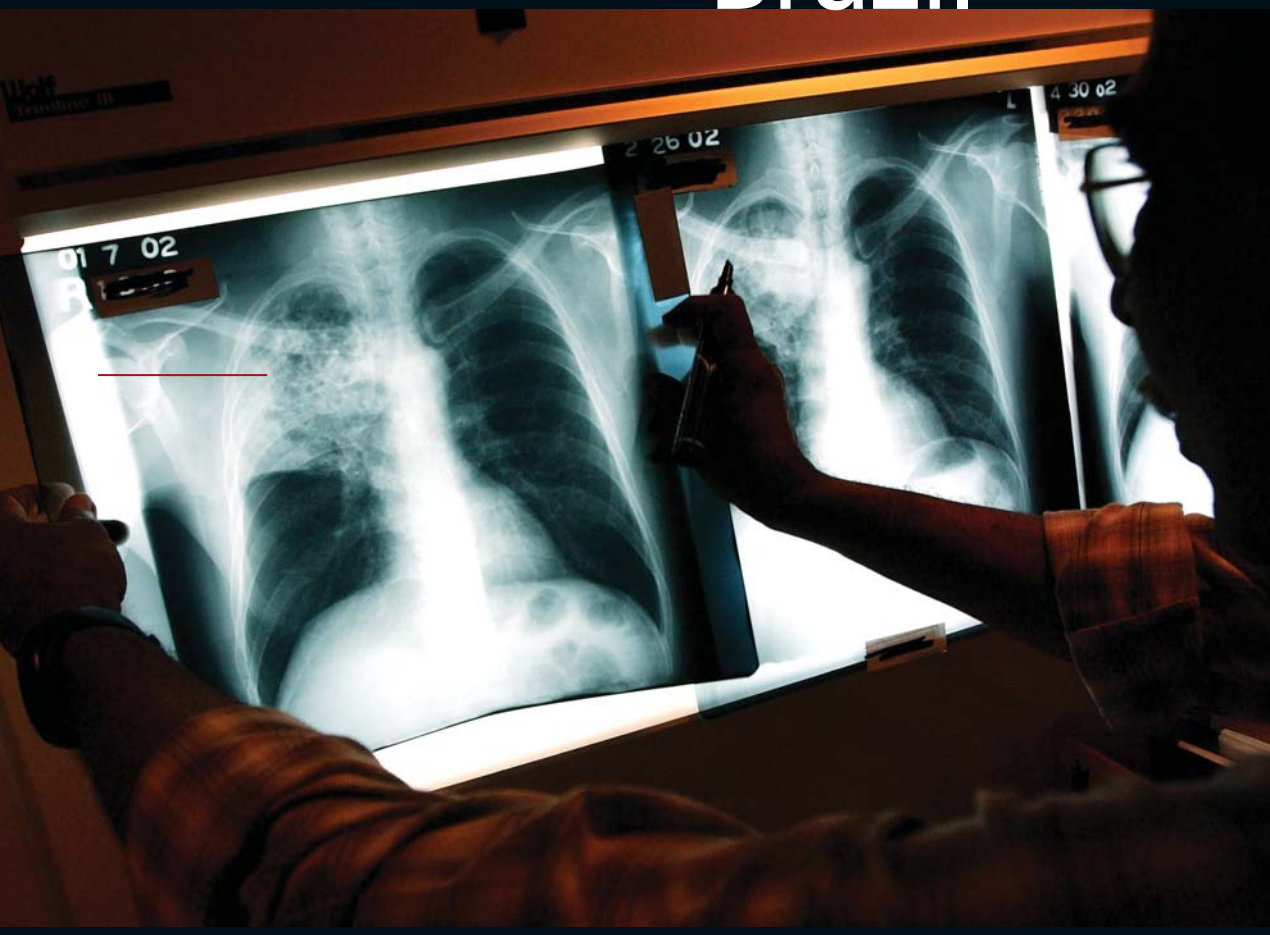
TB POLICY IN Brazil



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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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, *nongovernmental 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.

Acknowledgments

TB Policy in Brazil: A Civil Society Perspective was researched and drafted by Ezio Távora dos Santos Filho, an HIV/AIDS and TB activist and long-time survivor of the AIDS epidemic who has been treated twice for TB—the second time while researching this report. 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.

We would like to acknowledge the support provided by the Forum of NGOs Fighting TB in the State of Rio de Janeiro (Fórum de ONG de Combate à TB no Estado do Rio de Janeiro) and the very significant contributions of the Brazilian Advisory Group, which met on January 25, 2005 to suggest research guidelines. Under the guidance of this group and in light of resource and time constraints, research for this report has focused on urban areas in several regions of the country to allow for exploration of regional differences in policy and administrative structures. We would like to thank interviewees in the cities of Rio de Janeiro, Porto Alegre, São Paulo, Ribeirao Preto, and Brasilia for sharing their time and experiences.

Roundtable meetings were organized in Rio de Janeiro, São Paulo, and Brasilia in March 2006 to invite critical feedback and input on a first draft of this report. The final report has been amended significantly to reflect the feedback and suggestions of roundtable participants. We would like to thank all roundtable participants as well as those who shared their comments by telephone or email.

For the lists of participants in the roundtable meetings, interviewees, and others who contributed to this report, please see appendix.

Public Health Watch TB Monitoring Project

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

Abbreviations

ARV	Antiretroviral drugs
CCM	Country Coordinating Mechanism
CDC	U.S. Centers for Disease Control and Prevention
CRPHF	Centro de Referência Professor Helio Fraga (Brazilian National TB Reference Center)
DOT	Directly observed treatment
DOTS	The internationally recommended strategy for TB control
GAPA-RS	Grupo de Apoio à Prevenção à AIDS—Rio Grande do Sul (AIDS Prevention Support Group)
ICOHRTA	International Clinical, Operational and Health Service Research Training Award for Tuberculosis and AIDS
IPT	Isoniazid preventive therapy
IUATLD	International Union Against Tuberculosis and Lung Disease
LACEN	Laboratórios Centrais de Saúde Pública (Central Public Health Laboratories)
LNR	Laboratório Nacional de Referência (National Reference Laboratory)
MDR-TB	Multidrug-resistant TB
MoH	Ministry of Health
MSH	Management Sciences for Health
NIH	U.S. National Institutes of Health
NGO	Nongovernmental organization
NSAP	National STD/AIDS Program
NTCP, PNCT	National TB Control Program (Programa Nacional de Controle Tuberculose)
PCT-RJ	Rio de Janeiro State TB Control Program
PSF	Programa Saúde da Família (Program on Family Health)
SESP	Public Health Special Service Program
SISLAB	National System of Public Health Laboratories
STD	Sexually transmitted disease
SUS	Sistema Único de Saúde (Brazil's universal health care system)
USP	University of São Paulo
UFRJ	Federal University of Rio de Janeiro
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.[1]

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 reinvigorated 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;[2] 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.[3]

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."[4] 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,[5] 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."[6] 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.[7] In **Thailand**, the resurgence of TB and the number of patients coinfected 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.[8] As one Nigerian health care provider noted, "remove the donor, and everything would crash."[9] 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?"[10]

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. dos 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."[11]

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.[12] TB kills approximately 2 million people a year[13] 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. dos Santos Filho, Public Health Watch researcher, Brazil*[14]

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.[15] 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."[16] 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.[17]

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.[18]

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."[19]

In **Tanzania**, where over 50 percent of people living with HIV/AIDS are coinfected 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."[20] 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."[21]

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*[22]

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."[23] 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.[24] "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."[25] 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."[26] 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."[27]

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."[28]

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*[29]

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.[30] 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.[31] 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.[32]

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."[33] 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.[34] 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.[35]

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"[36]—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.[37] 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.[38] 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.[39]

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*[40]

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.[41] 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*[42]

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;[43] 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.[44] 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."[45] 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*[46]

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.[47] 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, . . . [b]ut . . . 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."[48] 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.[49]

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 coinfected 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]."[50]

Though the WHO has issued an Interim Policy on Collaborative TB/HIV Activities[51] to help countries frame a coordinated response to the challenges of diagnosing and treating coinfected 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.[52] 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."[53] 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[54]

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."[55]

The BRAC model of community-based care has achieved impressive results: treatment success rates at or above the global target of 85 percent,[56] at a cost of 50 percent less than the equivalent services in areas covered by the NTP.[57] 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.[58] 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.[59] 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.[60] In Temeke, too, the program both maintained quality of services and improved cost effectiveness by 37 percent.[61] 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,[62] 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,[63] and others report that the responsibility of providing community and patient education is too great to be left to volunteers.[64] 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."[65]

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*[66]

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."[67] 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;[68] 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.[69] 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.[70] 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.[71] 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."[72] 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. dos 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.[73] 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 or contact Public Health Watch at: phwinfo@sorosny.org.
2. The DOTS strategy has five principal components: sustained political commitment; access to quality-assured TB sputum microscopy; standardized therapy under proper case management conditions; uninterrupted supply of quality-assured drugs; and systematic recording and reporting of TB cases. Available at www.who.int/tb/dots/whatisdots/en/index.html (accessed May 17, 2006).
3. See Amsterdam Declaration to Stop TB, adopted at the Ministerial Conference on Tuberculosis & Sustainable Development on March 24, 2000, Amsterdam, The Netherlands, available at www.stoptb.org/stop_tb_initiative/amsterdam_conference/documents/decla.pdf (accessed May 16, 2006).
4. Executive director of the National Primary Health Care Development Agency (NPHCDA), *The Guardian*, May 30, 2005.
5. BRAC staff confirm a pressing need for more quality microscopes at the field level. Interview with Faruque Ahmed, director of health programs, BRAC, Dhaka, March/April 2005.
6. Comment by Afsan Chowdhury, Public Health Watch researcher and director of advocacy, BRAC, December 12, 2005.
7. NTBLCP/NASCAP Power point presentation, Graph 5: Trend of HIV seroprevalence in TB patients—1991–2001, NASCAP, 2001 Sentinel Survey Report.
8. "Table 1: NTLP 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.
12. "TB Overview," Global Health Reporting, available at www.globalhealthreporting.org/tb.asp (accessed May 25, 2006).
13. WHO, *Global Tuberculosis Control: Surveillance, Planning Financing,* (Geneva: WHO, 2006), p. 1.
14. Comment by Ezio T. dos Santos Filho, Public Health Watch researcher, Public Health Watch roundtable meeting, São Paolo, March 30, 2006.
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. dos Santos Filho, Public Health Watch researcher, observations from social mobilization workshops, Rio de Janeiro, 2003.
18. Study by Healthscope Tanzania and the NTLP, 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.
25. Comment by Razu Ahmed, *Daily Amar Desh* (daily Bangla language newspaper), BRAC/Public Health Watch roundtable meeting, Dhaka, December 12, 2005.
26. 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.
27. Presentation by Jamillah Mwanjisi, Public Health Watch researcher and director of Media Bank, Global Health Council panel discussion, Washington D.C., March 2006.
28. Presentation by Jamillah Mwanjisi, Public Health Watch researcher and director of Media Bank, Global Health Council panel discussion, Washington D.C., March 2006.
29. Comment by Yinka Jegede-Ekpe, coordinator, Nigerian Community of Women Living with HIV (NCW+), JAAIDS media roundtable meeting, Lagos, March 16, 2005.
30. 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.
31. Observations on basis of BRAC's experience at a DOTS treatment center in Chittagong. See also 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. 5, noting reports of people losing their jobs after receiving a TB diagnosis.
32. Interview with TB patient, Broad Street Chest Clinic, Lagos, February 10, 2005.
33. Presentation by Jamillah Mwanjisi, Public Health Watch researcher and director of Media Bank, Global Health Council panel discussion, Washington, D.C., March 2006.
34. Soonthorndhada et al., *Community Perceptions and Experiences of TB in Kanchanaburi, Thailand: A Gender Equity Analysis*. Institute for Population and Social Research. Mahidol University, 2003, Publication No. 287.
35. Fazlul Karim, Insana Begum, Akramul Islam, and AMR Chowdhury, "BRAC Research and Evaluation Division, September 2003, pp. 28–29.
36. Presentation by Jamillah Mwanjisi, Public Health Watch researcher and director of Media Bank, International Union Against Lung Disease and TB Annual Conference, Paris, France, October 21, 2005.
37. Statement by Lucia Maria Xavier de Castro, coordinator of *Grupo Crioula* (the Brazilian Association of Black Women), Brazilian CCM meeting, Brasilia, April 2005.
38. Ministry of Health and Family Welfare, *Study on Tuberculosis and Poor* (Dhaka: Government of Bangladesh, June 2002).
39. WHO/IUATLD, Global Project on Anti-tuberculosis Drug Resistance Surveillance, cited in WHO 2005 and Country Coordination Mechanism, *Application form for Proposals to the Global Fund* (Dhaka: Ministry of Health and Family Welfare, 2003), pp. 26–27, 112.
40. Interview with TB patient, Dar es Salaam, February 2005.
41. NTLP, "Comprehensive list of health facilities providing DOTS nationwide," January 2005.
42. *Report of Third Joint International TB DOTS/ HIV/AIDS Monitoring Mission to Nigeria*, March 2004, p. 21.
43. Ministry of Health and Family Welfare, *Study on Tuberculosis and Poor* (Dhaka: Government of Bangladesh, June 2002).
44. Comment by Pruthi Israngkul Na Ayudya, director, BMA Health Center 21, Public Health Watch roundtable meeting, Bangkok, December 6, 2005.

45. Comment by Salehuddin Ahmed, BRAC University, *Daily Star* roundtable meeting, Dhaka, December 13, 2005.
46. Comment by Rev. Sanan Wutti, The Church of Christ in Thailand, Public Health Watch roundtable meeting, Chiang Mai, December 9, 2005.
47. Interview with Attapon Cheepsattayakorn, director, 10th Zonal TB and Chest Disease Center, December 8, 2005.
48. Comment by Pruthi Israngkul Na Ayudya, director, Health Center 21, Bangkok, Public Health Watch roundtable meeting, Bangkok, December 6, 2005.
49. Interviews with TB patients and clinic staff in Rio de Janeiro, São Paulo, Porto Alegre, and Brasilia, November 2005–March 2006.
50. Comment by Rosemary Adu, National Reference Laboratory, Nigerian Institute of Medical Research (NIMR), JAAIDS media roundtable meeting, Lagos, March 19, 2005.
51. Available at www.who.int/hiv/pub/tb/tbhiv/en/ (accessed May 25, 2006).
52. "To enable them to adhere to treatment, TB patients need support and care that is sensitive to their needs. In practice it means providing a treatment partner or supporter acceptable to patients to reinforce their motivation to continue treatment and counter the tendency of some to interrupt treatment." WHO, "The Five Elements of DOTS," available at www.who.int/tb/dots/whatisdots/en/index2.html (accessed on May 17, 2006).
53. Abdul-Muyeed Chowdhury, executive director, BRAC, *Daily Star* roundtable meeting, Dhaka, December 13, 2005.
54. Presentation by Jamillah Mwanjisi, Public Health Watch researcher and director of Mediabank, Global Health Council panel discussion, Washington D.C., March 2006.
55. Interview with *shastho shebika* in the Dhamrai region, December 14, 2005.
56. A Mustaque, R Chowdhury, Sadia Chowdhury, Akramul Islam et al, "Control of tuberculosis by community health workers in Bangladesh," *The Lancet*, Vol. 350, July 19, 1997, pp.169–72. BRAC's 2004 annual report notes a treatment success rate for new patients of 89 percent. *BRAC Annual Report*, 2004, p. 49.
57. Md. Akramul Islam, AMR Chowdhury, J. Patrick Vaughan et al, "Cost-effectiveness of community health workers in tuberculosis control in Bangladesh," *Bulletin of WHO*, 2002; 80 (6) pp. 445–450.
58. Interview with assistant district TB and leprosy coordinator, Kilombero, February 2005.
59. Interview with assistant district TB and leprosy coordinator, Kilombero, February 2005.
60. Interview with male TB patient, Kilombero, February 2005.
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 (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 (accessed May 25, 2006).

