by the NTLP and the number recorded by the WHO, suggesting a lack of accurate data and unreported cases. For example, in 2004, the WHO estimated 137,000 cases of all forms of TB in Tanzania, or 371 cases per 100,000 people. In contrast, the *NTLP Annual Report* notes that the TB notification rate of all forms of TB in Tanzania was about 177 per 100,000, representing only 48 percent of the cases estimated by the WHO.<sup>88</sup>

In addition to problems of missing or delayed data collection and reporting, the NTLP's information management system is separate and parallel to the Health Management Information System (HMIS) used by all other MoH programs.<sup>89</sup> This means there are no direct linkages between data collection for TB and other diseases such as HIV/AIDS because the recording and reporting for these diseases are done separately.

## Targeting vulnerable populations

The NTLP has identified certain populations, including people living in poverty (particularly in urban areas), refugees, and prisoners, as vulnerable to TB infection. However, progress in developing targeted programs and services for these groups has been slow, and other groups, such as mineworkers and women, who are less likely to access services once infected, have not yet been identified as such in NTLP policy.

As noted, the NTLP's DOTS expansion strategy is trying to expand access to low-income areas through CB-DOTS and patient-centered programs. Several private hospitals are also implementing special outreach programs for individuals with TB who live in poor or remote communities.<sup>90</sup> For example, PASADA's home-based care program reaches out to people living in Dar es Salaam's overcrowded "rural and slum areas."<sup>91</sup> PASADA provides home-based TB treatment, care, and support and encourages persons who are able to visit

their clinics. PASADA'S outreach program targets children with TB who are now living with extended family members and provides food to low-income patients who request it as part of their TB treatment regimen.<sup>92</sup> Through its nutritional support program, PASADA provides extra food support to poor patients in the form of milk, sugar, rice, and maize flour. This nutritional support is important since TB drugs often make people nauseous if taken on an empty stomach and a good diet is an important factor in treatment outcomes. However, most private TB clinics do not have the capacity to incorporate such programs without government funding.

The NTLP plans to work with local governments, NGOs, the United Nations High Commissioner for Refugees (UNHCR), and council health management teams to implement targeted TB control activities for prisoners and refugee populations. Some prisons, such as the Ukonga prison in Dar es Salaam, have developed TB treatment programs and are isolating infected inmates, ensuring DOT, and providing special diets throughout the course of treatment;<sup>93</sup> and a number of private TB providers have developed programs for specific vulnerable populations, but so far this has occurred only on an ad hoc basis and with limited funding. Additional efforts and funding are required both to design more effective programming for these vulnerable groups and to ensure that this programming is implemented.

Women with active cases of TB appear to be less likely than men to access available treatment services. A 2001–2002 study conducted by the NTLP and Healthscope, a research NGO, found that fewer women than men seek TB treatment. The study found these gender differences to be strongly influenced by an individual's financial situation. For women, the decision to visit a health care facility depended largely on whether they had cash available or not. Without cash, a woman had to wait for the assistance of her husband or another family member. Even when money was available, women tended to weigh the financial implications of expending available resources on their own medical treatment against other family demands such as food, school fees for their children, books, uniforms, etc.<sup>94</sup> For women especially, it is essential for the NTLP to improve its efforts to disseminate information about TB and to identify and take measures to eliminate these “hidden costs” of accessing TB treatment services.<sup>95</sup>

Few TB clinics have the capacity to analyze patient data based on “specific characteristics such as gender, age or economic status.”<sup>96</sup> The community-based KITUPA program is a notable exception; KITUPA analyzes age (most of their patients are between 18 and 45 years old<sup>97</sup>) and gender (the male:female ratio in their program is approximately 2:1). However, KITUPA's budget does not allow other data on vulnerable populations to be collected. In the absence of such data, it is difficult to design appropriately targeted policies and services and to identify groups that may not be accessing TB services. The NTLP should encourage and support operational research and data collection to identify groups that are particularly vulnerable to TB and to identify the special obstacles those groups face

in accessing and completing treatment. This type of research could provide a sound basis for the development of more effective TB services for vulnerable groups.

## Program management

### Administration

Beginning in 1993, the MoH has implemented a series of health sector reforms with the goal of improving the efficiency and accessibility of health services. Thanks in part to these reform efforts, the NTLP is well organized and managed, and employs field staff down to the district level.

