

# Civil Society Perspectives ON TB/HIV Policy



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

**PUBLIC HEALTH WATCH**



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Public Health Program

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# Civil Society Perspectives on TB/HIV Policy

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**PUBLIC HEALTH WATCH**

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# Foreword

The most dramatic TB/HIV coinfection rate identified in this excellent report is in Tanzania at over 50 percent. That's pretty frightening. But in my experience it is indicative: throughout the hospitals in the high HIV-prevalence countries of southern Africa, the coinfection rates are above 50 or 60 or even 70 percent. When visiting the male and female adult hospital wards, I invariably ask about coinfection, and for the past five years the answers are always the same: the levels of TB/HIV are steadily rising.

In fact, the pattern of response is interesting. In 2001, 2002, and 2003, when I used the word "coinfection," the doctor or nurse on the ward would reply, "Do you mean HIV and tuberculosis?" From 2003 onwards, no clarification has been necessary.

Fortunately, it's now become commonplace in many health care settings to test for HIV in the presence of TB, and to test for TB in the presence of HIV. That, at least, makes appropriate treatment possible. What is not commonplace, alas, is the awareness that TB is a raging communicable disease, made ever more widespread by the contagion of AIDS.

Despite the memorable presence of Nelson Mandela on the platform at the International AIDS Conference in Bangkok in 2004, warning the world about coinfection and showing solidarity with Winstone Zulu, the wonderful Zambian activist who battles both TB and AIDS, very little has changed. TB is still not getting the emergency response that it should. It's not that HIV/AIDS is getting too much attention; it's that TB is getting far too little.

The experience of the five countries chronicled in this first-rate analysis is cause for alarm. The need for early identification and treatment of TB is desperately urgent. We must never forget that in many countries, the majority of people who die of AIDS succumb, specifically, to tuberculosis. TB and HIV act on each other with fatal force—a combination made in hell, which must be expunged from the catalogue of communicable disease.

—Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa

# A Call to Action on TB/HIV

HIV/AIDS is fueling a resurgence of TB in many areas of the world. Global incidence of TB has increased over the past 10 years,<sup>1</sup> killing approximately 2 million people annually.<sup>2</sup> At the same time, TB 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 HIV/AIDS, the lack of political commitment to TB control is striking.

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 and TB/HIV. This publication—which focuses specifically on TB/HIV policy and the effects of the HIV/AIDS epidemic on TB control efforts—is a preview of a series

## Estimated TB and TB/HIV Burden for Adults (aged 15-45 years)

	<i>TB Incidence (all forms) Number 1000s in 2004</i>	<i>TB Incidence (all forms) per 100,000 population in 2004</i>	<i>HIV Prevalence % in 2005</i>	<i>HIV Prevalence in Incident TB Cases % in 2004</i>
Bangladesh	319	229	<0.1	0.1
Brazil	110	60	0.5	17
Nigeria	374	290	3.9	27
Tanzania	131	347	6.5	36
Thailand	91	142	1.4	8.5

Sources: Data on TB incidence (all forms) and HIV prevalence in incident TB cases is from “Table 6: Estimated TB burden, 2004,” in WHO, *Global Tuberculosis Control Surveillance, Planning, Financing*, WHO, Geneva 2006, p. 28. HIV prevalence is from UNAIDS, *Report on the Global AIDS Epidemic*, UNAIDS, Geneva 2006.

of reports on TB policy in those five countries and was prepared for release at the 2006 16th International AIDS Conference.

While Bangladesh, Brazil, Nigeria, Tanzania, and Thailand face varying rates of TB/HIV coinfection, Public Health Watch research points to the need for decisive governmental action to coordinate TB and HIV/AIDS policies and programs both in countries with high coinfection rates such as Tanzania and in countries at high risk for a burgeoning coepidemic such as Bangladesh.

In addition to establishing linkages between TB and HIV programs, a comprehensive TB/HIV strategy must address the fact that HIV/AIDS makes TB harder to detect in coinfecting patients, who are more likely to have smear-negative and extrapulmonary cases of TB. Many laboratories lack the equipment to perform cultures, making proper diagnosis of TB among people living with HIV/AIDS extremely difficult. In Tanzania, for example, only 47 percent of TB cases are detected,<sup>3</sup> largely due to a lack of public awareness and a sharp increase in smear-negative and extrapulmonary cases.<sup>4</sup> Patients with infectious TB who go undiagnosed are likely to spread TB to more people, particularly in areas of high HIV prevalence. And for people living with HIV/AIDS, even a short delay in accessing TB treatment can be fatal.

The WHO's *Interim Policy on Collaborative TB/HIV Activities*<sup>5</sup> outlines a set of concrete recommendations for joint TB/HIV activities and calls upon countries to establish and implement mechanisms to decrease the burden of TB among people with HIV/AIDS and the burden of HIV among TB patients. The *Interim Policy* recognizes community-led monitoring and advocacy as an important way to promote and increase public demand for accelerated and improved TB/HIV programs and services.

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 and TB/HIV policy at the domestic or international level.

Community mobilization and participation have proven essential in advocating for research, development of new tools, and increased resources

for the fight against HIV/AIDS. But the people and communities most affected by TB often lack resources and opportunities to engage in policy processes. Others may wish to distance themselves from the disease—and the stigma attached to it—once they have been cured. Ezio T. Santos Filho, a long-time HIV/AIDS activist in Brazil, asserts that waiting for the kind of “bottom-up” engagement and activism that was undertaken by the well-educated and politically connected constituencies first affected by AIDS in countries such as Brazil and the United States may not be realistic when so many of those affected by TB and TB/HIV are from the poorest and most marginalized communities in their countries.<sup>6</sup> Greater social mobilization around TB and TB/HIV will be necessary to eradicate TB, but this will not occur without a concerted and sustained effort on the part of donors, policymakers, and community activists.