73. Meeting on March 9, 2006 between representatives from USAID and Public Health Watch staff and researchers, Washington, D.C.

II.
Report on TB Policy in Brazil

Executive Summary

After over a decade of weak, poorly coordinated policies, the Brazilian government has made a commitment to improve Brazil's shameful position of 16th on the World Health Organization (WHO) list of 22 TB high-burden countries. As a middle-income country with a proud record of offering universal access to health care and high-quality HIV/AIDS services, Brazil should be able to reach this goal, but only time will tell.

Many Brazilian health experts have suggested that the country's poor record on TB is the result of increasing poverty and deteriorating socioeconomic conditions. This report asserts that the Brazilian government's failure to control TB decisively is due to years of limited public engagement and insufficient political commitment to fighting TB as well as uneven application of TB control policy across the country.

Brazil's highly decentralized health care system grants significant autonomy to state and municipal authorities in the implementation of federal policies. The system functions relatively efficiently for some health programs, such as the National Program for Sexually Transmitted Diseases and AIDS (NSAP). However, until quite recently the federal government was not willing to implement its own TB policy. Many state and municipal authorities were unable and sometimes unwilling to put that policy into practice. Lacking sustained financial and technical support from the federal level, state and municipal governments developed and implemented independent TB policies without coordinating these policies either with each other or with the National TB Control Program (NTCP).

This lack of coordination on TB control efforts is perhaps best illustrated by the record of implementation of the WHO-recommended DOTS TB control strategy. The Ministry of Health (MoH) first recommended the adoption of DOTS as a national policy in 1996, and the NTCP subsequently affirmed DOTS as its recommended strategy in 1999. However, protracted academic debates about the relative merits of alternative approaches to TB control and strong opposition to the strategy from certain factions within the NTCP delayed the initiation of DOTS implementation countrywide until 2004.

Long-term neglect of the TB program is clearly reflected in national data. DOTS coverage in Brazil is still low, both in absolute terms and relative to other high-burden countries, though it should be borne in mind that expansion of services in a country the size of Brazil presents significant challenges. TB prevalence and mortality rates reflect broader socioeconomic patterns, with poor and disadvantaged communities suffering the greatest impact. State and municipal TB authorities have failed to respond to these demographic realities by designing and financing programs to minimize the hidden costs of accessing public TB services that are otherwise free of charge.

TB/HIV coinfection is a growing problem, and though official figures reflect success in treating cases of multidrug-resistant TB (MDR-TB), high rates of default on TB

treatment give cause for concern about a possible rise in levels of drug resistance. Generally speaking, the national infectious diseases surveillance system is weak: states with stronger institutional infrastructures have established relatively strong systems for monitoring TB rates, but it is likely that states with fewer resources are failing to diagnose and treat a significant number of TB cases.

Brazilian public health professionals are underpaid, and a lack of investment in human resources has led to difficulties in recruiting highly skilled staff, to low staff morale, and to deterioration in job performance. Many dedicated TB workers continue to serve even under these difficult circumstances, but there is an urgent need for a structural review of Brazil's human resource policies as a preliminary step to the development of long-term solutions.

From a civil society standpoint, the Brazilian government has simply not been held accountable for effective implementation of its stated TB policy, perhaps due in part to the absence of mechanisms to allow for public scrutiny of government efforts in this area, including by the people and communities most directly affected by TB. Public awareness of TB is low, even among groups at high risk of infection, such as people living with HIV/AIDS. Yet until quite recently, there were few efforts to harness the powerful social mobilization around AIDS to promote civil society engagement in TB policymaking processes, and the NTCP resisted community-led proposals to integrate TB and HIV policies.

However, this scenario is rapidly changing. There have been recent signs of renewed political commitment to TB control. First, the NTCP's adoption of clear policy guidelines and targets in 2004 has offered much-needed leadership and technical support to state and municipal authorities. Second, the initiation of regular regional meetings between national policymakers and state and municipal TB managers has led to visible improvements in communication and coordination. Third, the MoH has fostered the creation of a new Brazilian Partnership against TB, a clear sign of its support for renewed, integrated, and multisectoral TB control efforts. And finally, the federal government has called for increased collaboration on TB control among key international partners, different sectors of government and other MoH programs, including the NSAP and the Family Health Program (Programa Saúde da Família, or PSF).

The Brazilian government should reaffirm its willingness to be held accountable for ensuring that its national TB policy delivers positive outcomes and high-quality services for the people and communities affected by TB. It can do so by encouraging and supporting civil society groups to be substantively involved in designing and implementing a long-term strategy to raise public awareness about TB and TB/HIV; assisting with programs to encourage adherence to treatment by ensuring proper care and support for TB patients; and regular monitoring and review of TB policies at the federal, state, and municipal levels, including operational research to gauge user satisfaction with TB services over time.

Background

Patients arrive at the emergency room, dying of TB without ever having accessed diagnostic services.

—Margareth Dalcolmo, coordinator of the Outpatient Clinic, Centro de Referência Professor Helio Fraga, and president, TB Commission of the Brazilian Thoracic Society[1]

Despite a universal health care system and world-renowned health programs in a number of areas, Brazil records an unacceptably high number of new TB cases and deaths from TB annually. Moreover, official statistics may underestimate the problem, since many TB patients die without ever being formally diagnosed.

Baseline statistics

The Federal Republic of Brazil is the largest and most populous country in Latin America. As of 2006, Brazil's population was roughly 186 million,[2] with 81 percent living in urban areas.[3] According to the Pan-American Health Organization (PAHO), Peru and Brazil together are responsible for 50 percent of all TB cases in Latin America.[4] The MoH estimated that approximately 50 million Brazilians were infected with TB as of 2004,[5] placing the country 16th on the WHO's list of 22 TB high-burden countries.[6]

There are sometimes discrepancies between MoH figures and the figures reported in the WHO's annual *Global Tuberculosis Control* report. For example, the WHO report of March 2004 reported TB incidence to be 62 per 100,000 population, compared to MoH figures of 47.2 per 100,000 population for the same period.[7] Since the WHO relies on national ministries of health for data on TB, a difference of this magnitude is puzzling and merits explanation.

Brazilian MoH data indicates that TB incidence has declined significantly since 1982, though the decline has slowed in the past few years.[8] According to the WHO, prevalence has also declined, but is still high at 77 per 100,000 population.[9] TB is the fourth largest infectious cause of death in the country, accounting for more than 5,000 deaths every year.[10] It is notable that the slight decrease in treatment success rate (to approximately 75.2 percent)[11] has taken place in the context of rising case detection rates.[12] At the same time, approximately 9.5 percent of TB patients default on treatment[13] and a significant number of patients complete treatment without evidence of smear conversion. The MoH has

acknowledged its dissatisfaction with these figures.[14] Furthermore, some Brazilian experts have suggested that a concurrent growth in population and the decline in the quality of the TB surveillance system may be contributing to inaccuracies in current TB statistics.[15]

Official figures reveal significant regional disparities in the prevalence of TB. In the state of Rio de Janeiro, for example, prevalence is significantly higher than the national average at 99 per 100,000 population, with 17,000 new cases registered in 2004; the state's mortality rate reached 5.7 per 100,000 in 2003, which was twice the national average for that year.[16] Moreover, there are strong indications that many TB patients die without ever being formally diagnosed.[17] For example, the Rio de Janeiro state TB program estimates that "20 percent of patients are not diagnosed at an early stage, fueling transmission; many cases are only diagnosed in the hospital or after death."[18]

Regional disparities reflect broader socioeconomic patterns, with poor populations and regions suffering higher TB prevalence. There is an increased vulnerability to infection among certain groups, including Brazilians of African descent, who represent nearly 70 percent of those living in the greatest poverty and confront a history of discrimination and restricted access to health care.[19]

TB/HIV coinfection is an increasingly serious problem, particularly in those regions with high TB prevalence. Coinfection rates range from 25.9 percent in Porto Alegre, to 8.1 percent in Rio de Janeiro, and 2.5 percent in São Luiz.[20] According to official statistics, the incidence of MDR-TB is low: approximately 0.9 percent of all TB cases are HIV-positive. Some officials from the National TB Reference Center believe that an ongoing national assessment (the "National Inquiry on MDR-TB") may reveal that the incidence of coinfection is even lower than previously thought.[21] However, the high treatment default rate cited above gives cause for concern about a rise in rates of resistance to first-line TB drugs.

Brazilian health care system: universal access and decentralization

In 1990, Brazil adopted a universal health care system, the Sistema Único de Saúde (SUS), which is based on principles of universality, integrity, equity, and decentralization of health services.[22] The SUS is federally mandated and regulated, and implemented at the federal, state, and municipal levels through both public and private health services. Specific regulations guide the allocation of authority and financing for different health programs.[23] TB diagnostic and treatment services, including laboratory tests and drugs, are considered part of the basic public health care package in all regions and are provided free of charge to patients throughout the country.[24]

The quality of SUS services varies among different states and municipalities. Uniformity in service provision depends on the strength of a particular program's admin-

istrative structures and guidelines.[25] For example, the NSAP and the national cancer and heart disease programs have developed a strong administrative structure and clear operating guidelines and have been successful both in ensuring a consistently high quality of service and in winning prestige for their performance. NTCP administrative structures and guidelines have been weak. Thus the program has found it more difficult to ensure either consistency in the quality of TB service delivery across the country or implementation of federal policies such as DOTS. One researcher at the Federal University of Rio de Janeiro (UFRJ) noted that weak supervision from the NTCP in the context of Brazil's decentralized system has led to incoherence in TB control efforts and a lack of incentives for individual TB managers to coordinate their activities with other municipal and state authorities.[26] The adoption of clear federal TB policy guidelines in 2004 provides a strong basis for dramatic improvements in this area.

Many Brazilian experts agree that decentralization of TB services should be calibrated to the conditions prevailing in each state and municipality so that a "full decentralization at any cost" approach can be avoided.[27] In fact, the number of primary health care units offering TB services is determined in part by the level of decentralization in each state. For example, in São Paulo municipality, 350 of 390 primary health units offer basic TB diagnostic and treatment services, including sputum collection and provision of TB drugs.[28] However, the case of São Paulo is exceptional; in other municipalities such as Porto Alegre, TB services are available in "reference centers" (large health units) or hospitals, rather than in primary health units.[29] TB authorities in the state of Rio Grande do Sul have also decided to concentrate efforts to expand TB services in the 24 municipalities (out of 496) that carry 75 percent of the state TB burden; 232 other municipalities with much smaller populations offer TB services through designated reference centers.[30] In some cases, TB programs can utilize the infrastructure of other health programs such as the Family Health Program (PSF) to deliver TB services, but this is not an option in all states. In states and municipalities where TB services are more centralized, DOTS expansion and implementation is more difficult to achieve.[31]

Political commitment

> *The problems with the TB control policy will not be satisfactorily resolved if they are dealt with exclusively from a technical-normative perspective. On the contrary, [dealing with these problems] depends on a political solution, involving various state and social actors . . . the prioritization of TB in the SUS . . . [as well as] the development of mechanisms for inter-sectoral integration."*
> *—Antonio Ruffino-Netto, coordinator of epidemiology, and Tereza Cristina Scatena Villa, coordinator of operational studies, TB Network (Rede TB)*[32]

Brazil's position as a TB high-burden country is primarily the result of a general absence of governmental accountability on TB policy. And this situation can be attributed largely to lack of engagement in the development, implementation, and evaluation of TB policy by the people and communities most directly affected by the disease. However, this scenario is rapidly changing. Recent developments offer favorable evidence of renewed political commitment to TB control and augur well for the future.

Political commitment at the federal level

The MoH first recommended DOTS in 1996 with the launch of the Emergency Plan for TB Control.[33] Under the leadership of its manager at the time, the MoH formally adopted the DOTS strategy in 1999.[34] However, factions within the MoH as well as other Brazilian TB experts continued to regard DOTS as a "heresy" and actively opposed implementation of the strategy until 2003.[35] Moreover, until quite recently the NTCP did not encourage community engagement in TB service delivery or in monitoring TB policy implementation. The NTCP also actively opposed community-led proposals to harness the powerful social mobilization to combat AIDS in order to promote TB control and collaborative TB and HIV policies.[36]

In 2004, this situation changed abruptly as a result of growing domestic and external pressure on the federal government. First, international actors such as the WHO, PAHO, the U.S. Agency for International Development (USAID), the U.S. Centers for Disease Control and Prevention (CDC), and members of the global Stop TB Partnership and the International Union against Tuberculosis and Lung Disease (IUATLD) had become increasingly critical of the Brazilian TB situation. Secondly, both state government officials and community organizations expressed growing frustration with the absence of accountability for a federal TB policy that was not delivering positive outcomes, especially in the states of Rio de Janeiro and São Paulo. Thirdly, the federal government was reportedly embarrassed by the difference in performance between the NSAP and the NTCP. Finally, a number of

municipal and state-level initiatives supported by PAHO, USAID, and other international health institutions were clearly performing better than the NTCP and attracting considerable recognition and support.

In February 2004, the MoH responded to these pressures by adopting a new policy for the NTCP with clear guidelines and targets.[37] The 2004 policy represents a radical shift in the government's approach to TB control. It not only reaffirms the government's commitment to DOTS as stated in the 1999 policy, but also highlights the need for enhanced collaboration between the NTCP and the NSAP and the value and importance of community engagement. The 2004 policy also calls for regular meetings between national-level policymakers and state and municipal TB managers to encourage more coordinated implementation of TB control efforts.

This new NTCP policy and the shift in attitude it represents have already produced a number of encouraging results. Regional meetings of TB programs are now taking place regularly, with high-level participation from the NTCP, the MoH, the NSAP, and international organizations such as PAHO. These meetings are encouraging local TB managers to adopt DOTS and to work in a more collaborative manner with the NTP, producing a much-needed shift in attitudes and approaches to dealing with the disease.[38]

In November 2004, the minister of health officially announced the creation of the Brazilian Partnership against TB (the national equivalent of the global Stop TB Partnership);[39] since then, members of the Brazilian Partnership have also participated in regional coordination meetings.[40] The Partnership provides a mechanism for dialogue and cooperation among a broader group of key policy actors, including other federal programs (such as the NSAP) as well as international partners and domestic NGOs and networks. The formation of the Partnership represents a public acknowledgement of the government's intention to change its way of doing business and its support for a renewed multisectoral TB control effort.

Since 2004, TB has become a more common topic in the public statements of major political figures. For example, on November 6, 2005, President Luiz Inacio Lula da Silva made a joint statement with U.S. President George W. Bush in Brasilia on the need for enhanced international cooperation on TB, AIDS, and malaria control.[41] Such expressions of high-level political support have helped to effect changes in public perceptions of the disease and have given a new momentum to NTCP activities. Recent statements by MoH officials at public meetings and events suggest that higher priority is being placed on TB control activities than in the past.

While government health officials do not cite the Amsterdam Declaration to Stop TB, the Declaration's main points are reflected in NTCP policies and official statements. For example, the current federal NTCP manager has made reference to DOTS and other interna-

tional TB commitments in recent speeches at regional meetings of state NTCP managers.[42] The national secretary of health surveillance deserves particular credit for his candor in speaking about the current TB situation: "With the tools we have in Brazil, we could have gone farther than we actually have. This is why the Ministry of Health of this Administration has chosen [TB] as one of its top priorities."[43]

Political commitment at the state level

Brazil's decentralized political system coupled with the absence of a strong federal TB policy to date has led to considerable variations in levels of commitment to TB control among different states and municipalities and thus to variability in the effectiveness of state and municipal TB programs. Even where state and municipal officials are personally invested in the issue, they may face political and financial constraints to implementing effective TB control measures.