Administratively, the NTLP operates at three levels. At the national level, there is a Central Coordinating Unit within the MoH. The Central Unit is responsible for planning, monitoring, evaluation, and resource mobilization as well as for coordinating the activities of regional and district offices. The regional and district TB and leprosy coordinators (RTLCS and DTLCs) supervise the activities of hospitals and other health centers, sharing the responsibility for monitoring TB treatment outcomes and constraints to successful treatment. District-level staff plan, coordinate, and implement activities with minimal supervision from the NTLP's Central Unit. However, quarterly and annual meetings provide platforms for all RTLCS and DTLCs to interact and share reports with other stakeholders and officials at the national level.

Again, health sector reforms have led to the general health system taking on greater responsibility for delivering TB services and to the NTLP staff managing fewer functions at the central and district levels than in the past. Local governments now have a greater role in decision making, and a number of participatory structures such as Council Health Management Teams have been established.

Some health service providers and several DTLCs have expressed concern that this "horizontalization" of the TB program has resulted in lower quality of services and insufficient funding to sustain the successes registered under the more "vertical" program approach implemented in the past, particularly in light of the added strains on TB program implementation due to the HIV/AIDS epidemic.

Despite many positive developments in health outcomes brought by health sector reform, the translation from theory to action has worked better in some districts than others. For example, DTLCs are not always included in the district-level Council Health

Management Teams, which play an important role in health program planning in many districts.<sup>98</sup> Many district and regional coordinators are not fully aware of the ways in which TB control has been integrated into general health services and would benefit from the enhanced NTLF information and awareness-raising efforts recommended above.

## Staffing

*We are only three staff working [in the] TB department. This is not sufficient as [the] number of TB patients increases daily. I would like for every section to have sufficient and quality staff. This will make our jobs much easier than now.*

—Health care worker, PASADA Hospital<sup>99</sup>

While the NTLF has increased the number of DTLCs at the district level to accommodate the push for DOTS expansion, most DOTS facilities and laboratories are experiencing a severe shortage in trained staff. The NTLF attributes this to bureaucratic obstacles associated with hiring new staff, high turnover, and low salaries.<sup>100</sup> Another challenge is that NTLF staff cover both TB and leprosy.<sup>101</sup> The government's HIV/AIDS department has relatively more staff, and many health workers believe HIV/AIDS programs are usually given priority when the issue of understaffing is addressed.<sup>102</sup> Health workers report that patients must queue for hours due to staffing shortages.<sup>103</sup> Patients complain about the long waits, noting that they sometimes spend an entire day.

Many private and faith-based facilities also face human resource constraints. The PASADA health facility, for example, is seriously understaffed. At the end of the day, medical staff are overwhelmed with patients who have walked miles to reach the health center.

To address issues of understaffing and to support health sector reform efforts to promote “horizontalization” of TB control, the MoH is directing more primary health care facilities to provide DOTS. For instance, out of PASADA's 13 health care centers, four are now dealing specifically with TB. However, staffing in many primary health centers is not sufficient to manage the influx of TB patients.<sup>104</sup>

In addition to the lack of personnel, the NTLF acknowledges that many health workers and laboratory technicians lack necessary skills and training.<sup>105</sup> In 2003, the NTLF initiated an in-service TB training program for all health workers engaged in TB control efforts. The program aims to improve health workers' knowledge of TB and DOTS skills as a way of supporting more effective integration of TB services into general health care facilities at the district level.<sup>106</sup>

## Budgeting and expenditures

Limited political commitment to the health sector in general and to TB in particular has led to insufficient budgetary allocations. The resulting deterioration in the quality of basic health care services across the country has created additional challenges for TB and HIV control programs, including drug shortages, weak infrastructure, and a dearth of well-trained managers and health care workers.<sup>107</sup>

The government has a relatively low per-capita expenditure on health, which has not increased significantly in recent years despite the recent adoption of funding targets.<sup>108</sup> The NTLP budget has increased significantly, from \$5.5 million (TZS 6.9 billion) in 2002 to \$7.6 million (TZS 9.6 billion) in 2005.<sup>109</sup> However, while the total NTLP budget has increased, the Tanzanian government contributed 35 percent of the total budget in 2006.<sup>110</sup> Moreover, the government's sector-wide approach (SWAp) to finance health programs has shortchanged district-level budgets for TB control. Though intended to increase efficiency and rationalize use of available resources, in practice, the "common funding basket" system coupled with decentralization of health services and program management has resulted in the prioritization of HIV and malaria control budgets and activities over TB programs.