The 2006 16th International AIDS Conference in Toronto has been preceded by two other international HIV/AIDS conferences this year that adopted important TB/HIV benchmarks. At the Abuja +5 Summit in May 2006, African heads of state adopted new targets to extend universal access to prevention, care, support and treatment for HIV-related services by 2010, including ensuring access to voluntary counseling and testing and antiretroviral treatment services for all TB patients who are living with HIV/AIDS.<sup>7</sup> And in June 2006, the UN General Assembly Special Session on HIV/AIDS explicitly recognized the “need for accelerated scale-up of collaborative activities on tuberculosis and HIV in line with the *Global Plan to Stop TB 2006-2015* and investment in new drugs, diagnostics and vaccines appropriate for people with TB-HIV co-infection.”

At the 15th International AIDS Conference two years ago in Bangkok, Thailand, Nelson Mandela noted, “We cannot win the battle against AIDS if we do not also fight TB . . . . TB is too often a death sentence for people with AIDS.” This year’s International AIDS Conference is a critical opportunity to reaffirm the urgent need for greater engagement by HIV/AIDS organizations on TB and TB/HIV issues.

—Public Health Watch





# BANGLADESH

## Background

*We should take HIV seriously. There are concentrated epidemics in Bangladesh that give cause for serious concern.*

*—Member of Parliament and the Standing Committee on Health, TB and Malaria<sup>8</sup>*

An estimated 70,000 individuals die from TB each year in Bangladesh:<sup>9</sup> one death every 10 minutes. TB hits the poor and the economically most productive age group hardest. By contrast, HIV prevalence in the adult population is low: an estimated 13,000 people are HIV-positive<sup>10</sup> in a population of almost 142 million.<sup>11</sup> But HIV prevalence among high-risk groups is rising. Among injection drug users in central Bangladesh, for example, HIV prevalence was reported to be 4 percent in 2004 compared to 1.4 percent in 2000.<sup>12</sup> Behavioral surveillance has revealed low condom use, alarming rates of sexually transmitted infections, and low levels of risk perception.<sup>13</sup> Additional risk factors include a large clientele for sex workers, low levels of knowledge about HIV/AIDS, the commonplace practice of needle sharing among drug users, and high levels of illegal migration from neighboring India and Burma, countries with significantly higher HIV prevalence rates.

Although the proportion of HIV-positive patients among adult TB patients is currently low (0.1 percent),<sup>14</sup> the high incidence of latent TB infection in the country and rising HIV prevalence among high-risk groups present a ripe situation for a sharp increase in TB/HIV coinfection rates in the general population.

## Vulnerable populations

Poor people are relatively less likely to seek TB diagnosis and to complete treatment due to a variety of concerns, including lack of information about TB, the added expenses associated with lost work and travel, stigma, and passivity in the face of disease. TB treatment and associated costs are relatively higher for poor people. Although diagnosis and treatment at most of the over 600 National Tuberculosis Programme (NTP) and NTP-affiliated DOTS centers is free, private practitioners charge for consultations, diagnostic tests and drugs, and up to 70 percent of poor TB patients have consulted traditional healers, homeopathic providers, or allopathic doctors before seeking out DOTS services.<sup>15</sup> There are also significant costs related to lost productivity. As 90 percent of TB patients are in the economically most productive age group (15 to 54 years), the economic and social burden to their families is massive. In fact, the economic

impact associated with TB and TB coping strategies is credited with pushing 30 percent of non-poor patients below the poverty line.<sup>16</sup>

Nongovernmental organizations (NGOs) working in partnership with the NTP have greatly expanded access to home-based care in many areas of the country, minimizing direct and indirect costs for these patients. However, additional efforts are required to target slums and poor urban areas more effectively, including through expanded partnerships with NGOs and reinvigorated advocacy, communication, and social mobilization activities.<sup>17</sup>

In addition to the poor, women are especially vulnerable to TB. Both men and women experience and fear social stigmatization around TB infection, but women also face social disapproval for displaying physical symptoms such as coughing in public; more intense feelings of shame and loss of esteem; and greater prospect of rejection by their husbands (or by prospective husbands if they are unmarried). With more limited financial resources, women encounter added difficulties in covering the “hidden costs” of TB treatment, such as transportation. As a result, women are more likely to attempt to hide or deny TB infection, trying home and traditional remedies first, and seeking professional services only as a last resort.<sup>18</sup>

## Political commitment to TB control

*Without the involvement of community volunteers, DOTS would not be possible. . . . We've seen that it is not possible for patients to come to the health facility every day to swallow the drugs. We have to work through partners, who find the volunteers for providing DOT.*

—Vikarunnessa Begum, program manager, NTP<sup>19</sup>

The NTP has articulated a clear TB control policy and guidelines for implementation. Yet government spending on health in general and TB in particular has declined in recent years. To compensate, the NTP has forged successful partnerships with NGOs and international donors to expand its capacity to offer TB treatment services. Bolstered by an infusion of resources from the Global Fund to Fight AIDS, Tuberculosis and Malaria starting in 2004,<sup>20</sup> NGOs are now offering TB services in two-thirds of the country, demonstrating a model of community-based DOTS that delivers high-quality TB services effectively and cheaply. Effective partnerships with NGOs have been a key element of the NTP's successes in achieving 100 percent DOTS coverage and 85 percent treatment success.

