TB/HIV Monitoring & Advocacy: Experiences & Leadership by AIDS Activists

Compiled by Public Health Watch (PHW) and Treatment Action Group (TAG)

Introduction

The Open Society Institute's Public Health Watch (PHW)[1] and Treatment Action Group (TAG)[2] began working together through a common desire to enhance the capacity of community-based AIDS organizations to address the growing burden of TB/HIV coinfection in their communities. PHW brought experience in monitoring and advocacy and a mission of promoting the participation of civil society in the development of government policies that impact the lives of affected communities. TAG brought close partnerships with AIDS organizations and experience in providing advocacy skills training, treatment, policy and research literacy to community-based groups.

In 2004, PHW and TAG jointly launched what was to evolve into the **TB/HIV Monitoring & Advocacy Small Grants Project** to encourage implementation of the World Health Organization's *Interim Policy on Collaborative TB/HIV Activities*. PHW provided grants to support advocacy to increase collaborative activities, while TAG provided advocacy workshops on TB/HIV science and policy to the grantee organizations. The *TB/HIV Project's* goal was to build leadership amongst organizations of persons living with HIV so that they could effectively play a role in monitoring and advocating for the creation of national level policy and support the implementation of programs related to TB/HIV collaborative services. The decision to initiate the *TB/HIV Project* came directly from the *Interim Policy on Collaborative TB/HIV Activities*' explicit recognition of community-led monitoring and advocacy as important means to promote and increase public demand for accelerated and improved TB/HIV services. The *TB/HIV Project* has provided funding and technical assistance for community-based organizations to conduct monitoring of and advocacy on the need for more effective and coordinated TB/HIV programs and services. In the last four years, the *TB/HIV Project* has awarded 44 grants to 41 organizations in 30 countries.

The *TB/HIV Project* has galvanized great interest from AIDS activists in TB/HIV advocacy. In some cases, grantees played a key role in fostering coordination between historically parallel TB and HIV programs. Through their monitoring and advocacy, grantees have articulated practical concerns about the lack of TB/HIV coordination, including: the need for health care worker training in the area of TB/HIV coinfection; lack of referral mechanisms for patients accessing TB and HIV care; stigma and hidden costs as significant barriers to appropriate diagnosis and treatment; and lack of regulation of TB drugs. This new cadre of TB/HIV activists have brought these practical concerns to meetings with TB/HIV policy makers. Their knowledge of the needs and concerns of people living with HIV and/or TB has led to greater community representation in local and national decision-making bodies such as the TB/HIV Joint Coordinating Board (JCB), the national AIDS program body, or the Country Coordinating Mechanism (CCM) for the Global Fund for AIDS, TB and Malaria (GFATM). Several grantees have become global advocates as demonstrated by their participation as community representatives on core working groups of the Stop TB Partnership, a global body that brings together more than 400 policy makers, program personnel, researchers, and funders to devise strategies of how best to address TB and TB/HIV. Others serve on the UNITAID board, the non-governmental organization (NGO) delegations for the GFATM and the World Health Organization's (WHO) Strategic and Technical Advisory Group for TB.

Why is TB a Concern for PLWHA?

TB is the leading cause of death among people living with HIV in Africa and though curable, is the cause of nearly 15 percent of deaths among persons with HIV worldwide. HIV and TB are so closely connected that the term "coepidemic" or "dual epidemic" is often used to describe their relationship. In the past 15 years, the number of new TB cases has tripled in many countries with high HIV prevalence. HIV and TB form a lethal combination, each speeding the other's progress. People living with HIV have a 5–10 percent risk of developing TB *every year* compared to HIV-negative persons who have up to 10 percent risk over their lifetime. Only 310,000 (less than one percent) of the 33.2 million people with HIV were tested for TB in 2006, and about .08 percent of those who were eligible were offered isoniazid preventative therapy (IPT). In parts of sub-Saharan Africa, 50 percent or more of TB patients are infected with HIV. TB is also more difficult to diagnose and more complicated to treat among people who are HIV positive, leading to delays in TB treatment and increased risk for rapid disease progression. These factors combined represent a serious threat to gains made in scaling up access to HIV treatment in the developing world.

