Involving the Community in Responding to TB/HIV: Outcomes of Community-Led Monitoring and Advocacy

Public Health Watch, a project of the Public Health Program of the Open Society Institute, aims to strengthen meaningful and sustained engagement by infected and affected communities in the development, implementation, and monitoring of TB and HIV policies, programs, and practices. Public Health Watch supports advocates to identify, document, and articulate priority human rights issues, and to press for accountability at the national, regional, and global levels. Public Health Watch believes engaged, well-informed individuals and community groups are needed to ensure that government policies really live up to the commitments made at the international level; to scrutinize whether and how policies and guidance are implemented; and to point out where the numbers may not reflect the full reality on the ground.

Monitoring National Responses to TB/HIV: Key Findings

Civil society engagement in the design, implementation, and evaluation of TB/HIV policies at the national and international levels has been minimal. Yet, community-based groups are uniquely positioned to offer critical input on challenges faced by patients co-infected with TB and HIV in accessing care. Since 2004, Public Health Watch has supported 53 individuals and organizations in 38 countries to conduct monitoring and advocacy of policies on TB and HIV. Community groups have used international guidelines and commitments, such as the World Health Organization's (WHO's) Interim Policy on Collaborative TB/HIV Activities, the Amsterdam Declaration to Stop TB, and the United Nations Declaration of Commitment on HIV/AIDS, as monitoring standards to ensure governmental accountability. OSI's approach stresses multiple opportunities for dialogue and exchange with a broad range of policy actors, including representatives of affected communities, public health institutions, and government officials.

The following are the main findings of the OSI-supported, community-led monitoring projects:

1) **TB and HIV services often run as parallel programs; coordination and referral mechanisms between programs are limited or nonexistent.** Even policies that call for coordination between TB and HIV programs often do not translate into practice at the local level.
   - In **Ukraine**, there is limited coordination and referrals between HIV, TB, and drug treatment programs: "The majority of people living with HIV/AIDS are drug users, and about half of them have TB, so it's important that these programs cooperate better. People shouldn't have to visit up to three clinics to get proper treatment."[1]
   - Despite recognizing the growing challenge that HIV could present for TB control in **Bangladesh**, strong links between the National AIDS and Sexually Transmitted Disease Program and the

National TB Program have not been established and the budget for implementing such links has been minimal. There is no system in place to encourage nongovernmental organizations working in the field of HIV testing, counseling and care to refer people with TB symptoms to treatment centers, or to ensure HIV and TB treatments are coordinated.[2]

2) **Health care providers, media, policymakers, and affected communities lack sufficient knowledge of how TB and HIV interact**, including how to prevent TB among people living with HIV and how to effectively treat the two diseases in a coordinated manner.

- In **Thailand**, health workers are not well informed about or trained on how to put the national TB/HIV strategy into action. According to one TB doctor, TB clinical workers have not been trained on how to conduct HIV counseling and testing, while HIV clinical workers have little experience with TB.[3] In addition, health care providers often lack the training or resources to diagnose TB/HIV co-infection, and are unfamiliar with the interactions between TB drugs and antiretroviral drugs for HIV.

- In **Nigeria**, public awareness of TB is generally low, even among people living with HIV. Although many support groups for people living with HIV—especially in urban centers—alert members to warning signs of TB infection,[4] the general public and even members of these support groups often lack basic knowledge about TB, such as the location of treatment centers.

- In **Lithuania**, the TB and HIV programs do not contain specific recommendations for informing patients and the public about TB/HIV co-infection. A member of the Lithuanian Positive Group stated, "I never got any information about TB in the AIDS Center, which I visit regularly. I take interest in the problem at my own initiative as we have had members of our group with this problem who have unfortunately died already."[5]

- In **Zambia**, only officials from the Ministry of Health appear to have access to and are aware of important health plans and practices, such as the WHO's TB and HIV treatment guidelines. Health care providers responsible for implementation

remain unaware of such vital information and those in need of services do not have the information to demand the services and treatment they deserve.[6]

3) **Community-based organizations and advocates are often not included in the development of TB/HIV co-infection policies.**

- **Kenya**'s TB/HIV Joint Coordinating Committees, which include a central coordinating committee at the provincial level and additional committees at the local level, lack mechanisms for involvement by people living with TB or HIV at both the provincial and district levels.[7]