According to Faruque Ahmed, director of health programs for BRAC (Bangladesh Rural Advancement Committee), NGOs have greater flexibility, which enables them to respond more effectively to the requirements and demands of international donors; to receive and respond to input from consultants offering technical assistance; and to move more quickly in

solving problems that arise in connection with DOTS expansion, such as the need for additional program personnel. At the government level, adjustment of programmatic priorities takes more time due to bureaucratic requirements.

While the success achieved to date owes much to collaborative work with NGOs, the NTP's heavy reliance on NGO partnerships and external donor support raises some concerns about sustainability. The NTP has struggled to win sufficient funding to implement its strategic plan,<sup>21</sup> and on occasion has been compelled to postpone planned DOTS expansion activities to cover basic expenses such as TB drugs. The NTP should spearhead efforts to expand the capacity of the public health infrastructure to support DOTS expansion, including through infrastructural improvements such as additional microscopy and x-ray facilities and human resource development.

## **Government policy to control TB/HIV**

NTP officials acknowledge that the potential for an escalating HIV/AIDS epidemic presents an important challenge for TB control.<sup>22</sup> Despite this recognized concern, strong links between the National AIDS/STD Programme (NASP) and the NTP have not yet been established, and the budget for implementing such links has been minimal.<sup>23</sup> There is no system in place to encourage NGOs working in the field of HIV testing, counseling, and care to refer TB suspects to TB treatment centers or to ensure HIV treatment regimens are coordinated with TB treatment.

There is a clear need for dissemination of information to raise awareness about the threat of TB/HIV coinfection and to ensure that the NTP and NASP take effective and coordinated preventive action. It is crucial that the government as well as its NGO partners engage in outreach to HIV/AIDS workers to ensure rapid referral of symptomatic patients to TB testing centers.

# BRAZIL

## Background

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

—Margareth Dalcolmo, National Reference Center Prof. Helio Fraga and TB Commission of the Brazilian Thoracic Society<sup>24</sup>

Despite a universal health care system and high-quality HIV/AIDS services, Brazil ranks 16th on the WHO's list of high-burden TB countries. Approximately 50 million Brazilians were infected with TB as of 2004<sup>25</sup> and TB prevalence stands at 77 per 100,000 inhabitants.<sup>26</sup>

TB/HIV coinfection is an increasingly serious problem, particularly in 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.<sup>27</sup> Approximately 17 percent of adults with TB are estimated to be HIV positive<sup>28</sup> and an estimated 20 percent of people living with HIV/AIDS have pulmonary TB.<sup>29</sup> Moreover, there are strong indications that many TB patients die without ever being formally diagnosed;<sup>30</sup> for example, the Rio de Janeiro state TB program estimates that “20 percent of patients are not diagnosed at an early stage...[and] many cases are only diagnosed in the hospital or after death.”<sup>31</sup>

## Political commitment to TB control

Brazil's position as a high-burden TB country is primarily the result of a general absence of governmental accountability on TB policy. This situation can in turn be attributed largely to the lack of critical engagement in the development, implementation and evaluation of TB policy by the people and communities most directly affected by the disease.

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.<sup>32</sup> However, some Brazilian experts maintain that these statistics do not give an accurate picture of the situation on the ground and that meaningful expansion of access to TB services, including directly observed therapy, cannot be sustained without additional resources to improve the situation for TB workers and to ensure adequate social support for TB patients.

The decentralized political system coupled with the absence of a strong federal TB policy to date have led to considerable variability in the effectiveness of state and municipal level TB programs. Even where state and municipal officials are personally invested in TB con-

trol efforts, they may face political and financial constraints. While TB officials in the state and densely populated municipality of São Paulo have succeeded in securing considerable political support for their efforts, the situation in many other states is less favorable. For example, although the governor of the state of Rio de Janeiro identified TB and leprosy as key concerns during her election campaign, she transferred hundreds of millions of dollars from the Rio state health budget to its *Cheque-cidadão* program (a social welfare program) once she was in office,<sup>33</sup> leading to serious delays in implementation of the state TB control program.

Brazilian TB personnel are undervalued, underpaid, and face significant and unaddressed safety concerns. By contrast, health workers employed by the National STD/AIDS Program (NSAP) at all levels generally earn much higher salaries and enjoy greater prestige than workers in other health programs, including the National TB Control Program (NTCP). Structural changes to federal human resources policy will be necessary to allow for greater recognition and compensation for the work of civil servants in the health care sector, including TB workers, to improve TB control outcomes.

Recent developments offer favorable evidence for renewed political commitment to TB control. In February 2004, the Ministry of Health adopted a new policy for the NTCP, setting clear guidelines and targets, which represented a radical shift in the level of governmental commitment to TB control. The document reaffirms the government's commitment to DOTS, the need for enhanced collaboration with the NSAP, and the importance of community engagement. It also calls for regular meetings between national level policymakers and state and municipal TB managers to encourage more coordinated implementation of TB control efforts.

## Public mobilization

Public awareness of the threat posed by TB and TB/HIV is extremely low, even among those most at risk of infection, such as people living with HIV/AIDS. For example, a series of social mobilization workshops among HIV/AIDS activists in 2003 revealed a lack of awareness regarding even basic issues such as how TB is spread and the fact that the disease is curable.<sup>34</sup> Awareness is even lower among the poor and marginalized populations hardest hit by TB. 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 (Brasília 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.<sup>35</sup>

Low awareness and stigmatization are directly connected to the absence of broader public engagement around TB. In recognition of these obstacles and to stimulate demand for better TB services, government officials in the states of Rio de Janeiro and São Paulo independently decided to encourage social mobilization by supporting the establishment of NGOs and the engagement of existing HIV/AIDS NGOs around TB; these NGOs included the São Paulo

State Forum of AIDS NGOs, through which 180 community-based organizations have been fighting HIV/AIDS since 1996. Groups in both states have initiated efforts to engage and educate the broader public about TB and the relationship between HIV and TB. However, public mobilization efforts in the rest of the country have been minimal.