Global Impact

Since 2006, TB/HIV activists have been increasingly involved in global policy making for TB/HIV. Their contributions, such as advocacy for greater collaboration between global policy bodies such as UNAIDS and WHO, as well as for the acknowledgement of the importance of community engagement in TB programs has led to TB/HIV coinfection policies and declarations from both the TB and HIV communities. For instance, following the development of the Interim Policy on Collaborative TB/HIV Activities in 2004, community activists successfully advocated for the WHO to expand its TB control strategy in 2006. The new WHO TB strategy not only acknowledges the need for TB programs to address TB/HIV and MDR-TB, but also recognizes that the empowerment of people living with TB and their communities is core to addressing TB.

In 2006 as well, following a call from community activists, UNAIDS and WHO collaborated to create a TB focal point person position in UNAIDS to bring attention to the issue of TB/HIV. That same year, community advocacy during the United Nations High-Level Meeting on AIDS led to a Political Declaration on HIV/AIDS, where global leaders emphasized "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 for investment in new drugs, diagnostics and vaccines that are appropriate for people with TB-HIV coinfection." In June 2008, when the UN held the next High-Level Meeting on AIDS to take stock of progress on HIV, the specifics of the 2006 commitment were further clarified. As part of the 2008 High-Level Meeting, a Global Leaders Forum on TB/HIV was held to raise awareness of TB/HIV among national leaders present. Furthermore, a TB/HIV Declaration of Commitment signed by more than 200 international TB/HIV activists and organizations was circulated, asking global leaders to sign onto targets that would aim to reduce TB/HIV mortality by more than 80 percent by 2015, and commit $19 billion to ensure universal access to TB/HIV collaborative activities ($15 billion for scale up of TB/HIV services, and $4 billion for much needed research). Many activists have been involved in ensuring that at the highest level of global leadership, within the WHO and UNAIDS, there is a coordinated effort to ensure that people with HIV do not continue to die of TB.

These declarations and policy frameworks highlight TB/HIV issues and reflect new political support to address TB/HIV coinfection. As such, these documents are an explicit commitment by country leaders to address TB/HIV and provide an advocacy platform for activists to ensure that their governments are living up to these commitments. They create a mechanism to coordinate efforts, mobilize resources, and share successes and challenges. However, global commitments will only have the needed impact if they are translated into country specific targets with guaranteed funding, and are implemented and monitored. Civil society has used the global monitoring of TB/HIV declarations and implementation of policies as a means to encourage or shame governments to live up to their commitments.

What Needs to Happen? Future Directions

In 2006, almost 250,000 people with HIV were estimated to have died because of TB, a curable disease. Despite the fact that TB is a leading cause of death among persons with HIV, and that there are clear policies on what needs to happen to reduce the burden of TB among people with HIV, there are very few national AIDS programs that are shouldering their responsibility in addressing the challenge of TB/HIV coinfection. In countries where the burden of TB/HIV is high, increased HIV testing of persons with TB will strengthen the success of national AIDS programs by identifying previously undiagnosed HIV cases. Providing HIV care and treatment to persons coinfected with TB/HIV can reduce TB incidence and mortality significantly. Therefore advocacy for universal access to collaborative TB/HIV services should be a cornerstone of HIV advocacy in order to reduce the burden of TB on people living with HIV.

Infection control measures in both health care and community settings are critical to prevent TB transmission to people living with HIV. People with HIV have a right to access HIV treatment without fear of contracting TB. In addition, TB treatment for people living with HIV should be provided in a way that respects human rights and ensures the most success; namely, avoiding detention of TB patients (unless they refuse to adhere to treatment), and developing and using community-based models of care whenever possible. Infection control measures are especially important in the context of multi- and extensively drug-resistant TB (XDR-TB)[4], given high mortality rates and rapid disease progression in people with HIV. In January 2007, the WHO released Guidance on Human Rights and Involuntary Detention for XDR-TB Control, which states that detention must be viewed as a last resort, and justified only after all voluntary measures to isolate a patient have failed. Detention should be of limited duration and subject to review and appeal. NGO advocacy is sorely needed to avoid unnecessary detentions and to ensure effective infection control to protect both patients and health care providers.