- In **El Salvador**, there is a Joint Coordinating Group responsible for defining and implementing collaborative activities between TB and HIV programs, but this body lacks community representation. Community health workers are not aware of the group's structure and function, or that a strategic plan for TB/HIV collaborative activities has been developed.[8]

4) **Stigma is a significant barrier to appropriate diagnosis and treatment for TB/HIV co-infection.**

- In **Vietnam**, people living with HIV are kept in separate rooms when admitted to TB hospitals. TB patients who are co-infected with HIV appear more likely to receive substandard TB treatment. For example, National TB Program guidelines stipulate that TB patients who are HIV-positive should not receive injections; therefore, co-infected patients who cannot tolerate oral medication are not treated effectively for TB.[9]

- In **India**, people living with HIV report facing stigma and discrimination when seeking TB treatment and are sometimes even restricted from entering DOTS centers.[10]

- In **Cameroon**, TB and HIV-related stigma and discrimination sometimes drive people to opt against efficient treatment services offered by local facilities and to instead travel far from their families and communities for treatment.[11]

- In **Tanzania**, lack of information on TB and TB/HIV co-infection compounds stigma for infected individuals. "As soon as it is suspected that someone might have TB, everybody thinks that he or she also has HIV."[12]

5) **Lack of government regulation of TB drug procurement and oversight of service providers leads to drug resistance in patients, and incomplete data on the epidemic.**

- In **Georgia**, patients who seek care from private providers are not reflected in national policies or reporting procedures for TB and HIV. Including data from Georgia's seven private laboratories could contribute to more accurate epidemiological data that reflects the true extent of the epidemic. This data could prove key in advocating for new policies and resources. In addition, TB drugs are available over the counter, which can lead to self-medication and cause patients to develop a drug-resistant form of TB.[13]

- Although private providers in **Tanzania** must receive government approval to implement directly observed therapy for TB, many provide other TB services without approval or supervision. Interviews with private health care providers revealed that most are not well-versed on the DOTS strategy or the national TB program's public-private partnership guidelines.[14]

6) **There are often hidden costs of TB treatment that create an additional burden for people living with HIV.** Although TB treatment is free in many countries, many patients have to pay for diagnostic tests and transportation, which is particularly burdensome for people who must regularly travel to separate facilities for HIV treatment.

- In **Vietnam**, TB facilities have some of the least resources in the health sector. In order to increase revenues, facilities offering free treatment for TB charge for TB diagnostic tests (which is equivalent to about two months' income for some patients) and non-TB services, including testing and treatment for HIV and hepatitis. Facilities also sometimes increase costs by insisting on in-patient services. Since people living with HIV are more likely to test smear negative for TB, they require additional TB diagnostic tests, thus increasing their costs.[15]

- In **Zambia**, HIV testing is widely available, but TB testing has not been made available at the same rate. As a result, people living with HIV in rural areas are referred to the nearest provincial hospital for TB testing where tests cost between US$2.50 and US$5.00. Since 64 percent of the population lives on less than US$1.00 per day, a TB diagnostic test for people in rural areas costs several days of income. By obtaining services at a provincial center, patients incur travel and testing costs, which can deter them from accessing services.[16]

Outcomes of Monitoring and Advocacy

Though the importance of community involvement in addressing and highlighting the above issues is increasingly acknowledged, there are still far too few mechanisms and opportunities for meaningful participation. However, researching and documenting TB/HIV policies, including the translation of such policies into practices on the ground, have enabled community activists to become more credible advocates at the national and international levels.

Community groups and advocates have already demonstrated a positive impact in shaping civil society engagement in TB/HIV policies.

The following are examples of the impact of advocacy efforts by OSI-supported community groups:

1) **Greater community representation in TB, HIV, and TB/HIV policymaking, through participation in national and international bodies,** including:

International Bodies
- Stop TB Partnership Working Groups: DOTS Expansion; New Diagnostics; New Drugs; Advocacy, Communication & Social Mobilization; and Multidrug–Resistant TB;
- Stop TB Partnership's Coordinating Board, which monitors the implementation of agreed policies, plans and activities of the Partnership, and ensures coordination among Stop TB Partnership components;
- Community Task Force—a global network of TB/HIV advocates representing TB and TB/HIV community concerns within the framework of the WHO's Stop TB Partnership;
- UNITAID Board;
- Global Fund to Fight AIDS, TB and Malaria's support delegation;
- WHO's Strategic and Technical Advisory Group on TB (STAG); and
- National delegations to the 2006 United Nations high-level review on HIV/AIDS.