Perhaps due in part to its considerable institutional independence and generous budget, the NSAP has not considered collaboration with other programs such as the NTCP to be a priority. This does not mean that HIV/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 program's goals and on ensuring that they continue to have sufficient resources to carry out their activities. However, it must be acknowledged that a number of organizations dedicated to the fight against HIV/AIDS, such as the São Paulo State Forum of AIDS NGOs, have provided invaluable support to emerging TB community mobilization initiatives in Rio de Janeiro and in São Paulo. Engaging these and other organizations with significant experience on HIV/AIDS activism will be key to the development of community mobilization strategies to fight TB.

## National policy to control TB/HIV

*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. Santos Filho, Public Health Watch researcher and activist <sup>36</sup>

Prior to 2004, there was little communication or cooperation between the NTCP and the NSAP. However, the Ministry of Health's 2004 policy stipulates specific collaborative activities and affirms the NTCP's interest in learning from the NSAP's successful social mobilization efforts.

Integrated TB/HIV services are already available in some areas. For example, in the Federal District of Brasilia, HIV tests are routinely offered to any patient with respiratory symptoms, and lung examinations are carried out for all 1,500 registered HIV/AIDS patients at least once a year.<sup>37</sup> The Federal University of Espírito Santo is overseeing the introduction of rapid HIV testing for TB patients at TB clinics throughout the country.<sup>38</sup>

The NTCP's 2005 revised treatment guidelines include recommendations to improve access to voluntary counseling and testing (VCT) services for TB patients. And although the NTCP had rejected community proposals to increase collaboration with the NSAP on social mobilization as recently as June 2003,<sup>39</sup> there are now joint plans to launch integrated TB/HIV social mobilization activities on a national scale.

# NIGERIA

## Background

Nigeria ranks fourth on the WHO's list of high-burden TB countries and has the highest number of new TB cases in Africa.<sup>40</sup> An estimated 300,000 TB cases are recorded every year, resulting in more than 30,000 deaths annually.<sup>41</sup> HIV is fueling the TB epidemic, leading to a 6 percent annual increase in TB prevalence,<sup>42</sup> and a four-fold increase in HIV rates among people living with TB between 1991 and 2001.<sup>43</sup> The estimated proportion of smear-negative cases among all detected TB cases rose from approximately one-third in 1997 to nearly two-thirds in 2001, which is consistent with the rapid escalation of HIV prevalence among TB patients during that period.<sup>44</sup>

## Public awareness and stigma

*Stigma is frustrating access to TB treatment especially for people living with HIV/AIDS . . . 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, executive director, Nigerian Community of Women Living with HIV (NCW+)<sup>45</sup>

Although many HIV/AIDS support groups—especially those based in urban centers—generally provide information and promote discussion on the symptoms of TB along with information on other opportunistic infections,<sup>46</sup> the general public and even members of these support groups often lack basic knowledge about TB such as the location of treatment centers and the linkage between HIV/AIDS and TB.

Lack of accurate information fuels TB-related stigma. Many people continue to harbor misconceptions about TB, including the idea that people with the disease have been “poisoned.”<sup>47</sup> Former TB patients sometimes hold negative attitudes towards TB and TB patients, as they are afraid of reinfection.<sup>48</sup> The Chief Environmental Health Officer at a TB clinic in Oyo State noted that health care workers sometimes contribute to TB-related stigma, and that some personnel prefer not to be posted to TB clinics for fear of infection. To address this issue,

his clinic holds periodic “enlightenment” seminars and workshops for medical personnel on TB and TB treatment procedures.<sup>49</sup> “I have been working in the TB field for the past 10 years, and I am still hale and hearty,” he added.<sup>50</sup> Anti-stigma training and education can help ensure that health workers—both providers of TB services and administrative staff—receive accurate information about TB and develop greater sensitivity to the needs of TB patients.<sup>51</sup>

## Political commitment to TB control

The federal government formally launched the National TB and Leprosy Control Programme (NTBLCP) in 1991 and adopted the WHO-recommended DOTS strategy in 1993. President Olusegun Obasanjo has demonstrated his political commitment to TB control through his active participation in high-level meetings of the Stop-TB Partnership, the African Heads of State, African Union and World Economic Forum.

Yet public rhetoric has not been translated into funding allocations, either in the federal budget<sup>52</sup> or at the state level.<sup>53</sup> According to the NTBLCP, increased DOTS coverage has resulted in a near doubling in the case detection rate over the 2002-2003 period.<sup>54</sup> (The WHO attributes the rise in case notifications for the period between 1994 and 2004 to increased TB incidence associated with the spread of HIV.)<sup>55</sup> Nevertheless, the percentage of TB cases detected—21 percent of all TB cases<sup>56</sup>—is still far below the WHO target of 70 percent.<sup>57</sup> And while the TB treatment success rate hovered between 71 and 74 percent from 1996 to 2002—slightly below the global target of 85 percent—the current annual treatment success rate is only 59 percent<sup>58</sup> (most likely because of HIV/AIDS-related mortality prior to cure).

Much of the population remains underserved by TB diagnostic and treatment services. Even within a state, clients have been reported to travel a distance of about 40 kilometers every day to receive treatment,<sup>59</sup> which may be a contributing factor to relatively high rates of default on treatment. Patient-centered and community-based approaches—modeled after support programs for people living with HIV/AIDS—represent a promising model for achieving better DOTS coverage in a country as vast as Nigeria, though implementation will have to be adapted to different regional contexts. In addition, expanded partnerships with NGOs and volunteer programs could bring TB services closer to patients’ homes and help address the shortage of trained TB workers.



