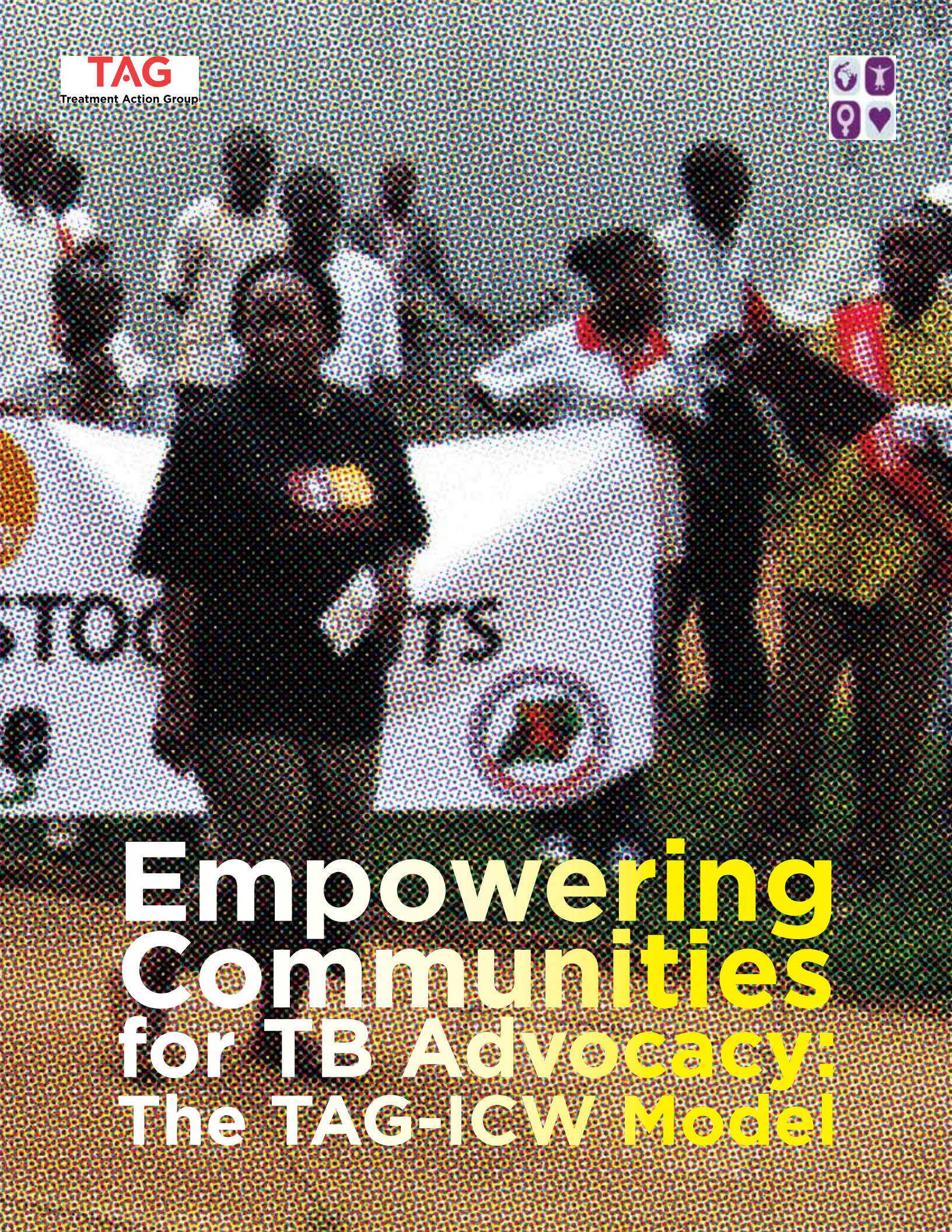


TAG
Treatment Action Group

Empowering Communities for TB Advocacy: The TAG-ICW Model

Acknowledgments

Our thanks go to all the activists whom Treatment Action Group (TAG) and International Community of Women Living with HIV–Eastern Africa (ICW) had the privilege of working with. Their inspired leadership and the information that they provided was essential to the success of the African activist capacity building activities of the TAG-ICW TB/HIV Advocacy Project that are documented here.