Though many more deaths can be averted by full implementation of current tools and the TB/HIV collaborative activities, it is also clear that the current tools at our disposal are inadequate to address the challenges of TB/HIV and drug resistant TB. New tools that can quickly diagnose and more effectively treat and prevent TB are desperately needed. The dearth of resources for TB research (about $430 million in 2006) must be addressed to get these new tools. TAG estimates that TB research funding needs to be increased to $2 billion annually for a comprehensive TB research agenda to be developed and realized. As AIDS activists revolutionized medical research by being at the forefront of discussions related to HIV research, resources, and access-related concerns, so too is there a need for people with HIV and TB to demonstrate similar leadership in the context of TB/HIV. Only with increased advocacy for full implementation of TB/HIV collaborative activities with current tools while pushing for research for the development of new TB tools will we ensure that people with HIV do not continue to needlessly die of TB.

4. TB that is resistant to isoniazid and rifampin as well as at least one fluoroquinolone and one of the second line injectables

TB/HIV Success Stories

Lithuania In Lithuania, the implementation of this project made the I Can Live Coalition a leading non-governmental body in the country dealing with TB/HIV coinfection issues and a partner of state institutions in forming policy in this field. People with HIV were involved in almost all project activities and in the process they were able to deepen their knowledge of TB/HIV coinfection and improve their skills in advocacy and policy making processes. Although there is no TB/HIV Joint Coordinating Body in Lithuania, an NGO representative has been included on the HIV/AIDS Council as a result of civil society advocacy.
–Erika Matuizaite

Mexico The Mexican TB Project, currently coordinated by Vivir. Participación, Incidencia y Transparencia, A.C., was originally housed at Fundacion Mexicana para la Lucha contra el SIDA, which received a TB/HIV monitoring and advocacy grant in 2004. Since then, they have received support from the United States Agency for International Development (USAID), the United States Mexican Border Health Association (USMBHA) and the Stop TB Partnership of the WHO to continue their work on TB/HIV and expand to address issues of drug resistance. The Mexican TB Project continues to use monitoring of policies as a tool to inform their advocacy through interviews with TB and HIV public health officials and representatives of civil society organizations. To date, 485 people living with HIV have been trained as peer educators/advocates on TB/HIV and MDR-TB.
–Francisco Rosas

El Salvador Vida Nueva in El Salvador succeeded in incorporating an objective on TB/HIV coinfection aimed at promoting collaborative activities in the TB proposal for the 8th Round of GFATM grants. As of July 2008, they have a person representing TB/HIV coinfection issues on the CCM of the GFATM. In addition to their involvement with the GFATM, they have mobilized 18 groups of people living with HIV based at national hospitals to include TB/HIV coinfection on their agendas.
–Jaime Ernesto Argueta

Zambia Treatment Advocacy and Literacy Campaign (TALC) of Zambia reports tremendous success integrating TB into existing HIV infrastructure: "More than thirty TB/HIV support groups have been formed at most rural and urban health centers that have ART facilities. Service providers also discuss TB and HIV openly with clients because clients are now enlightened and are able to ask questions. Nurses who work at the ART and TB centers are now demanding from the Ministry of Health and TALC for more training." In terms of policy making, TALC reports, "The JCB leadership have recognized that there is a need to have the voice of those living [with] the diseases [to] get involved meaningfully. The JCB has a patient organization on board and talks are on-going to increase the number of [affected community] representatives."
- Carol Nyirenda