## Collaboration with private sector

*TB is stigmatized for its association to HIV, hence patients will tend to seek private treatment to protect privacy and avoid stigma. Management of TB patients in private practice is not of acceptable quality. Diagnosis is often based on chest x-rays rather than sputum smear. Several different anti-TB regimens are prescribed depending on the experience of the private provider and on the patient's purchasing power.*

—*Report of Third Joint International TB DOTS/ HIV/AIDS  
Monitoring Mission to Nigeria*<sup>60</sup>

Private practitioners are estimated to provide up to 60 percent of health services in Nigeria.<sup>61</sup> There are several reasons for this: private providers are believed to offer higher quality care, more courteous service and shorter waiting times; greater accessibility (especially since public facilities are known to experience frequent strikes by health workers protesting non-payment of salaries and poor working conditions); and, as noted above, fear of stigmatization in public clinics. Yet few for-profit providers are collaborating with the NTBLCP on DOTS implementation. Because private providers do not operate under the auspices of the NTBLCP, quality assurance of the TB services they provide is an issue of concern, particularly for people living with HIV/AIDS, who may require a different ARV treatment regimen if taking anti-TB drugs.

## National policy to control TB/HIV

The National Policy on HIV/AIDS explicitly emphasizes the need to provide a comprehensive continuum of care for people living with HIV/AIDS, including nationwide access to cost-effective drugs to treat “tuberculosis and all other opportunistic infections,” and ongoing training on the management of opportunistic infections for all health care providers.<sup>62</sup> Linkages based on this policy between the NTBLCP and the National AIDS and STDs Control Programme (NASCAP) exist at the federal level and in some states. A series of training workshops on TB/HIV collaboration involving over 60 health care workers were conducted in four states (FCT, Bauchi, Anambra and Lagos) in July 2005, for example.<sup>63</sup> However, coordination between the NTBLCP and NASCAP needs to be expanded and strengthened; there are no line items in the federal and state budgets for TB/HIV integrated activities.

Some state and local TB control offices have begun to implement activities specified in the National TB/HIV Strategic Plan for 2006-2008.<sup>64</sup> For example, the NTBLCP and NASCAP have identified focal points to coordinate inter-agency activities.<sup>65</sup> TB/HIV pilot activities are underway in six states,<sup>66</sup> whose TB and HIV program managers meet regularly to discuss progress on their collaborative TB/HIV strategies.<sup>67</sup> Some state AIDS control programs are setting

up VCT services within DOTS centers,<sup>68</sup> and Asokoro Hospital in Abuja (which also houses a DOTS center) has begun to refer its TB clients for VCT services within the same facility.

But there are still a number of barriers to establishing effective TB/HIV services. First, even though early and appropriate diagnosis of TB among people living with HIV/AIDS is critical, many TB clinics are not equipped to diagnose TB in coinfecting patients.<sup>69</sup> A staff member from the National Reference Laboratory pointed out that:

*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].*

—Rosemary Adu, clinician, Nigerian Institute of Medical Research<sup>70</sup>

Presently, the Zankli Medical Center, a private medical facility in Abuja, is the only clinic in Nigeria equipped to perform cultures for TB patients.<sup>71</sup> Secondly, health care workers are often “territorial” and reluctant to collaborate with people working in other fields. Clinicians may also lack information about the reliability of existing tools such as smear tests in diagnosing coinfecting patients.<sup>72</sup>

Providing the equipment needed for early diagnosis of TB among people living with HIV/AIDS should be a top priority. Unlike TB tests, which are free, HIV tests sometimes have a fee attached. The Federal Ministry of Health should minimize or eliminate these fees. Both the NTBLCP and NASCAP should expand the reach of their training programs and provide ongoing training on TB/HIV for health care workers, emphasizing the importance of collaboration in achieving early TB diagnosis among people living with HIV/AIDS.<sup>73</sup> State governments also need to commit added resources and personnel to encourage more effective linkages between TB and HIV programs.<sup>74</sup>

# TANZANIA

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

—Acting District TB and Leprosy Coordinator, Kilombero<sup>75</sup>

## Background

Between 1977 and 1984, the National Tuberculosis and Leprosy Programme (NTLP) cut the number of TB cases by two-thirds, earning a reputation as one of the best performing disease-control programs in the world. However, HIV/AIDS has contributed to a marked resurgence of TB in recent years and placed a severe strain on the national health system.

Between 1983 and 2003, the number of TB cases increased by almost six-fold, from approximately 12,000 cases to 64,500.<sup>76</sup> According to the NTLP, “60 percent of the increase in the incidence of TB in Tanzania can be attributed to HIV.”<sup>77</sup> At the same time, TB is now the leading infectious cause of death among HIV-positive people, with more than 50 percent of all TB patients estimated to be HIV-positive.<sup>78</sup> In Tanzania, HIV/AIDS and TB may fairly be referred to as “twin diseases.”

## Vulnerable populations

People living in poor communities and women are especially vulnerable to TB and HIV/AIDS. The 2002 *National Health Policy* recognizes that low-income communities are among the hardest hit by both diseases.<sup>79</sup> Many people who are poor cannot afford the time away from their jobs and families or related costs such as transportation to the TB clinic, and for these reasons they forego or interrupt TB treatment. Although the government has provided first-line drugs for TB treatment free of charge since 1977, consultation and initial TB diagnostic tests are not always free. One patient explained the difficulties associated with standard clinic-based TB services this way: “First of all, the treatment takes too long . . . Also, you need to come to the hospital to take medication for two months every day. You may be living far from the hospital, but also you need to do some other activities to get some money for the family and also for transport to the hospital.”<sup>80</sup> While the NTLP is trying to expand access to TB treatment to low-income areas through community-based DOTS and patient-centered programs, its progress in scaling-up such services has been slow and lack of funding calls their sustainability into question.