For example, TB control officials in the state and municipality of São Paulo have succeeded in securing political support despite the considerable challenges of dealing with the epidemic in such a large and densely populated area. With clear political support, more consistent levels of funding, and better infrastructure than many other states and municipalities, the São Paulo state and municipal TB program operates relatively efficiently; it is well integrated with other municipal programs and services, such as the São Paulo state AIDS program, and has achieved good results, with approximately 85 percent of its municipal health units offering TB services.[44] The state of São Paulo's strong TB infrastructure has facilitated DOTS expansion, though directly supervised treatment (DOT) is still not a realistic option for many working people. With limited financial and human resources at their disposal, São Paulo municipal authorities have focused their efforts on providing DOT to groups of people who are at higher risk of defaulting on treatment, including alcoholics and homeless people.

In other states, where political support for TB control has been less consistent, there is a clear gap between policy and practice. For example, although the current governor of the state of Rio de Janeiro[45] identified TB and leprosy as the state's top disease concerns during her election campaign, she transferred hundreds of millions of dollars from the state health budget into its *Cheque-cidadão* program (a social welfare program). This move generated tremendous controversy, serious clashes between the legislative and executive branches of the state government, and significant media coverage. One component of the state's program stipulated payment of a monthly stipend to poor TB and leprosy patients to help them cover basic needs, but TB patients were never able to access the promised assistance, as a state act to regulate and provide for this program has never been signed.[46] The governor's

measures in reducing the health budget to provide welfare aid proved ineffective and led to significant delays in implementation of the state of Rio de Janeiro's TB control program (PCT-RJ).[47] In addition to these funding cuts, delays in receipt of international funding have contributed to a severe budgetary crisis for the state TB program.[48] Still, Lísia Freitas, head of the PCT-RJ, points out that "the program has continued to receive political support from the state authorities" and has registered progress on DOTS expansion through direct cooperation with municipal coordinators and the expansion of case detection services to prisons and hospital emergency rooms, despite all the difficulties.[49] It should be highlighted that during the same period the municipality of Rio de Janeiro made clear progress on DOTS implementation, with clear political support from the municipal government and a strong boost from international partnerships to fund operational research.[50]

In Rio Grande do Sul, though the head of the state TB program has expressed support for decentralization, municipal TB officers have put up strong resistance due to reduced personnel and administrative and financial constraints.[51] As a result, TB services are concentrated in the 24 municipalities that carry 75 percent of the state TB burden. In Rio Grande do Sul and many other states, the constraints faced by municipal officials, together with widespread belief in the efficacy of self-administrated treatment, lead to a clear resistance to the DOTS implementation.[52]

Public mobilization

> *People find it very strange when I speak openly about having TB—they feel ashamed of having the disease.*
>
> *—Ezio T. dos Santos Filho, Public Health Watch researcher*[53]

Many Brazilians, including those most vulnerable to TB infection, are unaware that TB is still a problem in their country. Stigmatization—and self-stigmatization—of TB patients is common. People commonly react with incredulity to a diagnosis of what is considered a disease of the past. TB is associated with poverty and poor sanitary conditions, and the country's long history of treating the disease in sanatoria is still alive in people's memories. Low awareness and stigmatization are the main reasons for the absence of social mobilization around TB and the lack of a strongly articulated demand for improved TB service delivery.

Public awareness of the threat posed by TB and TB/HIV is extremely low, even among groups most at risk of infection such as people living with HIV/AIDS. A series of social mobilization workshops for HIV/AIDS activists in Rio de Janeiro in 2003 revealed

a lack of awareness of even basic issues such as how TB is spread and the fact that the disease is curable; the majority of workshop participants had never heard of MDR-TB.[54] Awareness is even lower among the poor and marginalized populations that are hardest hit by TB. There is, at both the state and municipal levels, a general scarcity of information and educational materials that communicate the basic facts about TB and TB/HIV in clear, accessible, and nonscientific terms for the general public. As one activist noted, "we still need to take the scientific data and translate it into the language of civil society so it can be read, understood and acted upon."[55]

Rather than harboring particularly positive or negative attitudes about TB and TB patients, most Brazilians are ignorant of the fact that TB is an urgent current issue, rather than a problem of the past. At the same time, people who have been infected with TB often feel ashamed of their condition and actively seek to avoid being identified as a TB patient. For example, patients in the Federal District (Brasilia and surrounding cities) often choose to receive treatment at clinics farther from their homes to avoid letting people in their neighborhood find out that they have TB.[56]

In 2002, the Rio de Janeiro and the São Paulo state TB programs began to invest in social mobilization efforts with the objectives of promoting greater awareness of TB and TB/HIV, stimulating public demand for better TB services, and encouraging civil society monitoring of TB policy.[57] These important state-led initiatives have led to several of the most significant advances in awareness-raising and public mobilization over the past few years, most notably the establishment of the Forum of NGOs Fighting TB in the state of Rio de Janeiro and the Network for Social Control of Tuberculosis in the state of São Paulo. The Brazilian Country Coordinating Mechanism's (CCM's) successful Fifth Round proposal to the Global Fund to Fight AIDS, Tuberculosis and Malaria outlines plans to expand these efforts to other parts of the country, inspired by these examples.[58]

Stigma, low awareness, and the demographic profile of TB patients are all obstacles that will make spontaneous social mobilization, such as occurred with the effort to eradicate TB in the late 19th century and with the fight against AIDS in the 1980s, all but impossible. In this situation, the NTCP as well as state- and municipal-level officials have a special responsibility to encourage and support the participation of community organizations and people affected by TB in TB control efforts. Rather than seeing this as an additional financial obligation, the federal, state, and municipal governments should acknowledge that actively supporting social mobilization is the best way to promote civic monitoring of and public demand for improved TB services.

Communications policy

There is nothing more than a poster on the wall
in health facilities to promote awareness.
—Ezio T. dos Santos Filho, Public Health Watch researcher[59]

Prior to 2004, the federal government did not consider communications to be a necessary component of its TB strategy, and thus there was no national TB communications policy. There was little attention to TB as a serious and current public health issue in the Brazilian media. State and municipal governments implemented TB communications efforts in an ad hoc manner, mostly in health care facilities, if at all.[60] The Ministry of Health has not maintained an updated, systematic record of these activities or their impact, and the CRPHF (Centro de Referência Professor Helio Fraga or Brazilian National TB Reference Center) seems to be the only health institution with archives of TB campaigns from previous decades.[61]

The NTCP still lacks a strategic plan to help guide a sustained public mobilization and awareness-raising effort in states and municipalities throughout the country. The 2004 national TB policy does include a communications component, the implementation of which is overseen by a dedicated MoH official.[62] On the basis of this policy, the NTCP sponsored a national TB awareness campaign in 2004, involving TV and radio spots as well as advertisements in newspapers and magazines, in which a famous actor encouraged people with TB symptoms to be tested. Media coverage of TB has increased somewhat, but still tends to focus on World TB Day, special events such as the establishment of the National Partnership to Stop TB, or crises, like the interruption of TB services at the Raphael de Paula Souza municipal hospital in Curicica, Rio de Janeiro. However, there has been little follow-up to the 2004 campaign.

In 2005, a partnership involving the MoH, the Ataulpho de Paiva Foundation, and other institutions launched a new campaign, with production support from the British Broadcasting Corporation (BBC), this time with impact evaluation. Again, this latest initiative does not appear to be linked to a broader communications strategy that would require government planning and budgeting. The CCM's Fifth Round proposal to the Global Fund included a communications strategy component, which is to be developed over the next few years. For now, however, there is still no sign of a sustained and comprehensive communications effort that would integrate the ongoing participation of officials from the NTCP, its partners in the government sector, and civil society, rather than one-off campaigns as in 2004 and 2005.

Government program for TB and TB/HIV control

Historical development of TB control policy in Brazil

> *What you today call 'DOTS' was used long ago; we nurses . . . used to provide directly observed treatment for patients down in Picos, Piauí State, in the mid-1960s. We referred to it as 'supervised treatment.' Patients—men and women—received their medication on their way to do field work, very early in the morning. That was a comprehensive approach to treatment, which involved the family and attained very high cure rates.*
>
> *—Elsa Ramos Paim, former SESP nurse*[63]

To understand the current TB situation in Brazil, it is necessary to understand the historical process by which a highly effective national TB policy—which was the genuine product of a mass social mobilization movement—lost political and public support.

Brazil has a long history of both governmental and civic TB control efforts. At the turn of the 20th century, TB was the leading cause of death in Rio de Janeiro. In response, a coalition of influential medical, legal, and business professionals formed the League Against Tuberculosis to "implement in the country treatment and prophylaxis for tuberculosis, based on modern science."[64] In 1945, the government established the National Campaign Against Tuberculosis,[65] which quickly became a key public health program.[66] Throughout the late 1940s and the 1950s, the National Campaign managed an extensive network of public TB sanatoria with approximately 12,000 hospital beds for TB in-patients by 1950. In 1956, it introduced the daily "triple-scheme" therapy[67] to encourage out-patient treatment. The National Campaign received a significant portion of its budget from the National Health Department (over half for a period during the 1950s). Although criticized for being too centralized and government-driven and for focusing exclusively on the most affected areas while neglecting other areas the campaign achieved a spectacular reduction of TB rates in the major cities, and enormously decreased the number hospitalized TB patients.

One of the pioneering elements of the campaign was its partnership with the Special Service on Public Health Program (SESP),[68] which promoted greater involvement of nurses and nutritionists in TB control efforts. The SESP not only utilized "visiting nurses"—

a method that had been used since the 1920s—but also incorporated "assisted" or "observed" treatment by "health visitors."[69]

The SESP's investment in the recruitment and remuneration of highly qualified public health professionals is widely admired today. For example, the former head of the state of Rio de Janeiro's TB control program (PCT-RJ) noted:

> *Fundação SESP used to be the institution of excellence for public health. Professionals were of the highest level and received the best remuneration among the health institutions in the country. That was a good example of what can be done in health—when you invest in good health professionals and support their professional development.*[70]

The military coup of 1964 ushered in major changes to the public health system, including a shift toward privatization and decentralization of health services. From 1966 on, successive reforms to the health system led to the introduction of a contributive or social welfare approach (*previdenciario*) and a progressive decline in the Ministry of Health's budget.[71] Brazilian TB officials made courageous and creative attempts to respond to the dilemma posed by the drastic reduction in TB facilities and services which ensued.[72] Most notably, Germano Gerhard Filho, the director of the NTCP from 1979 to 1983,[73] introduced several revolutionary innovations. The most important of these was the six-month, short-course therapy that included rifampicin, a new and very expensive drug that would increase the cost of treatment 20-fold.[74] Gerhard Filho also initiated the combination of two drugs in the same capsule[75] and the creation of unified TB treatment guidelines in 1982. These bold steps are widely credited for the continued decline in TB incidence during this period. According to the current NTCP manager, "the short-course scheme broke with the paradigm of the in-patient and was an important tool for the reintegration of the TB patient into society and the labor market."[76]

A number of important structural changes also took place during this period, which coincided with that of Brazil's final military administration, that of President General João Baptista de Oliveira Figueiredo, which lasted from 1979 to 1985.[77] First, the budgets of the Ministry of Welfare and the Ministry of Health were merged. Second, while the new treatment scheme was 20 times more expensive,[78] it nonetheless helped significantly to reduce in-patient expenditures[79] since fewer patients had to be hospitalized. Third, several important aspects of NTCP management[80] were transferred from Brasilia to Rio de Janeiro,[81] which was seen as an effort to improve the efficiency of NTCP operations. However, the establishment of this separate "cabinet" location later led to conflicts between the NTCP in Brasilia and the CRPHF.

An unintended side effect of the new treatment regimen's success was a growing belief that TB should no longer be seen as a major public health issue, and the budget for TB control activities decreased steadily throughout the 1970s and early 1980s. In the context of decreasing remuneration, the prestige and high status previously attached to the public health profession continued to decline—a process that had started in the mid-1960s. During the 1980s, the public health community was focused on debates over whether to maintain a contributive social security system or to adopt a universal access approach. The adoption of a new constitution in 1988 signaled that the universal access model would prevail, and this in fact occurred with the initiation of SUS in 1990.

Also in 1990, President Fernando Affonso Collor de Mello declared publicly that TB was no longer a major public health problem in Brazil. Some observers believe his statement reflected general overconfidence at the successful transition from sanatoria-based TB services to ambulatory TB services. However, Margareth Dalcolmo notes that the TB situation at that time did not justify such confidence:

> *TB incidence was still at least 50 cases per 100,000 inhabitants [in 1990]. In other words, [TB was still] a public health problem of great magnitude, affecting people in their 20s and 30s, their most productive phase. [President Collor's misjudgment] led to the arbitrary decision to end the National TB Campaign and ignored all the knowledge that had been acquired over decades of work.*[82]

The timing of the president's statement could not have been more unfortunate for TB control efforts. Even as TB services were being reduced to the bare bone, HIV/AIDS was reaching epidemic proportions. In 1992, Brazil recorded the second-largest number of AIDS cases in the Americas,[83] and ultimately HIV/AIDS contributed to a resurgence in TB rates in the 1990s.

From the mid-1990s to the early years of the 21st century, the paths of the NTCP and NSAP diverged considerably. The NTCP continued to grow significantly weaker in terms of financial resources and strategic leadership, and Brazil eventually won the dubious honor of its current place among TB high-burden countries. By contrast, from 1992 the NSAP began to receive increased attention and funding, most notably from the World Bank in 1993, and went on to win global acclaim for its aggressive and effective response to HIV/AIDS.[84]

Program content

The 2004 national TB policy explicitly addresses all five elements of the DOTS strategy, adopts the global targets of 70 percent case detection and 85 percent treatment success, and includes policy implementation guidelines for regional and municipal officials. In addition, the Brazilian Society for TB and Lung Diseases (the Brazilian Thoracic Society) and the National TB Reference Center have developed and disseminated treatment guidelines.[85]

At the federal level, President Lula's "Fome-Zero" Program (a social welfare program) formally recognizes the need for a linkage between health programs and social welfare programs. Though very controversial in the early period of President Lula's administration, the program has shown some impressive results in the past few years, according to the *O Globo* newspaper."[86] Likewise, the Brazilian government has long recognized that it is necessary to provide incentives to encourage treatment adherence among the overwhelming majority of TB patients who are poor. For example, in 2002, the National Health Conference issued a general recommendation that health programs should provide funding for nutritional support as an important tool for promoting health.[87]

In some municipalities, including Rio de Janeiro and São Paulo, TB patients are eligible to receive monthly food baskets as well as food coupons and transportation subsidies, but this is not the case in many other areas of the country. Many health professionals and health managers are hesitant to adopt social assistance policies for fear of being associated with what some Brazilians consider to be populist measures. However, greater attention to the links between TB and poverty is crucial in order to improve national treatment success rates.

DOTS expansion

The 2004 national TB policy clearly embraces the DOTS strategy, setting a target to expand DOTS services by 2007 to 315 priority municipalities that carry over 80 percent of the national TB burden.[88] According to the WHO, DOTS coverage reached 52 percent in 2004, representing a rapid increase from 34 percent in 2003 and 3 percent in 1998.[89] The latest MoH data confirm this trend, recording an estimated DOTS coverage of 63.8 percent for 2005, and 76.4 percent by the end of 2006.[90]

This rapid increase in national DOTS coverage over the past few years can be attributed in part to the expansion of DOTS services, beginning in 1997, in Rio de Janeiro and São Paulo states (including both capital cities) as well as in six cities in the states of Paraíba[91] and Recife[92] (in the northwestern region) and in the mid-western region.[93] However, some

Brazilian experts maintain that MoH and WHO statistics do not present an accurate picture of the situation on the ground.