Ukraine Salvation of Ukraine advocated for a decree on the realization of TB/HIV collaborative activities for medical establishments in Kremenchuk city, which was signed by the Head of the Municipal Healthcare Department on April 21, 2008. The decree's directives include: TB case detection among people living with HIV, HIV case detection among TB patients, medical supervision and treatment for TB/HIV coinfected patients, and the implementation of a coordinating mechanism on TB/HIV collaborative activities. In order to get this decree signed and to garner support for its implementation, Salvation formed a working group consisting of several physicians in Kremenchuk who were experts on TB/HIV, TB and HIV and several civil society representatives. Building these partnerships "step-by-step to establish good working relationships" was key to their success.
–Yuliya Chorna

Georgia In their monitoring work, Georgia's Welfare Foundation found antituberculosis antibiotics were readily available over the counter, indicating that existing drug regulatory mechanisms were not effective. Their advocacy activities on this topic precipitated a meeting between key policy makers including the National TB Program Manager to discuss the availability of antituberculosis antibiotics without a prescription and the contribution of this practice to drug resistance. Following the meeting, the Welfare Foundation was asked to develop an analytical policy paper describing promising practices of other countries which have faced similar problems and how they have overcome them.
–Tamari Trapaidze

Indonesia The Spiritia Foundation in Indonesia has incorporated TB/HIV into their Treatment Educator Training since its first course in 2004. In this session, they draw particular attention to the issue of infection control in peer group meetings and counselling rooms. Since the Spiritia Foundation started work on TB/HIV in 1997, the TB community has expanded from solely medical providers to include non-governmental organizations and a newly formed national peer group for TB patients, in part due to Spiritia's awareness raising, community mobilization and advocacy in this area. Besides being receptive to input from communities of people affected, the TB program is also working closely with the National AIDS Commission and a new National TB Committee is now being formed under the Coordinating Ministry for People's Welfare.
–Chris Green

Kenya Multiface Development and Research Center (MDRC) of Kenya stated, "As far as the participation of community of people living with HIV and/or TB is concerned, the TB/HIV monitoring and advocacy project created a sustained awakening and responsibility at the community, provincial and national level." MDRC provided leadership in Nyanza province to mobilize communities to participate in the elections of community representatives to the Kenya CCM for the GFATM. MDRC advocates for improved TB screening for people with HIV, wider availability of IPT, and the integration of TB case reporting into the National Health Information Management System. In addition, they are in the process of forming the Kenya Health and HIV/AIDS Budget Tracking Core Project Team.
–Nelson Yuma Otwoma

India Through their monitoring and advocacy work, MISBAH in India discovered that although a policy on referring TB patients for HIV testing existed, it was not consistently implemented by two of the main East Delhi hospitals. As a result of their advocacy, the newly appointed TB/HIV coordinator for the Delhi State TB Control Board developed training on TB/HIV for hospital staff administering directly observed therapy for TB (DOT). Training began in March 2008 in Delhi and continues on a monthly basis. When the project began, women were not being referred to STI services, including HIV counselling and testing, from the hospitals in East Delhi. As of April 2008, referral is routinely practiced as a result of MISBAH's education and advocacy efforts. Currently, MISBAH is using their work in East Delhi as a model to advocate for the expansion of referral practices in health care facilities in other parts of India.
–Simon Lobo

If TB is not adequately treated, drug resistance can develop. Multidrug-resistant TB (MDR-TB)[3] is a particular risk for people with HIV because of their increased vulnerability to TB disease. The lack of access to drug-susceptibility testing or second line TB drugs complicates diagnosis and treatment of MDR-TB, which is three to four times longer and costs a hundred times more than treating drug-susceptible TB. There were an estimated 0.5 million cases of MDR-TB in 2006, and preliminary surveys in Latvia and Ukraine have found nearly twice the level of MDR-TB among TB patients with HIV compared with patients without HIV. In cases where diagnosis is delayed or drug susceptibility status is unknown, people with HIV and drug-resistant TB may be treated with a suboptimal TB drug regimen, creating increased risk of death.