The NTLP has received bilateral assistance from a variety of government agencies. In addition, in 2004, the Global Fund to Fight AIDS, Tuberculosis and Malaria awarded Tanzania grants of \$23.9 million (or TZS 30 billion) to be used in the scale-up to control TB/HIV coinfection control in selected pilot districts<sup>111</sup> and \$959,000 (TZS 1.2 billion) to implement DOTS activities in Zanzibar.<sup>112</sup> The MoH also receives funding from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) to implement TB/HIV programs.

The NTLP has underutilized the funding available from bilateral and multilateral donors. For example, in 2003 the NTLP only used about 64 percent of the donor support it received, or TZS 2,670,238,402 (\$2.3 million) out of the TZS 4,074,318,314 (\$3.6 million) received.<sup>113</sup>

## Monitoring and evaluation

As noted above, the NTLP has a system of collecting and analyzing TB data on a quarterly basis. In addition to these surveillance efforts, NTLP administrators at the central, regional, and district levels conduct regular monitoring and supervisory visits within their area of responsibility. They are required to visit assigned sites at least once a month to address issues that include drug logistics and supplies management, recording and reporting of TB cases at the health-facility and district levels, patient care and support, and staff performance.<sup>114</sup> However, due to lack of funds, heavy work loads, and poor transportation, these visits tend to be conducted on an ad hoc basis.

# Infrastructure, drugs, and research

## Primary health care system

The MoH claims that health care facilities are fairly well-distributed throughout Tanzania; the MoH reports that about 80.5 percent of the population has access to health services and over 90 percent live within 10 kilometers of the nearest health facility.<sup>115</sup> Government-owned facilities are arranged according to a pyramidal pattern, with multiple dispensaries, health centers, and district hospitals grouped around a smaller number of regional hospitals. Public facilities are complemented by a smaller (though significant) number of privately owned and funded clinics.

By 2002, there were about 4,990 registered health facilities in the country, of which 3,060 (61 percent) were government owned, 953 (19 percent) were either voluntary (nongovernmental or faith-based organizations) or parastatal owned (i.e., funded by public corporations), and 977 (20 percent) were for-profit—a slight increase in the total number of public and private facilities registered in 1999.<sup>116</sup> However, the country's population has been growing faster than the number of health facilities; fewer health care facilities are available relative to an “increased demand”<sup>117</sup> and the MoH has acknowledged that the quality of health care delivery does not meet an acceptable minimum standard.<sup>118</sup>

## Drug distribution system

The MoH's Medical Stores Department procures most of its TB drug supply from the Global Drug Facility, which enables the government to buy drugs at relatively inexpensive prices. Clinics throughout Tanzania are usually well stocked with essential TB drugs. Once registered at a DOTS clinic, patients can obtain TB drugs free of charge, though a number of factors noted above, including stigma, initial consultation fees, and transportation costs, may hinder initial registration by people who need TB treatment.

## Education and research

Research and knowledge about the TB epidemic, including information on health-seeking behavior and epidemiological trends, are crucial to the government's TB control efforts. The NTLF has conducted several studies in collaboration with other institutions and has utilized the results to improve NTLF activities.

In 2004, the NTLP identified several priority research areas, including patient-centered DOTS, adverse reactions to TB drugs, TB/HIV treatment protocols, and TB preventive therapy. In its new strategy, the NTLP aims to strengthen its capacity to conduct operational research that is relevant to TB and leprosy control in collaboration with other partners and institutions, such as the National Institute of Medical Research (NIMR), WHO, KNCV, and IUATLD. Studies underway in 2004 and 2005 are in different stages of implementation and include the following:<sup>119</sup>

1. TB Prevalence Survey: This surveillance effort will provide baseline data for TB prevalence in Tanzania.
2. Case Detection and Treatment Success: The Fidelis Project in collaboration with IUATLD is testing mechanisms to increase case detection and treatment success through DOTS in seven regions.
3. TB-HAART<sup>120</sup> Study: The NTLP in collaboration with the Special Programme for Research and Training in Tropical Diseases (TDR) is studying treatment regimens for patients coinfecting with HIV and TB.
4. Knowledge, Attitudes, Beliefs and Practices (KABP) Study: The PHC Institute is conducting a study on KABP-related factors that affect TB/HIV coinfecting patients in Iringa.

# Partnerships

## Collaboration with the private sector

*Public-private partnership in TB treatment is still minimal.*

*The government is virtually the sole provider and monitoring agent with little involvement from the private sector. Furthermore, there is no specific strategy to guide private sector participation in TB management.*

*In contrast, the government's partnership with the private sector in HIV/AIDS service provision is more extensive and further defined.*

— Fred Lwilla, program officer, NTLP<sup>121</sup>

There is limited coordination of TB control activities undertaken by public and private health providers. For the most part, the government remains the sole provider of DOTS services; there has been little involvement in DOTS implementation from the private sector or NGOs. Private providers must receive government approval to implement DOT, but many provide other TB services without this approval. Traditional healers provide alternative medicine to many people with TB symptoms and for-profit clinics offer TB medication, but most do not administer DOT. By contrast, the government has forged extensive and relatively well-defined partnerships with private providers in HIV/AIDS service provision.