In practice, capacity to implement DOTS varies considerably among and within states and municipalities, and full DOTS services (including DOT) are not always available even in areas considered to be "covered" by DOTS. Consultation with the NTCP revealed that "DOTS coverage" figures refer to the number of health clinics in the 315 priority municipalities that offer supervised treatment (DOT),[94] or full DOTS services. In other words, although 63.8 percent of municipal health units in the 315 priority municipalities already offer DOT, the entire population of these municipalities is not in fact "covered."[95] Moreover, as Afrânio Kritski of the Federal University of Rio de Janeiro commented, "There are several Brazils. . . . DOTS in one region may have nothing in common with DOTS in another region."[96] Finally, many TB officials assert that even if they support the DOTS strategy in principle, providing DOT to all patients is not feasible given the financial and human resources at their disposal. They argue that comprehensive implementation would require significant new funding to hire additional staff and to provide treatment incentives for TB patients.[97]

DOTS expansion would require a complete change in not only the current health system but also the mentality of health care providers. According to the head of the TB Division of the Sao Paulo State Health Department, Vera Galesi, "DOTS implementation is synonymous with a fully functioning health system." She went on to explain that if the health system is able to provide diagnostic sputum tests to all patients with respiratory symptoms of TB, offer directly observed short-course therapy, ensure a regular supply of medications, register the progress of each case in full, and guarantee political commitment to TB control, "then you have a system that is working well, and then you can ensure DOTS."[98]

There is broad consensus among Brazilian TB experts that effective expansion of access to TB services including DOT cannot be sustained unless additional resources are invested in strengthening health management capacity, improving the situation for health workers, and providing treatment support to TB patients.[99] At present, however, most TB facilities are still short on both staff and resources. Even where patients have the option of traveling back and forth to the health unit every day (or three times a week) to receive DOT, staff can ensure direct supervision only for the most "complicated" patients, including those with TB/HIV coinfection, homeless people, alcoholics, and others. Many patients choose to take responsibility for treatment themselves due to their work schedules or a wish to avoid being identified publicly as a TB patient.[100]

Still, anecdotal evidence suggests that the number of patients taking advantage of DOT increases when clear incentives are available. For example, one clinic in Rio de Janeiro provides TB patients who opt for DOT with supplementary medical services as well as food baskets and transportation subsidies; at that clinic, an estimated 88 percent of TB patients

have chosen to receive DOT.[101] The federal government has already begun to provide funding for DOTS expansion activities, and levels of support are due to increase dramatically with the recent award of a Fifth Round Global Fund grant.[102] Interviews with state TB control managers suggest that these resources will greatly enhance their capacity to implement DOTS fully.[103]

Even with increased resources, more work is still needed to win the hearts and minds of TB administrators and workers with regard to DOTS implementation. Many health workers and administrators, who have observed the response to the HIV/AIDS epidemic, point to the fact that complex antiretroviral (ARV) treatment regimens are largely self-administered as a justification for leaving TB treatment in the hands of TB patients. The NTCP should step up its efforts to develop and communicate clear and persuasive arguments for the importance of direct supervision in ensuring treatment compliance, reducing default rates and preventing the emergence of drug resistance. Doing so could have important implications for the NSAP as well, since ARV resistance is an increasingly important issue that has received insufficient attention to date.

The Brazilian scientific community provided an important source of support to the MoH's DOTS expansion efforts with the 2004 publication of its *TB Guidelines* (second edition).[104] Although the guidelines underline that "there is not enough scientific evidence to indicate supervised treatment as a universal regimen in the treatment of tuberculosis," they attach importance to DOTS expansion efforts and acknowledge positive outcomes, including improved management of TB services, greater adherence to treatment, and lower default rates in the states of Paraíba and São Paulo and the municipality of Rio de Janeiro.[105]

Finally, the current NTCP administration has demonstrated its capacity to implement the MoH policies published in 1999 and to accelerate DOTS implementation by avoiding the internal conflict and opposition to the strategy that plagued earlier administrations. Support for DOTS expansion from PAHO and USAID has also proven invaluable.

TB/HIV coinfection

> *At present, only an individual with good connections and access to top-quality medical assistance (including rapid TB diagnostic tests) can survive a complex TB/HIV coinfection in Brazil.*
>
> *—Ezio T. dos Santos Filho, Public Health Watch researcher*[106]

Managing TB/HIV coinfection presents a major challenge to the Brazilian health system. Prior to 2004, there was little communication or cooperation between the NTCP and the NSAP. However, the 2004 NTCP policy includes a strong TB/HIV component which stipu-

lates specific collaborative activities and affirms the NTCP's interest in learning from the NSAP's successful social mobilization efforts.

An estimated 10 percent of people living with TB are HIV-positive and an estimated 20 percent of people living with HIV/AIDS have pulmonary TB.[107] People living with both diseases face a significantly higher risk of death. For example, while the mortality rate for both TB patients and AIDS patients on ARVs is at or below 5 percent, coinfected persons who are diagnosed with TB at a later stage of infection (often in hospitals) tend to die within 30 days of diagnosis if they do not receive treatment. In these cases, according to Valéria Rolla, a research coordinator for lung diseases at IPEC-FIOCRUZ, "health professionals have to hold their breath and control their anxiety to treat the patient well." She emphasized that both the TB and HIV/AIDS guidelines recommend treating TB first, before initiating ARV treatment, in order to avoid "confusing side-effects, allergy and high toxicity, which can lead to hepatitis and other complications." She added: "[W]e treat many difficult cases of coinfection, but we see that initiating TB treatment first has a positive impact on both infections, even reducing the patient's viral load. Approximately 15 days after initiating TB treatment we check the patient's condition and start with ARV treatment about 30 days later." Rolla noted that enormous progress has been made in the last 15 years; if coinfected patients tended to die within a year from diagnosis in the early 1990s, "now they can survive much longer. It is very hard to estimate how long a patient can live, but less than 10 percent die, if treated."[108] Still, despite the overall decrease in the number of TB cases in the last 20 years, for people living with HIV/AIDS, TB is one of the top three causes of death from an infectious disease nationwide and the leading cause of death in the state of Rio de Janeiro.[109]

Integrated TB/HIV services are already available in some areas. For example, in the Federal District, HIV tests are routinely offered to any patient with respiratory symptoms of TB, and lung examinations are carried out for all 1,500 registered AIDS patients at least once a year.[110] The Federal University of Espírito Santo (UFES) has initiated production of rapid HIV testing kits and the MoH plans to introduce rapid HIV testing for TB patients at TB units throughout the country by the end of 2006. However, access to integrated services is still limited in most parts of the country.

The 2004 policy is already producing positive results in that it is encouraging joint planning as well as practical collaboration between the NTCP and the NSAP at the federal, state, and municipal levels. For example, the two programs have joined efforts to reconstitute a "TB/HIV Advisory Committee;" articulated plans for joint social mobilization activities (which have received support from the Global Fund's Fifth Round and the MoH); identified liaisons between programs at the state level; and taken steps to unify their respective strategies and guidelines on coinfection.

The Brazilian Thoracic Society's *2004 TB Guidelines* include clear recommendations on TB treatment and prophylaxis for HIV patients, and TB prophylaxis is generally available, though interruptions in drug supplies are not uncommon. NSAP treatment guidelines have included indications regarding TB prophylaxis since the early 1990s.[111] Of course, the effectiveness of these guidelines greatly depends on the extent to which they are applied by health workers.

Both the NSAP and the NTCP have also taken independent steps to promote TB/HIV collaborative policies. For example, the NSAP has appointed Fabio Moherdaui to act as a liaison officer in its headquarters office in Brasilia to ensure regular communication with the NTCP. According to Moherdaui, the NSAP has adopted the goals of integrating TB and HIV services in health units, improving case detection among contact persons with respiratory TB symptoms, and enhancing coordination and sharing of NTCP and NSAP surveillance data.[112] Moherdaui's appointment has led to strong NSAP participation in NTCP regional meetings and meetings of the Brazilian Stop TB Partnership, where he has been a strong proponent of community mobilization efforts, particularly the participation of community representatives in TB policy discussions. As recently as June 2003, the CRPHF decisively rejected community proposals to increase collaboration with the NSAP on social mobilization, but it has since revised this position. The CRPHF now publicly welcomes and supports social mobilization initiatives[113] and has in fact provided funding for several activities of the Forum of NGOs Fighting TB in the state of Rio de Janeiro.

MDR-TB

Official statistics suggest that MDR-TB is not currently a serious problem, with an incidence of 0.4 percent, or 400 new cases a year (which is below the WHO estimate of 0.9 percent). CRPHF epidemiological surveillance of MDR-TB, which was initiated in 2000, recorded a total of 2,350 MDR cases between March 2000 and March 2006. Forty-two percent of these cases were from the state of Rio de Janeiro, confirming historical trends in the epidemiological profile of TB in this region.[114] According to some experts, Brazil's currently low MDR-TB rates can be attributed to several factors, particularly the combination therapy introduced in the 1980s.

Both the CRPHF and the NTCP are justifiably proud of Brazil's comprehensive and well-maintained MDR-TB database,[115] which facilitates close and accurate tracking of the notification, progress of treatment, and outcomes of all reported MDR cases. However, weaknesses in the national disease surveillance system increase the likelihood that some MDR cases are being missed, especially in light of high treatment default rates. The National Reference Laboratory at the CRPHF is also responsible for performing quality control of

all cultures and drug-sensitivity tests, which are carried out by the Central Laboratories of Public Health (LACEN) at the state level.[116]

Standardized, high-quality treatment and supervision are available free of charge to all patients diagnosed with drug-resistant strains of TB, despite the high cost (an average of US$2,000 per patient for an 18-month course of treatment). The CRPHF sends the necessary medications directly to the health unit where the patient is being treated, and treatment is monitored by state and municipal-level reference units.

According to Margareth Dalcolmo of the CRPHF, Brazil's high treatment default rates give some cause for concern about the potential for an increase in the number of MDR cases in the future. Most MDR-TB patients tracked by the CRPHF have acquired (secondary) resistance, which results from ineffective or incomplete treatment of TB in the past. Rates of drug resistance are higher among certain groups, including hospitalized patients and confined populations such as prisoners. The CRPHF is currently conducting a comprehensive surveillance of MDR-TB nationwide[117] and expects to report its results in 2007. Preliminary findings suggest that MDR-TB incidence may be even lower than the current official rate.[118]

Case registration and surveillance

As noted above, the CRPHF closely monitors the diagnosis, treatment, and outcome of all MDR-TB cases throughout the country, resulting in successful treatment of the great majority of patients and a default rate of only 3 percent among out-patients treated in the CRPHF ambulatory facility.[119] This record compares favorably with treatment success and default rates for "regular" TB cases in the rest of the country, especially when one considers the complexity of MDR cases.

However, the system for surveillance of infectious diseases in general is weak, and the TB surveillance system has grown weaker under the past decade of decentralization. Some states, such as São Paulo, have established relatively strong TB surveillance systems, thanks to a robust institutional infrastructure. Thus, the fact that the state of Rio de Janeiro reports more cases of TB may not mean that this is the most affected area of the country, but rather that the system is recording a greater percentage of cases; TB may be an equally serious problem in other parts of the country, such as the Amazon Region, but poor surveillance makes it more likely that a significant number of TB cases—possibly including cases of MDR-TB—are not being diagnosed, treated, or reported.

Vulnerable populations

There is little information available on the impact of TB on specific vulnerable groups, though anecdotal evidence suggests higher rates among ethnic minority groups and in certain regions of the country. The prevalence of TB in some prisons is extremely high.

The NTCP has acknowledged that TB is a serious issue in tribal areas, where crowded living conditions are the norm, and it has developed special programs to reach these populations in these areas. Some activists in the Afro-Brazilian community assert that the Afro-Brazilian population, and especially Afro-Brazilian women, suffers a higher incidence of TB, because they are overrepresented among the poor and sometimes face discrimination in accessing health services.[120] However, little data is available on these issues and more research is needed to identify and quantify such regional and demographic disparities so they can be used as a basis for developing policies that will be more responsive to vulnerable populations. In fact, Brazil's successful Fifth Round Global Fund proposal includes provisions for more operational research to evaluate the impact of TB on women in particular, as well as other minorities and vulnerable populations.

There is strong evidence that TB prevalence in some prisons is many times higher than among the general population. For example, one recent study among county jail prisoners in the western sector of the municipality of São Paulo revealed a prevalence rate of around 70 times higher than among the Brazilian population as a whole and 79 times higher than in the rest of the municipality. Of these prisoners infected with TB, 9.5 percent were resistant to isoniazid and rifampicin, and 4.8 percent were resistant to these two drugs as well as pyrazinamide.[121] The Ministry of Justice is responsible for providing TB services to prison populations.

Program management

Management of TB control responsibilities is divided between the NTCP and the CRPHF, and this has led to serious conflicts over authority and competency with negative consequences for coherent development and implementation of the national TB policy.

The NTCP headquarters office and administration is based in Brasilia and oversees the development of national policy, surveillance, and communications efforts. The CRPHF, which is headquartered in Rio de Janeiro, has the responsibility of managing clinical research, developing and disseminating treatment guidelines, handling MDR-TB cases, and overseeing purchase and distribution of medications, all under the supervision of the MoH. The division of tasks and responsibilities between these two institutions was

intended to facilitate TB control efforts, but in practice has led to lack of clarity over respective areas of competency and protracted conflict over various policy issues, most notably DOTS implementation.

Confusion at the central level has seriously hampered TB control efforts. According to Betina Durovni, the head of the Transmissible Diseases Section of the Rio de Janeiro Municipal Health Division, the key problem in articulating TB control policies in Brazil is the "existence of two TB programs: one in Brasília and another in Rio."[122] This interpretation is confirmed by the author's own experience and comments from numerous TB control experts, managers, and researchers throughout the country. Without clear and consistent guidance on policy implementation, state- and municipal-level officials become disoriented, and the efficiency of programs and services for people with TB suffers.

According to some TB professionals, managers, and health care workers, the CRPHF is somewhat isolated from other research institutions,[123] which is reflected in the low visibility of CRPHF activities and limited circulation of its principal publication, *The Brazilian Lung Diseases Newsletter*.[124] The CRPHF would be in a better position to claim its rightful role as a leader in TB control research by disseminating its work through scientific publications and at conferences.

Administration

The NTCP is implemented through Brazil's 27 federal units (26 states and the Federal District) and 5,507 municipalities.[125] Each federal unit has its own TB program, as do the larger municipalities. Many of the municipalities that are not large enough to maintain their own TB programs appoint a dedicated municipal official to oversee health issues including TB, STDs, and HIV/AIDS.

In line with Brazil's broader decentralization policy, the role of the federal government is to encourage and support the national TB control policy, which is now aligned with the internationally recommended DOTS strategy. States are responsible for planning, programming, evaluating, and monitoring policy implementation; municipalities are responsible for actual delivery of TB services. Administrative systems vary from state to state. For example, in the state of São Paulo, state and municipal health authorities enjoy strong and consistent support from the state government. On the other hand, in the state of Rio Grande do Sul, the health administration has maintained strong centralized control over the TB program, devolving less authority to municipal health authorities.

NTCP officials are generally well respected, but have lacked sufficient resources to implement national TB policy effectively, as reflected in the low salaries and incentive structures for public health professionals working within state and municipal TB programs.

This is a structural issue rather than simply a question of resources, and as such requires attention from the federal government.

Staffing[126]

Brazilian health professionals face extremely difficult working conditions, impeding the implementation of TB control policy and making heroes out of the doctors, nurses, and other medical staff who persist in their efforts regardless. Significant political and administrative barriers have so far prevented the health policy reforms that are necessary to improve the situation.