National Bodies
- UN Development Program's Working Group on HIV/AIDS Prevention in Georgia;

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- National TB/HIV Working Committee in Nigeria; and
- Country Coordinating Mechanism for the Global Fund in Brazil.

2) **Positive change at the local, national, and international policy level.**
   - As the result of a civil society meeting, a TB/HIV target was included in the political declaration adopted by the UN General Assembly following the "Abuja +5" convening of African Heads of State in May 2006. The civil society meeting was organized by a Public Health Watch researcher from Journalist Against AIDS in Nigeria.
   - Community representatives have been included among featured speakers at national and international events, such as the World Lung Conference, the UNAIDS Programme Coordinating Board (PCB), and the Brazilian National Conference on TB Control.
   - Researchers shared their TB/HIV monitoring findings with the United States Agency for International Development's TB and HIV departments and the WHO Stop TB Department.
   - The WHO is developing guidelines for national TB programs on how to effectively involve communities in TB programs as a result of advocacy efforts.

3) **Higher profile of TB/HIV in the media.**
   - The release of in-depth TB and HIV monitoring reports resulted in dozens of national and international newspaper and magazine articles, as well as radio and television interviews.
   - The researchers from Nigeria and Tanzania co-authored an opinion piece on the urgent need to address TB/HIV co-infection in Africa that was published in United Kingdom's *The Guardian* and Namibia's *The Namibian*.

4) **Greater interest in TB/HIV by AIDS activists and international bodies.**
   - Support for community-led monitoring of TB and TB/HIV policies and their implementation helped to stimulate demand from community-based organizations to become actively engaged in TB issues. Most of these organizations had previously focused primarily on HIV.
   - OSI's TB/HIV grant-making competition informed the launch in March 2007 of the Stop TB Partnership's Challenge Facility for Civil Society, which "provides financial support to small groups of civil society organizations such as NGOs, self-help groups and women's groups seeking to make the collective voice of the TB community heard. It is targeted at civil society groups operating at the grass roots level and seeking to shape policy-making at local and national levels by giving a voice to people living with TB and those involved in their care."[17] In 2007, the Challenge Facility distributed a total of approximately US$384,000 to 22 organizations.

For more information, go to www.soros.org/health

NOTES

1. Comment by participant in ICPS/Public Health Watch roundtable meeting, Kyiv, February 24, 2006.
2. *Civil Society Perspectives on TB Policy in Bangladesh*, Open Society Institute, 2006, p. 56. This was echoed by the Country-Level TB/HIV Monitoring Final Grant Report, HIV/AIDS & STD Alliance Bangladesh (HASAB), 2006.
3. Comment from Attapon Cheepsattayakorn, director, 10th Zonal TB and Chest Disease Center, December 8, 2005.
4. Interviews with Pat Matemilola, national coordinator, NEPHWAN, Abuja, Feb. 7, 2005.
5. Country-Level TB/HIV Monitoring Final Grant Report, Coalition "I Can Live", 2006.
6. Final Grant Report, Treatment Action Literacy Campaign (TALC), 2006.
7. Final Grant Report, Multiface Development Research Centre (MDRC), 2006.
8. Final Grant Report, National Association of Positive Persons Vida Nueva, 2006
9. Oanh Khuat, "Access to TB Services among PLWH in Vietnam," speech presented at World Lung Conference, Cape Town, South Africa, November 2007.
10. Final Grant Report, Indian Network for People Living with HIV (INP+), 2006.
11. Final Grant Report, Cercle des Jeunes engages dans la lutte contre le SIDA, 2006.
12. Interview with F. Lwilla, Dar es Salaam, June 2005.
13. Final Grant Report, Welfare Foundation, 2006.
14. Interviews with private health care providers, *Walio Katika Mapambano na AIDS* Tanzania (Wamata) Clinic, Dar es Salaam, February 2005.
15. Oanh Khuat, "Access to TB Services among PLWH," speech presented at World Lung Conference, Cape Town, South Africa, November 2007.
16. Final Grant Report, Treatment Action Literacy Campaign (TALC), 2006.
17. http://stoptb.org/bi/cfcs/about.asp.