Recent research by the Tanzania Commission for AIDS (TACAIDS) suggests that women are disproportionately affected by HIV/AIDS.<sup>81</sup> And in the case of TB, women appear to be less likely than men to access available treatment services. One study conducted by the NTLF and a local NGO found that for women, the decision to visit a health care facility depended largely on whether they had cash available or not. Without cash, a woman had to wait for the assistance of her husband or another family member. Even when money was available, women tended to weigh the financial implications of expending resources on their own medical treatment against other family demands such as food and school fees for their children.<sup>82</sup>

## Lack of public awareness about TB and TB/HIV

*I know that many of my fellow Tanzanians are now afraid just to know that they have TB because they automatically assume that they also have HIV/AIDS. I want the press to tell people that, while there is a link between HIV/AIDS and TB, people should not be afraid to come forward. It is not true that every TB patient is HIV positive.*

—Anna Abdallah, Minister of Health<sup>83</sup>

Despite clear indications of a coepidemic, basic knowledge about TB and the interaction of TB and HIV is lacking among the general population as well as political officials and policymakers. In the absence of sufficient information about TB symptoms and the availability of free diagnostic and treatment services, people may be more likely to be swayed by superstition. The belief that TB patients have been bewitched is not uncommon,<sup>84</sup> and TB patients are often automatically considered to be HIV-positive as well.<sup>85</sup> This combination of low awareness and stigmatization may be a factor in discouraging people from accessing TB services: one recent study revealed that the median period between onset of TB symptoms and the first visit to a health facility was approximately eight months.<sup>86</sup> For many people living with HIV, failure to act promptly to receive treatment for TB is fatal.

TB awareness is low even among health policymakers, and some officials consider it politically risky to mention the disease due to its growing association with HIV/AIDS, which is still a sensitive issue.

## Political commitment to TB control

In part due to the absence of strong TB awareness and public demand for better services, political commitment to TB control has been inadequate. Most TB patients, activists, and some

medical personnel believe that the massive influx of international funding for ARVs, HIV/AIDS personnel, and other infrastructure for HIV/AIDS programs—while needed—has displaced attention and funding for non-ARV drugs and salaries for medical personnel working on other issues such as TB,<sup>87</sup> even as the HIV/AIDS epidemic has led to a resurgence in TB rates.

Recent health sector reforms have involved decentralization of priority-setting responsibilities to district-level health management teams. In some cases, this has led to deprioritization of TB services, especially where district level administrations lack the necessary information, training, resources and other forms of support to be sufficiently aware of and responsive to the increasing demand for TB services. In fact, many health facilities have phased out their TB departments to devote more attention to HIV/AIDS. Joint communications efforts by the NTLP and the National AIDS Control Program (NACP) should provide district level officials with clear and accessible information on TB diagnosis, treatment, and interaction with HIV to persuade them of the importance of devoting increased attention and resources to TB as an integral part of their HIV/AIDS control efforts.

### **Public-private collaboration**

For the most part, the NTLP is the sole provider of DOTS services. By contrast, the government has forged extensive and relatively well-defined partnerships with private providers—including NGOs—in HIV/AIDS control efforts. Private providers must receive government approval to implement directly observed treatment (DOT) for TB, but many provide other TB services without approval or supervision. Interviews with private healthcare providers revealed that most are not well versed on the DOTS strategy or the NTLP's public-private partnership guidelines.<sup>88</sup> Traditional healers provide alternative medicine to many people with TB symptoms and for-profit clinics offer TB medication, but most do not administer DOT.

### **National policy for TB/HIV control**

The development of collaborative TB and HIV policies and services has occurred primarily on an ad hoc basis and through “pilot projects.” Joint policy planning and implementation by the NTLP and the NACP has been limited.

For example, the NTLP has been operating pilot TB/HIV programs in Temeke, Iringa and Korogwe since 2003. In these three districts, the Ministry of Health has urged health officials to provide all TB patients with clinic-based, routine diagnostic counseling and testing for HIV and to encourage people with HIV to be tested for TB as early as possible. With funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria, the NTLP plans to expand this pilot project to 34 additional districts.<sup>89</sup> The NTLP has also provided support to a small number of private health care initiatives to encourage the integration of TB services into their existing

community health programs. The NTLP and NACP should apply lessons from these and other pilot TB/HIV projects to the development of collaborative TB/HIV policies and services that are informed by practical experience and that can be expanded country-wide.

According to its Strategic Plan for 2005-2009, the NTLP aims to develop a TB/HIV policy to guide greater collaboration with the NACP and TACAIDS and the introduction of TB/HIV programming. Reportedly, a draft of the policy includes several components: expanding access to voluntary counseling and testing (VCT) to reduce the burden of HIV in TB patients; introducing routine screening for TB and providing education on risk reduction strategies to reduce the burden of TB among people living with HIV/AIDS; and establishing TB/HIV coordinating committees at the district, regional, and national levels. However, the policy is still under development and has not yet been publicly released.