Applicants for the public health civil service pass a general written examination, and are then assigned to work in a particular health program. In most areas of the health system, civil servants are poorly paid, have few to no incentives to improve job performance, face significant and inadequately addressed safety concerns, and do not enjoy recognition or high prestige for their work. For instance, a high-level medical doctor or nurse who works in the public health system in the state of Rio de Janeiro makes approximately R$1,200 (approximately $585) a month, which does not compare favorably with similar level positions in the private sector. The salary situation is similar in most other states. As a result, many health professionals—even high-level public health officials—work two, three, or more jobs to pay their bills. This situation is so widespread that it is considered normal and, therefore, difficult to change; to increase the salaries of health care professionals working on TB would require broader reform of the payment structure utilized by the Brazilian civil service. However, improving the situation for health workers would have a tremendously beneficial impact on the quality of health services, including TB services.

This point is borne out by a comparison of the situation of health staff at the NSAP and NTCP. Health workers employed by the NSAP at all levels generally earn much higher salaries and enjoy greater prestige than those employed by other health programs. This is striking in light of the fact that in the early 1990s health workers commonly considered jobs in the AIDS sector to be undesirable and dangerous. However, it is important to note that many health professionals employed by the NSAP are not in fact civil servants, but consultants hired directly by multilateral agencies, with World Bank funding, to support NSAP implementation. The situation has led to some dissatisfaction and resentment among civil servants in other areas of the health sector. Also, it is not clear how AIDS programming activities will be maintained if and when the funding for these consultancy positions is discontinued or runs out.

State and municipal TB officials recognize the importance of this issue. Some states, such as Rio de Janeiro, held multiple meetings on how to address the situation in 2003 and 2004. The 2004 national TB policy includes plans to provide financial incentives

from the federal budget to state and municipal TB programs that are performing effectively; these programs could use the additional funds to recognize the performance of outstanding health care workers. However, the funding available for this purpose is still quite limited and only a few states and municipalities have benefited to date. To bring about meaningful, long-term changes, there is a need for federal, state, and municipal policies to be matched with budgetary allocations to recognize and reward the work of civil servants in the health care sector, including TB workers.

Budgeting and expenditures

Information on health budgets in general and TB budgets and spending in particular is not easily accessible to the public. Federal, state, and municipal health budgets are not disease-specific. Though certain line-items, such as the purchase of TB diagnostic kits and drugs, are easily identifiable, other significant funding streams, such as salaries for health care workers and maintenance of health units and laboratories, are not accounted for in a TB-specific budget. As a result, it is not possible to obtain a clear and comprehensive picture of overall spending on TB at the federal, state or municipal level.

Funding from international donors plays a critical role in TB control policy in Brazil, but it is not easy to obtain financial and budgetary information on their programs, particularly for NGOs. This makes it more difficult for NGOs to monitor effective utilization of donor funding by state and municipal TB programs. In fact, international donor funding has sometimes been delayed or misused due to complicated bureaucratic requirements and opaque budgetary processes.

Generally speaking, NGO staff lack the training and knowledge to conduct budget tracking and monitoring. Again, it is useful to contrast the TB situation with that of HIV/AIDS. During the 1990s, AIDS NGOs and activists became engaged in following budgetary processes, and as a result they were successful in winning sizable allocations to HIV/AIDS programs and services. To ensure greater public attention and additional resources for TB, NGOs should devote time and attention to learning more about how budgetary processes work to place themselves in a better position to engage with policymakers around these issues.

Monitoring and evaluation

The NTCP prepares regular progress reports on TB program implementation for the MoH. However, these reports are not published or widely publicized as a matter of course. There is sometimes a discrepancy between the detailed figures supplied to international bodies and information generated for internal reporting processes, suggesting that policymakers

may feel more accountable to international partners than to the Brazilian government and taxpayers.

For example, the process by which data is gathered for the Brazil chapter of the WHO's annual *Global Tuberculosis Control* report is not transparent or open to review by a broad range of Brazilian TB experts and civil society groups. As noted above, many Brazilian TB professionals have questioned the accuracy of the statistics on DOTS coverage presented in the report and the methodology for gathering the underlying data, by which an urban area is considered to be "covered" by DOTS even if only a few health units in a given municipality are applying the strategy.[127] By overstating progress, the WHO runs the risk of rewarding weak policies and undermining rather than reinforcing policymakers' motivation and commitment to improve performance. At a recent meeting in Geneva, one WHO TB official acknowledged these potential shortcomings of the methodology for calculating DOTS coverage, but there are no signs that the methodology will change.[128] There is currently no mechanism to allow for systematic input on this or other issues from country-level civil society organizations on the data submitted by the Brazilian government for the *Global Tuberculosis Control* report.

Infrastructure, drugs, and research

Primary health care systems

TB services are provided through primary health care centers throughout the country, the majority of which are municipally owned and operated and generally managed by a nurse.[129] Most do not offer DOT and there is little demand for this service from patients, who are largely unaware of what this would entail. In order to improve the quality of TB services and accelerate DOTS expansion, it is essential to persuade municipal authorities to expand their current approach to work with a broader spectrum of public service providers, including social services, the Family Health Programs, and the NSAP.

Laboratories

Though Brazil possesses a sophisticated network of public health laboratories, the number of TB diagnostic tests performed is low and the system for ensuring quality control is weak and poorly implemented.

Brazil's network of laboratories, SISLAB, forms part of the SUS universal health care system, and as such SISLAB is integrated into the broader decentralized network of health care services.[130] The complex network of SISLAB laboratories is divided into many subnetworks with different missions. For TB, there are three principal subnetworks: local laboratories, state laboratories (LACEN), and the National Reference Laboratory (LNR). Theoretically, municipal reference laboratories should operate at an intermediary level between local laboratories and LACENs, but these do not exist in all municipalities.

The MoH has adopted the DOTS target of diagnosing 70 percent of all pulmonary cases through bacillary TB diagnostic tests (sputum smear tests). Local laboratories, which are operated by private providers or municipalities, perform sputum tests, but cover only 1.6 TB patients per 100,000 inhabitants,[131] a relatively low figure. According to MoH data, 1,042,732 sputum tests were conducted in 2005;[132] the estimated required number of such tests is 3,700,000 annually.[133]

Given the importance of accurate sputum testing, effective quality control is essential. However, MoH officials interviewed for this report estimated that state laboratories are only able to perform 36 percent of the surveillance measures necessary to ensure quality control in local laboratories.[134] According to these officials, LACENs do not have the capacity or resources to carry out their quality control responsibilities effectively, and local laboratories do not send samples to their respective LACENs for review and analysis on a regular basis.[135] According to the head of the Transmissible Diseases Department of the Rio de Janeiro Municipal Health Secretariat, Betina Durovni: "Reference laboratories are light years away from being effective, and there is no quality control policy."[136]

There are also problems with culture and sensitivity testing for TB medications. Culture testing is necessary to certify the negative result of a bacillary diagnostic test; it is also highly important for diagnosis of nonpulmonary TB cases (which can also be confirmed through histopathology). Sensitivity tests are also important for follow-up on cases that have not responded to treatment administered according to national guidelines. MoH officials state that only since 2005 have all 27 federal units started to employ culture and sensitivity testing. Only 62 percent of the laboratories in the LACEN network are equipped to perform culture tests, and there are only one or two such laboratories in each state capital. This gives a clear picture of the bottleneck at the state level with regard to culture and sensitivity testing.

Rio de Janeiro State provides a snapshot of how this problem manifests itself at the state level. According to Rossana C. Britto, culture testing is recommended for TB/HIV cases (roughly 10 percent of all TB cases), extrapulmonary cases (between 10 and 15 percent), MDR-TB cases, and symptomatic cases that are not confirmed through sputum testing. In Rio state, which registered 17,000 new TB cases in 2004 and in which an estimated 20

percent of all cases are not registered,[137] this would mean "initial" as well as "follow-up" culture testing for 5,000 patients annually.[138] In fact, according to PCT-RJ, the Rio state LACEN performs 4,000 cultures a year; one municipal official commented that the Rio LACEN is simply unable to keep up with the demand for sensitivity testing, leading to serious delays in responses to requests for lab tests.[139] By comparison, one major hospital, the UFRJ's Hospital Universitário Clementino Fraga Filho, performs 5,500 cultures a year for its own in-patients, as well as an average of 150 TB patients a year who are registered through the hospital's public outreach services to surrounding districts of the city and university research initiatives. Considering that in-patients require a greater number of follow-up visits and confirmation cultures, and that around 20 percent of TB cases are diagnosed in public hospitals, many of which do not offer necessary laboratory testing services,[140] these figures illustrate the severity of laboratory capacity problems at the state level.

LACENs should also be subjected to close quality control by the National Reference Laboratory (LNR), which is located in the facilities of the CRPHF in Rio de Janeiro. In addition to its quality control responsibilities, the LNR is supposed to provide support to the NTCP in developing its strategy on laboratory diagnostics, to collaborate with the Epidemiological Surveillance Department on the articulation of laboratory guidelines, to review all nonconclusive samples from the state level, provide capacity building and training support for laboratories, to conduct diagnostics research and studies in partnership with state laboratories, and to oversee the production and supply of reagents, culture kits, and biological products necessary for TB diagnostics. The LNR also provides testing for the MDR-TB cases it follows in its own out-patient clinic and for the neighboring municipal hospital, Raphael de Paula Souza—a total of approximately 300 patients annually.[141]

According to the CRPHF 2005 report, the LNR achieved its 2004 objective to produce and distribute 1,000 culture kits and 200 TB drug sensitivity tests.[142] However, these figures are far from reflecting actual needs. The report goes on to state that "3,080 high complexity exams, including diagnostics for multi-resistance and mycobacterium" were performed,[143] but it fails to identify or even estimate how many of these exams were requested or required. It asserts that "370 [sensitivity] tests each containing six tubes with culture kits to the states . . . and 1,100 culture kits for routine tests were provided to the Instituto de Infectologia São Sebastião in Rio de Janeiro," but does not specify how many quality control tests the LNR is performing in the rest of the country. Participants at the Public Health Watch roundtable in Rio de Janeiro affirmed that the LNR takes "up to four months to give results back to the other labs,"[144] and is unable to provide effective quality control services to the LACEN in Rio itself.

The federal government has taken some steps to respond to the shortage of resources and qualified personnel within Brazil's laboratory network.[145] For example, in

2004 the NTCP trained 400 LACEN laboratory professionals, including representatives of units from all 27 states and 315 priority municipalities. Moreover, the MoH purchased microscopes and other essential laboratory equipment in 2005.[146]

Drug distribution systems

The federal government is responsible for providing TB drugs to state governments.[147] TB drugs are available free of charge through the public health system and cannot be obtained at regular pharmacies. Under the supervision of the MoH, the CRPHF oversees purchase and distribution of all TB drugs (including for MDR-TB) to states and municipalities. States can purchase medications directly only in emergency situations, if they experience a sudden shortage; this is sometimes necessary because there are sometimes problems with the supply of drugs from the federal government.[148]

The responsibility for purchasing HIV/AIDS prophylaxis and for AIDS treatment (including treatment of AIDS-related opportunistic infections) is divided among the federal, state, and municipal governments.[149] The federal government is responsible for purchase of ARVs, while state governments are supposed to ensure prevention and treatment of opportunistic infections, according to the terms of the "Tripartite Agreement."[150] In this sense, TB prophylaxis for HIV/AIDS patients (isoniazid) is generally accessible in the same public health unit pharmacies, either through the NTCP or the NSAP.

The quality and steady supply of TB drugs has been an issue, which may be a factor contributing to low national treatment success rates. ANVISA, the supervisory body with competence to oversee regular quality control inspections of drug supplies, lacks sufficient resources to perform its responsibilities consistently throughout the country. In response, and with support from USAID and Management Sciences for Health (MSH), the CRPHF initiated quality testing of the TB medications produced by and distributed among public laboratories in Brazil. The investigation led to the identification and elimination of a number of medications that were shown not to be working effectively.[151] However, the issue of ensuring sufficient domestic capacity to monitor drug quality on an ongoing basis has not yet been addressed.

Education and research

TB does not receive adequate attention in Brazil's medical school curriculum, and clinical and operational research on TB has been lacking. Increased public investment in academic study and operational and health systems research could help generate a more comprehensive, multisectoral response to TB.

According to some observers, lack of investment in TB research has led to diminished academic and public engagement on TB. This in turn limits the possibilities for developing innovative clinical approaches to TB control. It also means that NTCP policy planning is not accompanied by adequate evaluation and assessment, raising the risk that ineffective approaches will be duplicated over time without sufficient regard to outcomes and that valuable and limited public resources will be misspent or mismanaged.[152]

There has been little research on bio-safety issues related to treatment of infectious diseases in hospital environments and little attempt to monitor implementation of existing rules and regulations for the protection of health professionals.[153] Research has also been lacking on socioeconomic and cultural issues, such as patients' perspectives on the effectiveness of different approaches to TB treatment, user satisfaction with TB services, and the role of TB awareness and treatment literacy in boosting treatment adherence.[154]

Moreover, TB policy planning tends to occur without extensive participation from other sectors of the government, though the TB epidemic is widely acknowledged to be the product of a complex range of socioeconomic factors. The MoH should pursue partnerships with other ministries to cosponsor TB research efforts. Engaging other actors, such as the Ministry of Science and Technology, to which a number of important research institutions are linked,[155] would have the dual benefit of promoting a more multisectoral approach to TB control and of increasing overall levels of investment in clinical and operational research on TB.[156]

In the context of insufficient public investment in TB control, several private institutions have played an extremely important role. For example, the Scientific League Against TB[157] sponsors a range of efforts to encourage medical students and physicians to become involved in TB research and treatment and care, including awareness-raising activities, fundraising for clinical research and grant making to support academic research, attendance at international conferences such as the International Union Against Tuberculosis and Lung Disease (IUATLD), and publication of articles in magazines and scientific journals. The Scientific League is comprised mostly of physicians, researchers, and medical students, many of whom are students or graduates of private universities, and thus from middle- or lower-income backgrounds—a possible reflection of the demographics of TB in Brazil, where the most prominent and well-financed universities are public. In light of the lack of attention to TB in the medical school curriculum, Scientific League activities are particularly important. Despite the very limited resources at its disposal, the Scientific League has played an indispensable role in maintaining attention to TB within and beyond the scientific community.

More recently, in 2001, the establishment of the Brazilian Network for TB Research (Instituto Milênio Rede TB—Rede Brasileira de Pesquisas em Tuberculose) at the USP Medical School of Ribeirão Preto and at the UFRJ campus has begun to spark renewed

interest in TB. The network promotes interdisciplinary research and provides support to organizations and institutions as well as to individual researchers and managers. It has also designed a series of courses and research activities to encourage the development of a cadre of professionals who are committed to fighting TB over the long term. Finally, the network has sought international partnerships, of which the International Clinical, Operational, and Health Services Research Training Award for AIDS and Tuberculosis (ICOHRTA) is a notable example. ICOHRTA is funded by the U.S. National Institutes of Health (NIH) and encourages partnership on TB and AIDS research between Brazilian and U.S. universities, notably Johns Hopkins University, the University of California at Berkeley, and Cornell University in New York.[158]

The MoH and NTCP stand to benefit from making an increased public investment in academic research on various aspects of TB control, in partnership with other government departments and ministries whenever possible. Greater exposure to systematic review and informed critique of its policies and services by academics, patients, and other actors would help the NTCP determine which approaches are working and which are not.

Partnerships

Collaboration with the private sector

When patients are diagnosed with TB by a health professional employed in the private sector, they are immediately referred to the public health care system for treatment. The majority of TB medications cannot be obtained in private pharmacies, but only through the public health care system. In practice, the majority of physicians in Brazil are both public servants and private health care providers. Thus, they can easily "switch hats" to provide TB care, and TB diagnosis, treatment, and reporting by private providers is seamlessly integrated into the public health care system.

Private sector practitioners do not widely consider DOTS to be the reigning paradigm for TB treatment, though all Brazilian health professionals are supposed to follow TB treatment guidelines. Private clinicians commonly believe that patients are capable of following the TB treatment regimen without supervision. As noted above, even public health units may offer DOTS, but most do not consider compliance with all aspects of the strategy mandatory and instead allow patients to decide whether they consider it necessary to come to the clinic for directly observed treatment.[159]

Still, TB control efforts are focused exclusively on the public health care system; the fact that private practitioners also provide services to TB patients is not factored into public debate.