Despite limited public-private collaboration to date, the government has taken some steps to expand opportunities for partnership. In the past, the government viewed private providers as competitors rather than collaborators and placed some restrictions on private health providers in terms of the services they were allowed to provide. Since 1991, the government has been working harder to foster public-private partnerships in the provision of social services, including health services.

The Health Sector Strategic Plan (HSSP) of 2003–2008's Strategy 7 specifically addresses the need for the MoH to strengthen public-private partnerships. To this end, the government established a working group consisting of representatives from the MoH, the private health sector, faith-based groups, development partners, as well as the Tanzania Public Health Association (TPHA). To create an environment that is conducive to increased partnership between the private and public health sectors, the government is to focus on policy formulation, governance, regulation, financing, monitoring, and quality assurance of health services.

Private health facilities, which include not-for-profit facilities such as those run by faith-based organizations as well as for-profit facilities, are increasingly incorporating DOTS

into their services. The NTLP has encouraged private hospitals such as the Aga Khan, Hindu Mandal, and PASADA hospitals in Dar es Salaam to develop TB clinics. These private health facilities receive free drugs from the MoH and are required to report case data to the MoH along with public facilities.

Despite this evidence of the NTLP's initial efforts to expand partnerships with the private sector, such partnerships are still on a limited scale and quality assurance is sometimes an issue of concern. And despite some effort on the part of the government to provide guidance in management of TB to private providers, interviews with private health care providers revealed that most are not well versed on DOTS strategy or the public-private partnership guidelines.<sup>122</sup> A study commissioned by the MoH is currently underway to assess the extent to which private health service providers are aware of the government's strategies and to assess how public-private relationships could be improved.

The NTLP should make greater efforts to disseminate its guidelines for TB management to private providers. The government could also think more creatively about how to encourage the private sector to fund and support community-based initiatives, including CB-DOTS and social mobilization and awareness-building efforts. The Kahama and the Geita mining companies, for example, have set positive examples by establishing DOTS programs in the workplace. Encouraging these types of programs would help to make the government less dependent on foreign donors.<sup>123</sup>

## **Collaboration with NGOs/community organizations**

Few civil society organizations are including TB in their HIV/AIDS-control efforts. This results in part from the MoH's inadequate leadership and coordination on this issue. There has been minimal information-sharing and exchange between the government and civil society organizations on TB. Many civil society activists working in the areas of TB and HIV interviewed have little knowledge of international commitments to control TB such as the Amsterdam Declaration or the Washington Commitment.

As noted, a few organizations (mostly hospitals run by faith-based organizations) have been collaborating with the NTLP by providing DOTS services, by monitoring and reporting to the MoH, and by engaging in public awareness-raising activities. However, site visits revealed that few civil society organizations are actively engaged in either TB advocacy or DOTS services provision, especially when compared to the level of engagement in HIV/AIDS activities.<sup>124</sup> WAMATA, which provides care and support to people living with HIV/AIDS, for instance, focuses primarily on HIV/AIDS activities; their involvement in TB has been limited to referral of clients to the nearest DOTS centers whenever TB symptoms are observed.

The NTLP should promote greater civil society engagement in TB control activities, especially from organizations of people living with HIV/AIDS and from former TB patients, by delineating clear opportunities for consultation, participation, and input. The NTLP should devote effort and resources to building the capacity of civil society organizations by providing training on the DOTS strategy and key aspects of NTLP policy and by partnering with these organizations to conduct information, treatment literacy, and public awareness-raising campaigns as well as to increase and enhance programs to provide additional support to people suffering from TB symptoms and undergoing TB treatment.

## **Collaboration with multilateral organizations and bilateral donors**

At least 65 percent of the NTLP's budget comes from external bilateral and multilateral donors; these donors provide indispensable financial and technical assistance to the NTLP. However, the lack of domestic investment in TB control has raised serious concerns among Tanzanian experts and program officials about "donor-dependence" and long-term sustainability.