## Collaboration with NGOs and community organizations

*There is quite a lot of room for social mobilization around TB—for activists to get involved. The problem is that TB is so closed to the experts.*

*— Jamillah Mwanjisi, Public Health Watch researcher and director of Media Bank<sup>90</sup>*

A large number of NGOs and community organizations have initiated projects to respond to various aspects of the AIDS epidemic. However, few organizations have integrated TB into their HIV/AIDS control efforts, and even fewer focus on either service delivery or advocacy related to TB.<sup>91</sup>

The NTLP should take an active role in promoting greater civil society engagement in TB control activities, especially by organizations of people living with HIV/AIDS and former TB patients, by delineating clear opportunities for consultation, participation, and input into TB policymaking processes. Moreover, the NTLP should support capacity-building for civil society organizations to take full advantage of these opportunities by providing training on the DOTS strategy and key aspects of NTLP policy. Through partnership with NGOs and community organizations, the NTLP will be able to extend its own capacity to conduct much-needed information, treatment literacy, and public awareness-raising campaigns as well as to increase TB case detection and treatment success rates by ensuring community support and encouragement to those suffering from TB symptoms or undergoing TB treatment.

# THAILAND

## Background

In the context of rapid socioeconomic development and increased investment in health, the National Tuberculosis Control Programme (NTP) succeeded in reducing TB incidence by 50 percent, from 150 cases per 100,000 people in 1985 to 76 per 100,000 in 1991.<sup>92</sup> However, TB incidence rose again in the 1990s with the emergence of the HIV/AIDS epidemic.<sup>93</sup> The estimated prevalence of HIV in Thailand is among the highest in Southeast Asia, with an infection rate of 1.5 percent among adults aged 15-49.<sup>94</sup> About one-third of people living with HIV also have TB.<sup>95</sup> The deadly interaction of TB and HIV has raised new challenges to TB control efforts.

## Lack of awareness and stigmatization

There is a lack of easily accessible, accurate information about TB and TB/HIV, and public awareness of the basic facts about TB is low. TB is widely viewed as a curable but rare disease, while HIV/AIDS is seen as a fatal disease deserving more attention.<sup>96</sup> Where communities lack a clear understanding of how TB is spread and treated, stigmatization of persons who have TB and TB/HIV is common, presenting a significant barrier to treatment.

Upon being diagnosed with TB, both women and men report experiencing stigma. However, there are some indications that women are affected more severely. For example, one recent assessment in Kanchaburi found that TB is perceived as a “male” disease associated with behaviors such as working in an unsanitary environment, drinking, smoking, and overindulging in nightlife activities. Women infected with TB are therefore seen as being at odds with social norms and expectations of “female” behavior, intensifying the level of stigmatization they experience.<sup>97</sup>

Some community activists have warned that lack of information about the interaction between TB and HIV/AIDS is particularly severe, noting that it is a challenge to raise awareness about the interaction of the two diseases without increasing stigma.<sup>98</sup> This makes it extremely important for the NTP and the National AIDS Control Programme (NACP) to work together on the design and dissemination of materials that provide accurate and accessible information about TB as well as the interaction between TB and HIV. To ensure that such materials are also sensitive to local context and the potential of stigmatization, they should be developed in close partnership with civil society organizations that can offer perspectives from the most affected and high-risk communities.

## Political commitment to TB control

*We need someone to show the flag. . . . If we have political commitment at the highest levels, then district level officials and provincial level examiners will be more cooperative; but if TB isn't on the 'priority list' of health inspectors, district and provincial officials will not make a commitment to TB work.*

—Petchawan Pungrassami, MD, Office of Disease Prevention and Control Region 12<sup>99</sup>

The NTP adopted DOTS as its core policy in 1996. By 2002, the NTP reported that 100 percent of the population had access to DOTS services. According to the most recent government figures, the NTP detects 71 percent of the estimated total number of TB cases, surpassing the 70 percent global case detection target. Of these, 73 percent are treated successfully, still short of the 85 percent global treatment target.<sup>100</sup>

Some observers assert that there is still insufficient political recognition of the persistence and severity of TB as a public health threat. Political commitment to TB control is particularly weak at the regional, provincial, and district levels, where officials often place higher priority on other health issues such as HIV/AIDS, dengue fever, avian flu and diarrhoea.

## Community participation in TB control

*People living with HIV/AIDS become actively involved: 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.<sup>101</sup>*

—Rev. Sanan Wutti, The Church of Christ in Thailand, Chiang Mai<sup>102</sup>

Participation by NGOs in TB policy development and implementation has been minimal, particularly when contrasted with the level of NGO mobilization around HIV/AIDS. This contributes to a sense that TB control is best left to the specialists, limits the level of “political buy-in” from other government ministries, and reduces the likelihood that public pressure will play a role in prompting more effective government action.

A network of almost 900 groups of people living with HIV/AIDS provides an array of services ranging from prevention campaigns to community support for HIV/AIDS patients.<sup>103</sup>



In recognition of their key role in both advocacy and service delivery, the Ministry of Public Health (MoPH) provides approximately \$2 million (75.6 million baht) annually for the activities and services provided by these NGOs.<sup>104</sup>

By contrast, NGO involvement around TB has been minimal, and has tended to focus on service delivery. Some NGOs also consider the low level of general awareness about TB to be one of the principal barriers to greater community involvement. TB is considered a highly “academic” subject, and community activists often feel they lack the necessary expertise to engage with health workers and policymakers. Some community activists claim that they have experienced resistance from public health experts when they have tried to learn more about TB and to become involved in TB policymaking processes. This suggests a need for stepped-up NTP and international support for TB treatment literacy activities. Ensuring that accurate, nonacademic, Thai-language information about TB is readily available at the community level is the first step to increasing demand for high-quality TB services.