Collaboration with NGOs and community organizations

Community activism on TB has been limited to date, especially when compared with the level of activism around HIV/AIDS. However, with increasing encouragement and support from a range of international and domestic sources since 2002, and with the initiative of both the Rio de Janeiro and the São Paulo state TB programs to encourage social mobilization, a diverse group of civil society representatives is becoming more engaged in the development and implementation of TB control policy.

As noted above, the heads of the TB programs in the states of Rio de Janeiro and São Paulo independently decided to initiate support for efforts to promote greater social

mobilization around TB through workshops and meetings with community organizations. As a result, the Rio de Janeiro State Forum of NGOs Fighting TB was created in August 2003, and it has since been able to raise the political profile of TB issues by networking both at national and international forums. The São Paulo State Forum of AIDS NGOs, which includes 180 community-based organizations that have been engaged in fighting HIV/AIDS since 1996, has shown leadership in placing TB and TB/HIV high on its agenda.[160] More recently, the creation of the Network for Social Control of TB in the state of São Paulo has launched a number of TB activities. Together, these initiatives have had an enormous impact on the visibility of TB issues in Brazil. They have articulated a strong demand for community participation in TB events and have already succeeding in making this a *sine qua non* of TB policymaking forums.

Officials from these states say their decision to engage with NGOs on TB stems from their perception that civil society participation is essential for effective TB control, and that the shortcomings of Brazilian TB control efforts have been due to the absence of effective social mobilization on TB until 2002.[161] These initiatives are taking active steps to engage and educate the broader public about TB and the relationship between HIV and TB.

A number of other groups have also begun to integrate TB awareness efforts into their existing activities, including well-established NGOs such as Bem-Estar Familiar (BEMFAM),[162] faith-based groups such as the National Bishop's Conference (CNBB) and Pastoral da Saúde, and trade unions such as the Serviço Social da Indústria (SESI)[163] and the Conferência Nacional da Indústria (CNI).[164] However, public mobilization efforts around TB outside of Rio de Janeiro and Sao Paulo have been minimal.

As noted in previous sections of this report, government support for community involvement in TB control prior to 2002 was extremely limited. However, the adoption of the national TB policy has been followed by concrete action, most notably the establishment of the Brazilian Stop TB Partnership, which currently includes the NTCP, the NSAP, the Rio de Janeiro Forum of TB NGOs and several international NGOs and private agencies among its members and aims to expand its membership to engage as many actors as possible in the fight against TB.

A particular aim of the Partnership is to increase the levels of involvement and investment in TB control from wealthy Brazilian companies and international companies based in Brazil, though it has not achieved notable success in doing so to date. A number of companies have sought to associate themselves with the fight against AIDS for public relations purposes, but they have so far not invested significant resources in supporting the activities of the many NGO-led service and care initiatives around either AIDS or TB. For example, when the managers of the Buddy Brazil Network, a community-based care project that provides treatment support to over 600 AIDS patients throughout the coun-

try, approached private companies for financial contributions, they were repeatedly told that that these activities should be funded by the government or carried out at no cost by volunteers.

Collaboration with HIV/AIDS NGOs

The NSAP has developed a significant degree of institutional independence, primarily thanks to an extremely successful fundraising strategy with the World Bank.[165] As a result, collaboration with other programs, such as the NTCP, is not strictly necessary and therefore not a priority. This does not mean that AIDS organizations and policymakers are unwilling to take on TB issues or to work with others; rather, they are simply focused on accomplishing their own goals, and on ensuring that they have sufficient resources to continue their activities.

Prior to 2003, the NSAP supported several meetings to promote comprehensive mobilization strategies around TB/HIV, but it did not receive full support for these efforts from the NTCP.[166] As detailed in previous sections, the policymaking environment has changed considerably since 2003, and a number of organizations dedicated to the fight against HIV/AIDS, such as those involved in the Rio de Janeiro and São Paulo forums of AIDS NGOs, have provided invaluable support to emerging TB community mobilization initiatives in their states, including by developing coordinated interstate activities. Expanding and intensifying the involvement of these and other organizations that have experience with HIV/AIDS will be key to the development of strategies to engage communities and the broader public in TB control efforts.

Collaboration with multilateral organizations and bilateral donors

Brazilian TB control efforts have received considerable financial and technical support from a range of international partners and bilateral donors, only some of which can be named here. The Global Fund's requirement for community participation as part of its application process has galvanized civil society involvement in TB policymaking, and groups that were involved in developing Brazil's successful Fifth Round proposal plan to press for continued involvement during the course of grant implementation.

USAID and CDC have provided considerable support to state TB programs in Rio de Janeiro and São Paulo for a number of initiatives, most recently to promote coordination among municipal TB managers and encourage the introduction and expansion of the DOTS strategy. USAID in particular provided critical support to the NTCP and its DOTS expansion efforts by funding the employment of PAHO/WHO consultants in Brasilia, who in turn helped develop Brazil's successful Fifth Round proposal to the Global Fund.

As noted above, TB research has also received an important boost from international partners, including the NIH, USAID, and CDC as well as private foundations such as the Consortium to Respond Effectively to the AIDS/TB Epidemic (CREATE), which has supported research on TB/HIV coinfection through the "THRio" project.

Brazil's application to the Global Fund's Fourth Round was not approved, partly due to a failure to demonstrate sufficient community representation on the Country Coordinating Mechanism (CCM). In fact, many community groups claim they were completely unaware of the fact that the government had developed and submitted a proposal. In an attempt to respond to this issue, the NTCP invited the participation of several community groups, including the Rio de Janeiro State Forum of NGOs Fighting TB in the preparation of its Fifth Round application. As the invitation came only at a relatively advanced stage of planning, many groups initially expressed dissatisfaction at the extent to which they were able to influence the content of the proposal. However, through regular participation in the CCM, NGOs have proven their capacity to influence the direction of the grant process. The Global Fund approved Brazil's Fifth Round proposal in September 2005, and major new funding for TB and TB/HIV activities is expected in mid-2006. Brazilian NGOs have been encouraged by the Global Fund's innovative requirement for multisectoral participation, and they welcome the opportunity to be integrally involved in the next chapter of TB control efforts in Brazil.

Recommendations

To improve TB control efforts, the government of Brazil and the NTCP should:

- **Publicly maintain commitment to a national TB policy** and to strong and coordinated implementation of that policy as a fundamental and ongoing responsibility of the federal government.
- **Support NTCP leadership** on official TB control efforts and encourage adherence to NTCP policy by relevant health sector departments and authorities as well as by international and national partner organizations.
- **Engage other governmental sectors and ministries, such as the Ministry of Science and Technology, in TB control efforts**.
- **Promote and develop effective mechanisms to encourage better coordination** among federal, state, and municipal health councils.
- **Redouble efforts to raise public awareness** about the magnitude of the TB problem and to publicize the availability of TB services.
- **Create incentives for closer linkages between state and municipal TB control programs** and for the integration of their strategies and activities, especially with regard to DOTS implementation.
- **Strongly encourage municipal and state health councils to set aside funding to help poor and otherwise disadvantaged TB patients cover the hidden costs of TB treatment.**
- **Initiate the structural and institutional changes necessary to attract and support qualified public health care workers** with increased salaries, benefit packages, performance-based incentives and other forms of compensation.
- **Improve laboratory services and quality control mechanisms** to assure proper coverage of national TB testing needs.
- Support operational research to:
  - **identify and quantify regional and demographic disparities in TB prevalence** and use this information as the basis for developing policies to ensure the most-affected populations greater access to TB services;

- **articulate the application of bio-safety regulations** and measures to prevent transmission of diseases in hospital and day clinic (out-patient) environments;
- **measure levels of satisfaction with service delivery among TB patients** throughout the country on an ongoing basis;
- **identify the most effective and efficient approaches** to TB service delivery.

- **Ensure opportunities and mechanisms for communities and people affected by TB to become substantively involved in TB policy development and implementation**.
- **Empower and support community leadership** to take advantage of these opportunities by providing appropriate technical support and training for community groups.

To complement the government's TB control activities, civil society organizations should:

- **Step up engagement in TB policymaking processes** by:
  - deepening their own knowledge about TB, TB treatment regimens, the interaction between TB and HIV/AIDS, and other technical aspects of the disease and its treatment;
  - intensifying activities to encourage greater community and public awareness about the risks of TB, the availability of treatment, and the importance of treatment compliance, particularly among the poor and other vulnerable groups;
  - adapting advocacy approaches and techniques that have proven to be effective in other areas of health policy, such as HIV/AIDS, to the area of TB control;
  - building skills to monitor TB policy development, including skills to track the federal budget process;
  - fostering relationships with municipal councils of health to encourage greater awareness and budgetary allocations in support of a sustained and strategic response to TB and TB/HIV;
- **Ensure that efforts to monitor and critique government TB control policy are complemented by constructive recommendations for positive change.**

To support TB control efforts in Brazil, international organizations should:

- **Support initiatives by Brazilian civil society organizations to promote TB and TB/HIV awareness and treatment literacy**, particularly those already engaged in similar activities on HIV/AIDS and other health issues.
- **Support programming to build capacity among Brazilian civil society and community-based organizations to conduct monitoring and advocacy on TB**, to encourage greater public demand for improved TB control policies and services and as a critical complement to international efforts to promote government accountability.

Appendix

Participants in roundtable meetings, principal interviewees, and contributors

Ricardo Gadelha de Abreu, Assistant, Department of Epidemiological Surveillance, SVS-MoH[***]
Ademir de Albuquerque Gomes, MD, Consultant, PAHO
William Amaral, President, Grupo Pela VIDDA-RJ; RJ Forum of TB NGOs[*]
Denise Arduini, TB Nurse CMS Pindaro de Carvalho Rodrigues, Gávea, Rio, RJ
Susana Ayres, Nurse with TB Program, Basic Health Unit, Jardim Guanabara, SP

Carlos Basília, IBISS, Forum of TB NGOs RJ, Secretary of Brazilian Stop-TB Partnership
Marcia Bello, MD, PCT-RJ, Scientific League Against Tuberculosis
Ana Luiza Parentone Bittencourt, Assessor in Dermatology, SES-RJ
Rossana Coimbra Brito, MD, PCT-RJ, Scientific League Againt Tuberculosis

Arachu Castro, Assistant Professor, Harvard Medical School, and Director of the Institute for Health and Social Justice, Partners In Health
Ingrid Carvalho, Legal Department, Grupo Pela VIDDA-RJ
Solange Cavalcanti, MD, Head, PCT, SMS-RJ
Rodolfo Rodríguez Cruz, Consultant for TB, PAHO, Brasília

Margareth Pretti Dalcolmo, MD, Coordinator, Outpatient Clinic, CRPHF; Pres, TB Comm., SBPT[*]
Renaldo Dietze, Professor, UFES; Coordinator of Clinical Research Rede-TB
Betina Durovni, MD, Coordinator, Transmissible Diseases Division, SMS—Rio[*]

César Espina, MD, Coordinator, PCT-RS

André Falcão, Communication Department, Health Surveillance Secretariat, MoH
Nadja A. Faraone, São Paulo State Network for Social Monitoring on Tuberculosis[**]
Sumie Matai de Figueiredo, Supervisor, Data bank, Municipal PCT-SP
Germano Gerhardt Filho, MD, President, Ataulpho de Paiva Foundation, Rio de Janeiro
Lísia de Freitas, Coordinator, MD, PCT-RJ

Vera M. N. Galesi, MD, Coordinator, Tuberculosis Division, SES-SP[**]
Claudio Galvez-Kovacic, Director, SOIS Institute: Innovation and Development in Health[**]
Denise Garrett, MD, Consultant, CDC; IUATLD; to the Brazilian PNCT
Ana Glória, BEMFAM, Rio de Janeiro[*]
Necha Goldgrub, CVE; CCD, São Paulo[**]

Ildinei, Nurse responsible for the TB program Unidade Mista, Brasília, D.F.
Eri Ishimoto, CCD-TB, SMS-SP[**]

Célia Kamita, Nurses Director, Municipal Emergency Hospital 21 de Junho, SP, SP
Naomi Kawaoka Komatsu, MD, CCD-TB; Head, PCT-SMS-SP[**]
Joël Keravec, Project Director, MSH, at CRPHF
Marcio Koshaka, Grupo Estruturação, Brasília
Mônica Kramer, MD, Researcher, UFRJ; member of the TB Network[*]
Afrânio Kritski, Professor, MD, UFRJ; Diagnostics Section, TB Network*

Regina Lemos, CCD-TB, SMS-SP[**]
Expedito Luna, MD, Director, Department of Epidemiological Surveillance, SVS–MoH[***]

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Mariliana M.R. de Mattos, MD, Coordinator, Basic Health Unit Jardim Guanabara, SP, SP
Alexia Meurer, GAPA-RS
Fabio Moherdaui, MD, Focal Point for coinfections, PN-DST/Aids, Brasília
Murilo Mota, Transformarte, Rio de Janeiro[*]

José Marcos Oliveira, RNP+ Sorocaba, SP Forum of AIDS-NGOs, National Health Council

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Claudia Paz, IBISS, Rio de Janeiro[*]
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Joseney dos Santos, MD, Coordinator, PNCT[***]
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Maria Alice Santos, Nurse support, Basic Health Unit Jardim Guanabara, SP, SP
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Lia Selig, former Coordinator, MD, PCT-RJ; Scientific League Against Tuberculosis[*]
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Members of the AIDS-NGOs Forum of São Paulo state
Members of the AIDS-NGOs Forum of Rio de Janeiro state
Members of the Forum of NGOs Fighting Tuberculosis in Rio de Janeiro state
. . . And the many other patients and health professionals who were interviewed for this report.

[*] Participant, Public Health Watch Roundtable, Rio de Janeiro, March 28, 2006
[**] Participant, Public Health Watch Roundtable, March 30, 2006
[***] Participant, Public Health Watch Roundtable, March 31, 2006

Maria Helena Falcão prepared the Portuguese translation of the report, and **Zaïra Machado dos Santos Gomes** assisted with editing and revision.

Please see www.publichealthwatch.info to obtain the report in Portuguese.