A range of technical support and financial partners involved in TB control have formed an Interagency Coordination Committee that meets once a year. Many of these development partners have been supporting NTLP activities for several decades. Several development partners provide valuable technical assistance to the NTLP; the Royal Netherlands Tuberculosis Foundation (KNCV), for example, monitored NTLP performance in 2003. Most external monitoring reports, including that of the KNCV, remain within the NTLP's Central Unit; the government should make such reports available to the public.

Greater political commitment to TB control must be reflected in increased allocation of domestic resources to core TB control activities. Donors should take care to ensure that assistance programs reinforce NTLP leadership, contribute to strengthening the Tanzanian health system, and do more to foster the involvement of civil society groups, particularly organizations of people living with HIV/AIDS, in TB control activities.

# Recommendations

**To improve its TB control efforts, the government of Tanzania and the NTLP should:**

- **Expand DOTS services**, including by:
  - Examining community-based DOTS closely as a potentially sound basis for expanding access to DOTS services throughout the country;
  - Ensuring adequate human resources for DOTS expansion;
  - Expanding community outreach activities and the number of diagnostic centers to place more emphasis on early case detection.
- **Increase government expenditure in health** to \$12 (TZS 15,130) per capita in order to fulfill the vision of the National Health Policy. An increase in health resources will help to improve health outcomes, including those in the area of TB control, for the poor and vulnerable populations and will also sustain the good macroeconomic performance seen in recent years.
- **Pay more attention to the needs of vulnerable populations**, including by:
  - More aggressively addressing the many treatment barriers for TB patients living in poverty, including diagnostic and medical consultation fees, transportation costs, and lack of nutritional support;
  - Encouraging and supporting operational research and data collection to identify groups that are particularly vulnerable to TB and the special obstacles they face in accessing and completing treatment. This type of research could provide a sound basis for the development of more effective TB services for vulnerable groups.
- **Increase TB/HIV programmatic linkages**, including by:
  - Expanding TB/HIV programs further to make “one-stop” testing and treatment centers for TB and HIV a priority;
  - Articulating a transparent strategy with clear budget lines for integrated TB and HIV programs and services;
  - Promoting NGO engagement—especially among HIV/AIDS organizations—on TB control by setting policy guidelines and supporting capacity-building training on various aspects of TB and TB policy for civil society organizations.

- **Review efforts to integrate TB treatment into the general health care delivery system** to identify and minimize negative impact on TB control efforts and to better serve the comprehensive health needs of communities.
- **Provide clear guidelines on public-private partnership** for TB management to private providers and monitor their implementation.
- **Undertake a sustained communications and awareness-raising initiative** (which should target not just the general public, but also HIV/AIDS providers and decision makers at the district and community levels), including by:
  - Developing treatment-literacy programs for new TB patients and the general community that engage people who have successfully recovered from TB;
  - Expanding TB education and awareness programs.

**To step up their contribution to TB control efforts, private companies and industries can:**

- **Investigate the possibility of offering TB services in the workplace, following the lead of the mining industry;**
- **Provide funding for media and community mobilization campaigns** to raise awareness about TB;
- **Engage with district health management teams** in the areas where they operate to ensure adequate allocation of resources to TB control.

**To enhance their efforts to complement government TB control policy, non-governmental and community organizations should:**

- **Mainstream both HIV and TB** into existing programs on human rights and poverty alleviation;
- **Organize media trainings and journalism workshops** to counteract negative stereotypes and misconceptions and to encourage greater coverage of TB in the print and electronic media;
- **Follow the model of PASADA** and other NGOs that are already successfully employing models of patient-centered and community-based DOTS programs.

**To enhance the effectiveness of its support for TB control activities, the international community should:**

- **Ensure that assistance programs reinforce NTLP leadership** and contribute to strengthening the Tanzanian health system;
- **Monitor the utilization of TB/HIV funding** to see that it is effectively reaching target communities, including by supporting and engaging with community-level observers;
- **Support operational research** to assess the impact of TB/HIV interventions;
- **Review efforts to integrate TB treatment into the general health care delivery system** in order to identify and minimize negative impact on TB control efforts and to better serve the comprehensive health needs of communities.

# Notes

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**WE RECOGNIZE THAT: THE GLOBAL tuberculosis emergency . . . cannot be defeated by the health sector acting alone; CONFRONTING tuberculosis requires collaboration across government sectors & action across society.**

**—Amsterdam Declaration to Stop TB**

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Public Health Watch promotes informed civil society engagement in policymaking on tuberculosis and HIV/AIDS. The project's monitoring reports offer a civil society perspective on the extent to which government policies comply with international commitments such as the Amsterdam Declaration to Stop TB and the Declaration of Commitment on HIV/AIDS—and on the extent to which those policies have been implemented.

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