HIV/AIDS NGOs could play a leadership role in sparking greater community activism around TB, as they have demonstrated the effectiveness of treatment literacy activities in enhancing the accessibility of scientific knowledge; increasing the demand for services; and positioning community activists as key participants in the design, implementation, and evaluation of HIV/AIDS policies and services. Enhanced NGO partnerships could also be a particularly critical tool for the NTP to improve its access to marginalized groups such as migrant workers, ethnic minorities, and former prisoners.<sup>105</sup>

## **Collaboration with private sector**

Workplace programs on HIV/AIDS could provide an important model for public-private collaboration for TB control activities. The Thailand Business Coalition on AIDS established the Business and AIDS Network in 1999 to provide a forum for business managers to exchange successes and challenges in effectively managing HIV/AIDS workplace programs, but has not focused on TB. The network, which now has over 150 members, meets on a quarterly basis in two provinces to evaluate and provide accreditation for such programs, with the aim of creating workplaces that are sensitive to the needs of people living with HIV/AIDS. Since the difficulty of obtaining time off from work presents a significant barrier to accessing TB treatment, particularly for laborers and migrant workers, increasing workplace flexibility for TB patients could improve treatment adherence and outcomes.

## Government policy to control TB/HIV

The MoPH established a national TB/HIV coordinating body in 2001, which has been implementing TB/HIV collaborative services since 2004. Critics contend that the strategy is still incomplete; that health workers have not been trained or provided with resources to implement it; that “integrating” TB and HIV has often meant that the NTP is subsumed within the more powerful and better resourced NACP; and that there is an urgent and unfulfilled need for better coordination between TB and HIV/AIDS services at the field level.

The 2004 strategy stipulates that HIV/AIDS programs should include TB counseling and screening services; TB treatment should be provided to all HIV patients with active TB; and efforts should be made to identify latent TB cases, particularly among people living with HIV/AIDS, and to provide prophylactic treatment.<sup>106</sup> The content of the strategy, with its emphasis on provision of TB services to people living with HIV/AIDS, may be a reflection of effective advocacy efforts by HIV/AIDS NGOs.

A number of challenges have become immediately apparent in the implementation of the national TB/HIV policy. Health workers are not well informed about the policy, nor are they trained in how to put the policy into operation. Particularly in the northern region, health officials contend that the lack of integrated services and the difficulties in diagnosing TB among people living with HIV/AIDS have led to a drop in TB treatment success rates and rising mortality rates among people living with HIV/AIDS.<sup>107</sup> The interaction between TB drugs and ARVs is not well understood among health practitioners, and the NACP is not always well-equipped to cope with the needs of people living with HIV/AIDS who become ill with TB.<sup>108</sup>

Some TB experts have asserted that the integration of TB and HIV/AIDS programs happened too quickly, resulting in the dominance of the NACP over the NTP and the downgrading of TB services. For example, the director of one zonal TB center has insisted that both programs must be independently effective for integration to be mutually beneficial. In his view, an effective TB policy requires the employment of specialized TB staff, and a “second health reform” is needed to reinstate an independent TB division and to pave the way for more effective integration of TB and HIV services at the field level.<sup>109</sup>

## Notes

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101. Comment by Rev. Sanan Wutti, The Church of Christ in Thailand, Public Health Watch roundtable meeting, Chiang Mai, December 9, 2005.
102. Comment by Rev. Sanan Wutti, The Church of Christ in Thailand, PHW roundtable meeting, Chiang Mai, December 9, 2005.

103. For example, the Thai NGO Coalition on AIDS (TNCA) and the Thai Network of People with HIV (TNP+) each represent over 300 organizations, and both are represented on the National Committee.
104. Bureau of Policy and Strategy, Ministry of Public Health (MoPH), *Health Policy in Thailand*, 2003, p. 7.
105. Comment by Voravit Suwanvanichkij, MD, Public Health Watch roundtable meeting, Chiang Mai, December 9, 2005.
106. An earlier pilot program in the northern provinces enjoyed considerable political commitment from high-level policymakers. This integrated strategy, which included early TB screening and care for people living with HIV/AIDS, provided a visible example of how the NTP and National AIDS Program could work closely together at all levels. See MoPH, “National recommendations Guideline: the Integrated HIV-TB Care Strategies for the Control and Prevention of Tuberculosis in Thailand,” 2001.
107. Comment by Sumalee Amarinsangpen, Office of Prevention and Disease Control Region 10, Public Health Watch roundtable meeting, Chiang Mai, December 9, 2005.
108. Comment by Karyn Kaplan, Thai AIDS Treatment Action Group (TTAG), Public Health Watch roundtable meeting, Bangkok, December 6, 2005.
109. Interview with Attapon Cheepsattayakorn, MD, director, 10th Zonal TB and Chest Disease Center, Chiang Mai, December 8, 2005.

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## Public Health Watch

Public Health Watch supports independent monitoring of governmental compliance with the Amsterdam Declaration to Stop TB as part of its mandate to promote informed civil society engagement in policymaking on TB 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 government efforts to comply with the United Nations Declaration of Commitment on HIV/AIDS and the World Health Organization’s (WHO’s) *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 to Stop TB 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.

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 learn more about Public Health Watch, including the HIV/AIDS Monitoring Project and the TB/HIV Monitoring and Advocacy Project, please see: [www.publichealthwatch.info](http://www.publichealthwatch.info).

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## Public Health Program

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

## Open Society Institute

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

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

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

“We cannot win the battle against AIDS if we do not also fight TB. . . . We have known how to cure TB for more than 50 years. . . . What we have lacked is the will and the resources to quickly diagnose people with TB and get them the treatment they need.”

—Nelson Mandela, at the 15th International AIDS conference in Bangkok, July 2004

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Public Health Watch, an initiative of the Open Society Institute’s Public Health Program, 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 Tuberculosis and the Declaration of Commitment on HIV/AIDS—and on the extent to which those policies have been implemented. TB monitoring reports include assessment of policies in Bangladesh, Brazil, Nigeria, Tanzania and Thailand.



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