Notes

1. Telephone interview with Margareth Dalcolmo, coordinator of the Outpatient Clinic, National Reference Center Professor Helio Fraga (CRPHF), and president, TB Commission of the Brazilian Thoracic Society, June 24, 2006.
2. UNAIDS/WHO Epidemiological Fact Sheet–2004 Update, Brazil, p. 3. www.unaids.org/EN/Geographical+Area/by+country/brazil.asp
3. Instituto Brasileiro de Geografia e Estatística (IBGE), www.ibge.gov.br (accessed June 20, 2006).
4. OPAS-OMS, Comunicación social en el control de la tuberculosis—Las Américas 2005, Regional Tuberculosis Program slide presentation by Rodolfo Rodríguez, in Santa Cruz de la Sierra, Bolivia, May 31, 2005.
5. See dtr2001.saude.gov.br/svs/epi/Tuberculose/tuberculose_00.htm (accessed June 12, 2006).
6. WHO, *Global Tuberculosis Control: Surveillance, Planning, Financing* (Geneva: WHO, 2006), p. 77.
7. WHO, *Global Tuberculosis Control: Surveillance, Planning, Financing* (Geneva: WHO, 2004), p. 58; Ministério da Saúde, *Programa Nacional para o Controle da Tuberculose,* Brasília, February, 2004 (Word document on file with author).
8. In 1982, the incidence rate was 90.3 percent; in 1993, 54 percent; and in 2002, 44.5 percent. See dtr2001.saude.gov.br/svs/epi/Tuberculose/INCIDENCIA.xls (accessed June 12, 2006).
9. Compare with prevalence rates in 1990 (221,034/100,000) and 2002 (141,115/100,000), WHO, *Global Tuberculosis Control: Surveillance, Planning, Financing*, (Geneva: WHO, 2006), pp. 77, 166.
10. See dtr2001.saude.gov.br/svs/epi/Tuberculose/Mortalidade.xls (accessed June 12, 2006).
11. Ministério da Saúde, SVS/SINAN, slide presentation by Joseney dos Santos, head of the NTCP, June 6, 2006.
12. WHO, *Global Tuberculosis Control: Surveillance, Planning, Financing*, (Geneva: WHO, 2006), p. 77.
13. Ministério da Saúde, SVS/SINAN, slide presentation by Joseney dos Santos, head of the NTCP, June 6, 2006.
14. Statement by head of the National TB program, meeting of the Country Coordinating Mechanism (CCM), Brasilia, November 22, 2005.
15. Interviews with TB officials in Brasilia, Rio de Janeiro, and Porto Alegre, March 31–July 5, 2005.
16. See www.saude.rj.gov.br/Acoes/tuberculose.shtml (accessed June 13, 2006).
17. Interview with Lia Selig, former director of the Rio de Janeiro State TB Control Program and member of the Scientific League Against Tuberculosis, in reference to her PhD study on TB death records (on file with the author).
18. See http://www.saude.rj.gov.br/Tuberculose/oque_e.shtml (accessed June 13, 2006).
19. CCM Proposal to Global Fund, "Strengthening of the DOTS Strategy in Large Urban Centers with High Tuberculosis Burden in Brazil," June 2005, p. 5.
20. CCM Proposal to Global Fund, "Strengthening of the DOTS Strategy in Large Urban Centers with High Tuberculosis Burden in Brazil," June 2005, p. 38.
21. Interview with Margareth Dalcolmo, CRPHF, July 5, 2005.
22. Sistema Único de Saúde, Federal Act nr. 8,080 of 1990, previewed in the Federal Constitution of 1988.
23. Federal Act 8,142 of Dec. 28, 1990.
24. Ministry of Health, *Guia de Vigilância Epidemiológica*, (Brasília: FUNASA, 2002), p. 58, Item 4.4 ("Atribuições das Instâncias").
25. Federal Act 8,142 of Dec.28, 1990, describing the devolution of authority under SUS to states and municipalities to establish their administration guidelines.

26. Interview with Mônica Kramer, UFRJ researcher, Rio de Janeiro, May 24, 2006.
27. Interview with Vera Galesi, head of the Tuberculosis Division, São Paulo State Department for Health, July 8, 2005.
28. Interviews with managers of the municipal TB control program, health officials, health unit managers, doctors, nurses, and patients in four municipal health units, Municipal Program for TB Control, Municipality of São Paulo, July 8, 2005.
29. Visits to reference centers in Porto Alegre, March 31 and April 1, 2005.
30. Interview with César Espina, head of the TB Control Program for the state of Rio Grande do Sul, Porto Alegre, March 31, 2005.
31. A. Ruffino-Netto and T.C. Scatena-Villa, *Tuberculose—Implantação do DOTS em algumas regiões do Brasil—Histórico e peculiaridades regionais* (São Paulo: Instituto do Milênio Rede TB, 2006), p. 200.
32. A. Ruffino-Netto and T.C. Scatena-Villa, *Tuberculose—Implantação do DOTS em algumas regiões do Brasil—Histórico e peculiaridades regionais* (São Paulo: Instituto do Milênio Rede TB, 2006), p. 43.
33. See http://dtr2001.saude.gov.br/svs/epi/Tuberculose/tuberculose_00.htm (accessed June 20, 2006).
34. Ministry of Health, Plano Nacional de Controle da Tuberculose, Secretaria de Políticas de Saúde; Departamento de Gestão de Políticas Estratégicas de Saúde. Coordenação Nacional de Pneumologia Sanitária; Fundação Nacional de Saúde; Centro Nacional de Epidemiologia; Centro de Referência Hélio Fraga. Brasília, 1999, pp. 6–31.
35. Email message, Ruffino Netto, March 28, 2006. For Ruffino-Netto's description of efforts to introduce the DOTS strategy and resistance to these efforts from within the NTCP, see minutes of the 119th ordinary meeting of the National Health Board, May 8–9, 2002, p. 9 (copy on file with the author).
36. Author's personal experience presenting a proposal for TB/HIV mobilization activities involving the NSAP and CRPHF (represented by then Director Miguel Aiub Hijjar and Training Manager Maria José Procópio), June 11, 2003.
37. Ministry of Health, Programa Nacional de Controle da Tuberculose, Secretaria de Vigilância em Saúde; Departamento de Vigilância Epidemiológica; Coordenação Geral de Doenças Endêmicas; Área Técnica de Pneumologia Sanitária, Brasilia, February 2004 (word document on file with the author).
38. These comments are based on the author's participation in some of these regional meetings on invitation of the NTCP throughout 2005, which allowed for direct observation of implementation of the new policy and multiple interviews with state and municipal officials.
39. For details, see http://dtr2001.saude.gov.br/svs/destaques/tb_forum.htm (accessed June 20, 2006).
40. See http://dtr2001.saude.gov.br/svs/destaques/tb_forum.htm (accessed June 20, 2006).
41. See Brazilian Department of State (Foreign Office, Palácio do Itamaraty) website at www.mre.gov.br/portugues/politica_externa/discursos/discurso_detalhe.asp?ID_DISCURSO=2719 (accessed June 24, 2006).
42. Speeches by Joseney dos Santos, head of the NTCP, Regional Meeting of TB Program Managers of the Southern Region, in Porto Alegre, RS, March 31, 2005.
43. Statement by Jarbas Barbosa, national secretary of health surveillance, during launch of the Brazilian Stop-TB Partnership, November 2004, Brasilia.
44. Interviews in São Paulo and Ribeirão Preto, April 4, July 7–8, 2006; interviews in São Paulo included officials of the State TB Division and the Municipal TB Control Program, health professionals, and patients at a number of different health units.
45. Rosângela Rosinha Garotinho Barros Assed Matheus de Oliveira has served as governor since January, 2003.
46. Statement by Ana Luiza Bittencourt, Rio de Janeiro state Leprosy Program, meeting of the Forum of NGO fighting TB in the State of Rio de Janeiro, October 2005, confirmed by phone on June 28, 2006.

47. Secretaria de Estado de Saúde do Rio de Janeiro, Plano Estratégico para o Controle da Tuberculose no Estado do Rio de Janeiro, 2003 a 2005, Rio de Janeiro: Programa para o Controle da Tuberculose, 2003 (also known as (*Força Total)*.

48. Personal observations by the author while working as a consultant to the state TB program throughout 2003.

49. Email message, Lísia Freitas, coordinator, Rio de Janeiro State Tuberculosis Control Program, April 25, 2006, attaching "Main targets attained—USAID Agreement, 2004–2005," Rio de Janeiro, 2005 (word document on file with the author).

50. These have included partnerships with Johns Hopkins University, supported by funding from the U.S. National Institutes of Health (NIH) as well as the "THRio" project, which focuses on TB/HIV coinfection as part of the Consortium to Respond Effectively to the AIDS TB Epidemic (CREATE), with funding from the Bill and Melinda Gates Foundation.

51. Interview with César Espina, head of the Rio Grande do Sul State TB Program, in Porto Alegre, March 31, 2005.

52. A. Ruffino-Netto and T.C. Scatena-Villa, *Tuberculose—Implantação do DOTS em algumas regiões do Brasil—Histórico e peculiaridades regionais* (São Paulo: Instituto do Milênio Rede TB, 2006), pp. 199–200.

53. Statement by Ezio T. dos Santos Filho, Public Health Watch researcher.

54. Author's personal observations at social mobilization workshops, organized by him in Rio de Janeiro in 2003. These workshops culminated with the creation of the Forum for NGO fighting TB in the Rio de Janeiro State, in August 2003.

55. Comment by roundtable participant, Public Health Watch roundtable meeting, São Paulo, March 30, 2006.

56. Interviews with Mario A.V. Pessolani, a doctor, and Nurse Ildinei, as well as TB patients, administrators, and other health workers in the Unidade Mista, Brasilia, D.F, April 7, 2005.

57. The author was a consultant on social mobilization for the PCT-RJ in 2002–2003, as part of a project of Management Sciences for Health (MSH) in Rio de Janeiro, with funding from USAID. The author also worked as a consultant for the TB Division at the São Paulo State Health Department in early 2004.

58. CCM Proposal to Global Fund, "Strengthening of the DOTS Strategy in Large Urban Centers with High Tuberculosis Burden in Brazil," Objective 2, Service Area 1: "Activities for social mobilization and behavior change," June 2005.

59. Comment by Ezio T. dos Santos Filho, Public Health Watch researcher, roundtable meeting, Sao Paulo, March 30, 2006.

60. Interviews with several health care professionals and AIDS activists in different parts of Brazil: Sandra Perin and Alexia Meurer, GAPA-RS; José Marcos Oliveira, RNP+ Sorocaba, São Paulo State NGO Forum to Fight Aids; Marcio Koshaka, Estruturação Group, Brasília; and various members of the Rio de Janeiro State NGO Forum to Fight TB, between March 31 and July 5, 2005.

61. The author was unable to obtain records on communications campaigns in recent years, telephone and email communications with the MoH, Brasilia, 2005.

62. Interview with André Falcão, communications officer, Brazilian Ministry of Health, during Communication and Social Mobilization Workshop on TB by PAHO in Santa Cruz de la Sierra, Boliva, May 31, 2005.

63. Piauí State is located in the northeastern region, and is the poorest state in Brazil. Interview with Elsa Ramos Paim, former SESP nurse, Rio de Janeiro, August, 2005.

64. Dilene Raimundo Nascimento, Fundação Ataulpho de Paiva—Liga Brasileira contra a tuberculose—Um século de luta. Rio de Janeiro: FAPERJ; Quadratim, 2002, p. 30.

65. Government of Brazil, Decree 9,387/45, 1945.

66. Ieda de Alencar Barreira, *A enfermeira Ananéri no país do futuro: a aventura da luta contra a tuberculose*, (Rio de Janeiro: Universidade Federal do Rio de Janeiro, 1993), PhD dissertation, first part.

67. Ieda de Alencar Barreira, *A enfermeira Ananéri no país do futuro: a aventura da luta contra a tuberculose*, (Rio de Janeiro: Universidade Federal do Rio de Janeiro, 1993), PhD dissertation, p. 100. The therapy, known also as "the Crofton scheme" was composed of the new drugs isoniazid (IZH, 1952), para-amino-salicilic acid (PAS, 1948), and streptomycin (SM, 1946) and indicated a year-long initial treatment to all patients to avoid primary resistance, which was already occurring under mono-therapy.

68. Serviço Especial de Saúde Pública, later transformed into a foundation, Fundação SESP. The foundation was assimilated by the FUNASA, Fundação Nacional de Saúde, created in the 1980s.

69. "Visitadoras Sanitárias" were trained health care support workers, generally women, who delivered home supervised TB treatment. Interview with Elsa Ramos Paim, Rio de Janeiro, June 10, 2006. See also Ieda de Alencar Barreira, *A enfermeira Ananéri no país do futuro: a aventura da luta contra a tuberculose* (Rio de Janeiro: Universidade Federal do Rio de Janeiro, 1993), PhD dissertation.

70. Telephone interview with Lia Selig, June, 2005 and informal conversation with Joseney dos Santos, MD, current head of the NTCP, Brasília, December, 2005.

71. Ieda de Alencar Barreira, *A enfermeira Ananéri no país do futuro: a aventura da luta contra a tuberculose* (Rio de Janeiro: Universidade Federal do Rio de Janeiro, 1993), PhD dissertation, p. 110.

72. The number of hospital beds for TB was reduced from 23,000 to less than 3,000. Partly because of this, TB case notifications rose from 47,000 in 1974 to 88,000 in 1984. Ieda de Alencar Barreira, *A enfermeira Ananéri no país do futuro: a aventura da luta contra a tuberculose* (Rio de Janeiro: Universidade Federal do Rio de Janeiro, 1993), PhD dissertation, p. 160.

73. Germano Gerhard Filho was head of the NTCP from 1979 to 1983 and currently serves as president of the Fundação Ataulpho de Paiva. Ieda de Alencar Barreira, *A enfermeira Ananéri no país do futuro: a aventura da luta contra a tuberculose* (Rio de Janeiro: Universidade Federal do Rio de Janeiro, 1993), PhD dissertation, p. 155.

74. This treatment scheme became popularly known as the RIP scheme: rifampicin, isoniazid and pirazinamid. The addition of rifampicin rendered the scheme much more effective. It is interesting to note that Gerhard Filho was sharply criticized both nationally and internationally for introducing the use of such an expensive new drug among the entire population.

75. The MoH began contracting for production of these capsules from two laboratories (Lepetit and Cyba-Geiger, both of which have since closed) in 1979 with Rifampicin 300mg + Isoniazid 200mg for adults and 150mg+100mg for children and underweight adults. Interview with Germano Gerhardt Filho at the Ataulpho de Paiva Foundation in Rio de Janeiro, May 25, 2006.

76. Interviews in Porto Alegre on March 31, 2005 and during the CCM meeting on June 1, 2005 in Brasilia.

77. See The Planalto Presidential Palace website at https://www.planalto.gov.br/ (accessed on June 25, 2006)

78. Ieda de Alencar Barreira, *A Enfermeira Ananéri no país do futuro: a aventura da luta contra a tuberculose*, (Rio de Janeiro: Universidade Federal do Rio de Janeiro, 1993), PhD dissertation, p. 154.

79. Germano Gerhardt Filho affirmed that 90 percent of the annual budget of the NTCP during this period was expended on drug acquisition and in-patients. The new scheme reduced in-patient expenses and thus expenses on TB overall. Interview with Germano Gerhardt Filho, Ataulpho de Paiva Foundation, Rio de Janeiro, May 25, 2006.

80. At that time, the NTCP was under the National Division for Lung Diseases (Divisão Nacional de Pneumologia Sanitária or DNPS), which in 1976 assumed the position of the previous DNT (National Division of Tuberculosis or Divisão Nacioanal de Tuberculose) and the National Campaign against Tuberculosis (Campanha Nacional Contra a Tuberculose or CNCT). A number of other administrative reforms have been carried out among these TB institutions over the past decades. See Ieda de Alencar Barreira, *A Enfermeira Ananéri no país do futuro: a aventura da luta contra a tuberculose,* (Rio de Janeiro: Universidade Federal do Rio de Janeiro, 1993), PhD dissertation, pp. 142–171.

81. Ieda de Alencar Barreira, *A Enfermeira Ananéri no país do futuro: a aventura da luta contra a tuberculose,* (Rio de Janeiro: Universidade Federal do Rio de Janeiro, 1993), PhD dissertation, pp. 154–155.

82. Interview with Margareth Dalcolmo, MD, CRPHF, July 5, 2005.

83. The World Bank, *Staff Appraisal Report—Brazil—AIDS and STD Control Project—October 8, 1993*, Report no. 11734-BR. Doc in Word. Internal Document, Annex B, page 47. Brazil had 24,704 reported AIDS cases up to March 31, 1992, compared to 218,301 U.S. cases.

84. Ezio Távora dos Santos Filho, *Out of the shadow: the Brazilian Social Movement in the loan by the World Bank to the Brazilian National AIDS Program*, master's dissertation, Institute of International Relations, Pontifical Catholic University of Rio de Janeiro, Rio de Janeiro, 2002.

85. SBPT; CRPHF, M.P. Dalcolmo (Ed.), *II Diretrizes Brasileiras para Tuberculose—2004*, *Jornal Brasileiro de Pneumologia*, Vol. 30, supplement 1, June, 2004.

86. *O Globo*, Primeiro caderno, Section "Opinião," "Nova pesquisa do IBGE reafirma e redime o Fome Zero," (New research by IBGE reaffirms and redeems Fome Zero program), June 22, 2006, p. 7.