In order to address the TB/HIV coepidemic, new tools including rapid and accurate diagnostic tests, shorter and more potent drug regimens that are compatible with ARVs and a vaccine that is safe and effective in people with HIV are needed. Today's most commonly used TB diagnostic, sputum microscopy, is more than 125 years old. It detects only half of the cases of TB in patients tested, and is particularly ineffective for diagnosing TB in people with HIV whose immune system is severely compromised. As a consequence, many co-infected patients die without ever receiving a diagnosis. Today's TB drugs are more than 40 years old and must be taken for six to nine months to treat drug-susceptible TB and at least 18 months for drug-resistant TB. Rifampin, a cornerstone of current TB treatment, cannot be used concurrently with some of the commonly used ARVs. New tools need to be complemented by increased political commitment, resources, and community engagement to effectively address TB and integrate TB and HIV services to address the devastating impact of these diseases.

To provide a framework of collaboration between TB and HIV programs, in 2004 the WHO released policy guidelines titled, *Interim Policy on Collaborative TB/HIV*. This policy lists 12 activities that countries need to implement to effectively respond to TB/HIV. These activities include: establishing mechanisms for collaboration, decreasing the burden of TB in people living with HIV and decreasing the burden of HIV in TB patients. Three of these 12 components focus on the detection, prevention, and treatment of TB in people with HIV; implementation of these components has been lagging behind the rest of the policy recommendations. These components, referred to as the 3I's, include intensified case finding (ICF)—TB screening for people with HIV, isoniazid preventative therapy (IPT)—treatment for people latently infected with TB, and infection control (IC)—measures to decrease the risk of TB transmission. The 3I's need to be primarily implemented by HIV programs and active engagement of community advocates is important to encourage more rapid scale-up. Besides the 3Is, the WHO global policy framework also provides guidelines to facilitate the coordination and joint planning, financing, and monitoring of the collaborative TB/HIV activities, as well as steps that are essential to ensure that HIV-positive TB patients are identified and treated appropriately, and to prevent TB in people with HIV, all of which are vital to reducing the burden of TB/HIV.

Lessons from HIV/AIDS teach us that community-based activists are in a unique position to monitor the implementation of TB/HIV policies on the ground, identify gaps, and advocate for policy and programmatic change. To ensure TB/HIV services are meeting the needs and respecting the rights of infected and affected communities, people with HIV need to have input and leadership opportunities in the implementation of collaborative policies. PHW and TAG initiated the *TB/HIV Project* to support HIV activists' interest in TB/HIV coinfection and provide them with funding and training to engage in monitoring and advocacy in this area. The results of three rounds of small grants demonstrate a variety of successes in treatment literacy, improvements in local and national TB/HIV collaborative policy implementation, leadership development of TB/HIV activists, and greater awareness of TB/HIV coinfection amongst health care providers. These stories are part of a growing movement of HIV activists who recognize the problem that TB presents to their communities and advocate for policies and programs that address the problem using patient-centered approaches.

1. **Public Health Watch (PHW)** is a project of the Public Health Program of the Open Society Institute, an operational and grant making foundation. PHW aims to strengthen meaningful and sustained engagement by infected and affected communities in the development, implementation, and monitoring of TB, HIV and TB/HIV policies, programs, and practices. PHW supports advocates to identify, document, and articulate priority human rights issues, and to press for accountability at the national, regional, and global levels. PHW believes engaged, well-informed individuals and community groups are needed to ensure that government policies 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.

2. **Treatment Action Group (TAG)** is an independent AIDS research and policy think tank fighting for better treatment, a vaccine, and a cure for AIDS. TAG works to ensure that all people with HIV receive life saving treatment, care, and information. TAG is composed of science-based treatment activists working to expand and accelerate vital research and effective community engagement with research and policy institutions. TAG catalyzes open collective action by all affected communities, scientists, and policymakers to end AIDS.

3. resistance to at least rifampicin and isoniazid—two first line antituberculosis drugs

All statistics in this document can be found on the TB section of the WHO website: http://www.who.int/tb/en/, or for specific inquires, please contact phwinfo@sorosny.org.