87. Item 93 of the *12th National Conference on Health Report*. Brasília: Ministério da Saúde, 2003, p. 96, available at: http://www.ensp.fiocruz.br/radis/web/relatoriofinal12.pdf. Email message from Mario Scheffer, journalist, São Paulo Regional Medical Council and former member of the National Councils of Health, June 27, 2006.

88. CCM Proposal to Global Fund, "Strengthening of the DOTS Strategy in Large Urban Centers with High Tuberculosis Burden in Brazil" June 2005, p. 9.

89. WHO, *Global Tuberculosis Control: Surveillance, Planning, Financing* (Geneva: WHO, 2006), p. 79. See also A. Ruffino-Netto and T.C. Scatena-Villa, *Tuberculose—Implantação do DOTS em algumas regiões do Brasil—Histórico e peculiaridades regionais* (São Paulo: Instituto do Milênio Rede TB, 2006), pp. 40, 51, confirming increasing DOTS coverage from three percent in 1998 to present rates, and recording the initiation of DOTS implementation in 1997 in mid-western Brazil.

90. Ministério da Saúde. Secretaria de Vigilância em Saúde, "Avaliação e Monitoramento da Tuberculose 2006,".slide presentation by Joseney dos Santos, head of the NTCP, June 2006, Slide 11. See also A. Ruffino-Netto and T.C. Scatena-Villa, *Tuberculose—Implantação do DOTS em algumas regiões do Brasil—Histórico e peculiaridades regionais* (São Paulo: Instituto do Milênio Rede TB, 2006), p. 40.

91. A. Ruffino-Netto and T.C. Scatena-Villa, *Tuberculose—Implantação do DOTS em algumas regiões do Brasil—Histórico e peculiaridades regionais* (São Paulo: Instituto do Milênio Rede TB, 2006), pp. 141–165.

92. A. Ruffino-Netto and T.C. Scatena-Villa, *Tuberculose—Implantação do DOTS em algumas regiões do Brasil—Histórico e peculiaridades regionais* (São Paulo: Instituto do Milênio Rede TB, 2006), pp. 167–179.

93. A. Ruffino-Netto and T.C. Scatena-Villa, *Tuberculose—Implantação do DOTS em algumas regiões do Brasil—Histórico e peculiaridades regionais* (São Paulo: Instituto do Milênio Rede TB, 2006), pp. 49–72. Interviews with Ademir de Albuquerque Gomes at PAHO and with health professionals in Brasília, April 7, 2005.

94. Ministério da Saúde, Secretaria de Vigilância em Saúde, *Programa Nacional de Controle da Tuberculose* (Brasilia: MoH, February 2004), p. 4 (word document on file with author). The document defines supervised treatment as administration of drugs under direct observation for the first two months of treatment, and two observations a week for the following four months of treatment.

95. Email message from Joseney dos Santos, head of the NTCP, June 26, 2006.

96. Comment by Afrânio Kritski, Federal University of Rio de Janeiro/TB Network, Public Health Watch roundtable meeting, Rio de Janeiro, March 28, 2006.

97. See generally A. Ruffino-Netto and T.C. Scatena-Villa, (Org.), *Tuberculose—Implantação do DOTS em algumas regiões do Brasil—Histórico e peculiaridades regionais* (São Paulo: Instituto do Milênio Rede TB, 2006).

98. Interview with Vera Galesi, head of the TB Division of the São Paulo State Health Department, São Paulo , July 8, 2005.

99. A. Ruffino-Netto and T.C. Scatena-Villa, *Tuberculose—Implantação do DOTS em algumas regiões do Brasil—Histórico e peculiaridades regionais* (São Paulo: Instituto do Milênio Rede TB, 2006), pp. 42–44.

100. Interviews with TB patients and clinic staff in Rio de Janeiro, Sao Paulo, Porto Alegre, and Brasilia, March 31–July 8, 2005 and with a former nurse in Bahia state, São Paulo, December 2005.

101. Interview with a health care worker at TB service in the Gávea Municipal Health Center, Rio de Janeiro municipality, March 2006.

102. The Global Fund grant will cover DOTS expansion activities in a total of 57 municipalities in 10 metropolitan regions and the municipality of Manaus, which together encompass 30 percent of the Brazilian population and 43 percent of the national TB burden. See CCM Proposal to the Global Fund, "Strengthening of the DOTS Strategy in Large Urban Centers with High Tuberculosis Burden in Brazil" Brasilia, June 2005, p. 11. www.theglobalfund.org/programs/grantdetails.aspx?compid=964&lang=en&CountryId=BRA (accessed June 14, 2006).

103. Meeting of the Brazilian CCM with representatives of the 57 municipalities schedule to receiving funding under the Global Fund grant, Hotel Gloria, Rio de Janeiro, March 29, 2006.

104. *Jornal Brasileiro de Pneumologia*, Volume 30, Suplemento 1, June 2004, p. 35. The *Brazilian Journal of Lung Diseases* is an official publication of the Brazilian Thoracic Society (Sociedade Brasileira de Pneumologia e Tisiologia), edited by Margareth Pretti Dalcomo, president of the Scientific Commission of TB of the Brazilian Thoracic Society.

105. Interview with officials of the Scientific League, Hospital da Santa Casa da Misericórdia, Rio de Janeiro, March 14, 2005.

106. Statement by Ezio T. dos Santos Filho, Public Health Watch researcher.

107. Ministry of Health, Co-infecção TB/HIV, slide presentation by Fabio Moherdaui. Brasília, PN-DST/Aids (MoH), April, 2005.

108. Telephone interview with Valéria Rolla, researcher and coordinator for lung diseases at IPEC-FIOCRUZ, Rio de Janeiro, July, 2005 and June 26, 2006.

109. Telephone interview with Fabio Moherdaui, focal point for coinfections, NSAP Brasília, June 26, 2006. This data is derived from information from the System for Mortality Information (Sistema de Informações em Mortalidade or SIM) and the National System for Diseases and Case Registration (Sistema Nacional de Agravos e Notificações or SINAN).

110. Interview with Mario A.V. Pessolani and nurse Ildinei, in charge of the TB program at the Brasília Mixed Unit, Federal District Government, April 7, 2005.

111. The inclusion of TB prophylaxis in the STD/AIDS treatment guidelines in the early 1990s was largely due to the efforts of M. Dalcolmo, CRPHF.

112. Ministry of Health, *Co-infecção TB/HIV*, PowerPoint presentation at NTCP regional meetings with state TB managers, presented by Fabio Moherdaui, NSAP liaison officer, Brasília, PN-DST/Aids (MoH), April, 2005.

113. Personal observation by the author, southeastern region meeting of state TB managers and the NTCP, Hotel Gloria, Rio de Janeiro, March 27-28, 2006.

114. Interview with Margareth Dalcolmo, CRPHF, Rio de Janeiro, July 5, 2005 and confirmed by an email message on May 29, 2006.

115. Site visit to the CRPHF, Rio de Janeiro, July 5, 2005.

116. CCM proposal to the Global Fund, "Strengthening of the DOTS Strategy in Large Urban Centers with High Tuberculosis Burden in Brazil" June 2005, p. 40.

117. The "National Inquiry on MDR-TB (*Inquérito Nacional para TBMR*), conducted with the support of MSH, funded by USAID.

118. Interview with Margareth Dalcomo, CRPHF, July 5, 2005.

119. Interview with Margareth Dalcolmo, CRPHF, July 5, 2005.

120. Lucia Maria Xavier de Castro, coordinator of Grupo Crioula, Brazilian Association of Black Women, Brazilian CCM Meeting, Brasilia, April 2005.

121. R.M. Abrahao, P.A. Nogueira, and M.I. Malucelli, "Tuberculosis in County Jail Prisoners in the Western Sector of the City of Sao Paulo, Brazil," *International Journal of Tuberculosis and Lung Disease*, vol. 10, No 2, February 2006, pp. 203–208.

122. Comment by Betina Durovni, head of the Transmissible Diseases Section of the Rio de Janeiro Municipal Health Division, Public Health Watch roundtable meeting, Rio de Janeiro, March 28, 2006.

123. Interviews with TB professionals, managers, and health care workers, Rio de Janeiro, São Paulo, and Brasília, 2005 and 2006.

124. CRPHF, *Boletim de Pneumologia Sanitária*, v. 13, n. 1, 2005.

125. Instituto Brasileiro de Geografia e Estatística (IBGE), Brazilian National Census, 2000. See www.ibge.gov.br/ (accessed June 26, 2006).

126. The information in this section reflects the author's extensive contacts with health care workers during his years of treatment for HIV/AIDS and TB.

127. Multiple Brazilian health professionals participating in Public Health Watch roundtable meetings in Rio de Janeiro, Brasilia, and Sao Paulo, March 2006.

128. Meeting between the Community Advisory Committee to the Open Society Institute/Treatment Action Group TB/HIV Monitoring and Advocacy Project and WHO officials, Geneva, March 2006.

129. Observation on site visits to primary health care units in Porto Alegre, Brasilia, and Sao Paulo throughout 2005.

130. For more details about Brazil's laboratory network, see "Strengthening of the DOTS Strategy in Large Urban Centers with High Tuberculosis Burden in Brazil" June 2005, pp. 39–42, available at www.theglobalfund.org/programs/grantdetails.aspx?compid=964&lang=en&CountryId=BRA (accessed June 14, 2006).

131. CCM proposal to the Global Fund, June 2006, p. 42.

132. Data from the MoH DATASUS database on out-patient services (*Produção Ambulatorial*), (www.datasus.gov.br, accessed on June 27, 2006). Information provided by technician in Brasilia on May 2006.

133. This figure is based upon the estimated number of patients with respiratory TB symptoms (1 percent of the population of roughly 186 million) and two sputum tests a year for each patient. This figure does not compare favorable with Peru's estimated 1,400,000 sputum tests annually among a population of 23 million. A. Ruffino-Netto, Impacto da reforma do setor saúde sobre os serviços de tuberculose no Brasil. Boletim de Pneumologia Sanitária, v. 7, n. 1, jan/jun 1999.

134. Interviews with MoH officials, Rio de Janeiro and Brasília in May 2006.

135. Phone interview with Maraci Marques Pereira, coordinator of quality control of the LACEN Rio de Janeiro, on June 29, 2006.

136. Comment by Betina Durovni, head of the Transmissible Diseases Sector of the Rio de Janeiro Municipal Health Division, Public Health Watch roundtable meeting, Rio de Janeiro, March 28, 2006.

137. See www.saude.rj.gov.br/Acoes/tuberculose.shtml.

138. "Cultura de entrada" and "cultura de acompanhamento," terminology employed in telephone inteview with Rossana Coimbra Brito, PCT-RJ, June 27, 2006.

139. Comment by municipal TB official, Public Health Watch roundtable meeting, Rio de Janeiro, March 28, 2006.

140. A.L. Kritski, M.B. Conde, G.R. Muzy de Souza, *Tuberculose. Do Ambulatório a Enfermaria*, São Paulo: Editora Atheneu, 2005—3a edition, p. 259

141. Information received during local visit to CRPHF on July 5, 2005.

142. CRPHF, *Boletim de Pneumologia Sanitária*, v. 13, n. 1, Rio de Janeiro, 2005, p.42.

143. CRPHF, *Boletim de Pneumologia Sanitária*, v. 13, n. 1, Rio de Janeiro, 2005, pp. 44–45.

144. Public Health Watch roundtable meeting, Rio de Janeiro, March 28, 2006.

145. CCM Brazil proposal to the Global Fund in the Fifth Round, "Strengthening of the DOTS Strategy in Large Urban Centers with High Tuberculosis Burden in Brazil," June 2005, available at www.theglobalfund.org/programs/grantdetails.aspx?compid=964&lang=en&CountryId=BRA (accessed June 14, 2006).

146. Information obtained at a CCM meeting from laboratory technicians at the Ministry of Health, May, 2006.

147. Ministry of Health, *Guia de Vigilância Epidemiológica*, Estrutura Organizacional do Programa Nacional de TB; Atribuições das Instâncias. Brasília: FUNASA, 2002, p. 58.

148. Comment by Margareth Dalcomo, director of CRPHF, Public Health Watch roundtable meeting, Rio de Janeiro, March 28, 2006.

149. Ministry of Health, ANEXO 04 da Norma Técnica—Incentivo HIV/Aids e outras DST—Nffl 01/2002 Portaria (Ministerial Decree) Nffl 2314, de 20 de Dezembro de 2002.

150. This agreement was the result of the meeting of the Inter-manager Commission of the MoH (Comissão Inter-Gestores), which is comprised of the MoH Technical Group, members of National Council of State Health Secretaries and representatives of the National Council of Municipal Secretaries of Health, Brasilia, July 1998. Telephone interview with Ingrid Carvalho, attorney, head of the Legal Department of Grupo Pela VIDDA-RJ, June 26, 2006.

151. Interview with J. Keravec, project director, MSH, at the CRPHF, Rio de Janeiro, July 5, 2005.

152. Comments by Afrânio Kritski, Federal University of Rio de Janeiro and member of the TB Network, Public Health Watch roundtable meeting, Rio de Janeiro, March 28, 2006. Information confirmed by email on June 28, 2006.

153. Comment by Lia Selig, former head of the PCT-RJ, during Public Health Watch roundtable meeting, Rio de Janeiro, March 2006.

154. Email message from Fabiana S. Vasques, nurse, Guarulhos, SP, sent on May 1st, 2006 by Enrico Sena from Brazilian Network of People Living with HIV and AIDS (RNP+) and participant at the Public Health Watch roundtable meetingin São Paulo, March 30, 2006.

155. Research institutions linked to the Ministry of Science and Technology include the National Council for Scientific and Technological Development (CNPq) and Funding for Studies and Projects (FINEP). See http://www.mct.gov.br/index.php/content/view/778.html (accessed on June 26, 2006)

156. Comments by Afrânio Kritski, Federal University of Rio de Janeiro and member of the TB Network, Public Health Watch roundtable meeting, Rio de Janeiro, March 28, 2006.

157. Interview with the Scientific League physicians and researchers Lia Selig, Marcia Bello, Anete Trajman, Rossana Brito, at the Hospital da Santa Casa da Misericórdia do Rio de Janeiro, March 14, 2005.

158. ICOHRTA partners in Brazil include the Adolfo Lutz Institute in São Paulo and the Infectious Diseases Unit of the Federal University of Espírito Santo as well as the USP and UFRJ.

159. Personal experience of author when receiving TB treatment, Copacabana Municipal Health Care Center (one of the largest TB treatment clinics in Brazil), Rio de Janeiro, 2004–2005.

160. Since 2003, the representative from the São Paulo Forum of AIDS NGO and the Brazilian Network of People Living with HIV/AIDS (RNP+) at the National Council of Health, José Marcos Oliveira, has acted as the key contact person for TB-HIV issues.

161. Personal observations of the author on the basis of his experience as a community mobilization consultant to PCT-RJ in 2003–2004. The project was funded by USAID, with technical assistance from MSH.

162. Bem-Estar Familiar no Brasil focuses primarily on family and reproductive health and is based in Rio de Janeiro. See www.bemfam.org.br (accessed June 20, 2006).

163. *Serviço Social da Indústria*, a powerful social and health institution of the Brazilian industrial association, established in 1946, with 2,285 units in 1,565 Brazilian municipalities. See www.sesi.org.br.

164. Conferência Nacional da Indústria, the largest industrial membership organization in Brazil, established in 1938. See www.cni.org.br (accessed June 20, 2006).

165. See Ezio T. dos Santos Filho, "Out of the shadow: the Brazilian Social Movement in the loan by the World Bank to the Brazilian National AIDS Program," master's dissertation, Institute of International Relations, Pontifical Catholic University of Rio de Janeiro, Rio de Janeiro, 2002.

166. Author's personal experience as a consultant for the PCT-RJ between 2002 and 2003.

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

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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