About TAG

Treatment Action Group 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 lifesaving treatment, care, and information. We are 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 policy makers to end AIDS.

About ICW

ICW–Eastern Africa is based in Kampala, Uganda. ICW is the only international network run for and by HIV-positive women. It was founded in response to the desperate lack of support, information, and services available to HIV-positive women worldwide and their need for influence and input on policy development.

Contact TAG

Treatment Action Group
611 Broadway, Suite 308
New York, NY 10012
tel: +1 212 253 7922
tax: +1 212 253 7923
tag@treatmentactiongroup.org
www.treatmentactiongroup.org

Contact ICW

International Community of Women
Living with HIV/AIDS (ICW) EASTERN AFRICA
Plot 16, Tagore Crescent
P.O. Box 32252, Kampala, 0414, UGANDA
tel: + 256 414 53 19 13
fax: + 256 414 53 33 41
eastafrica@icw.org
www.icw.org/icw_east_africa

Contents

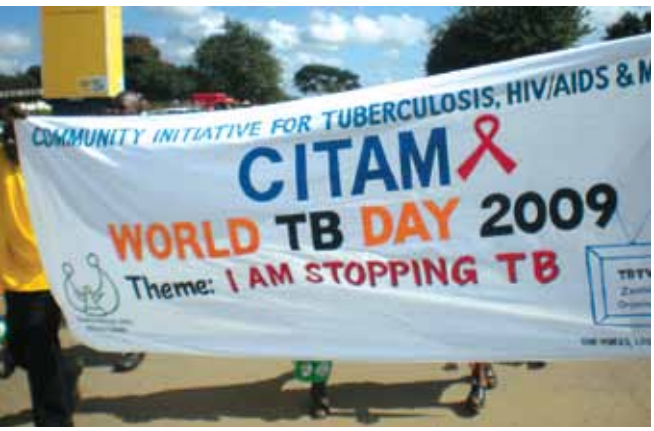
Community members learning about TB/HIV at a workshop organized by Tikodane Women's PLWHA Support Group, Malawi.

I. The Goal of this Publication

This publication by TAG and ICW provides activists, policy makers, and donors with lessons learned from two years of capacity building for HIV treatment activists to integrate tuberculosis (TB) and TB/HIV collaborative activities into their advocacy work. The TAG-ICW capacity building model can be used by program implementers, funders, and policy makers to help implement the component of the World Health Organization's (WHO) 2006 TB control strategy that identifies the need to empower TB patients and their communities. Despite its rich history of community mobilization and activism over the past century, in recent decades, broad-based community advocacy for TB care and control efforts have become increasingly rare. TAG and ICW developed this model from our experience building the capacity of Africa-based HIV activists to take on TB advocacy. We strongly believe that the components of the model can be applicable to strengthen TB advocacy globally.

Besides describing the TAG-ICW activist capacity-building strategies, this document also contains case studies which highlight what activists have accomplished through their TB/HIV advocacy efforts in the brief time since TAG-ICW initiated our TB/HIV advocacy capacity-building efforts in September 2007.

II. The Need for TB/HIV Advocacy



The Community Initiative for Tuberculosis, HIV/AIDS and Malaria (CITAM+) marches to commemorate World TB Day 2009 in Zambia

Tuberculosis is the leading cause of death among people living with HIV in Africa and accounts for nearly 25 percent of deaths among persons with HIV worldwide. The WHO's *Global TB Control 2009* report estimated that at least one-third of the 33 million people living with HIV worldwide are infected with TB, and they are 20–30 times more likely to develop active TB than those without HIV. The global burden of TB disease among people with HIV is concentrated, like the HIV pandemic itself, in sub-Saharan Africa. According to the WHO's *Global TB Control 2009* report, 456,000 people globally died of HIV-associated TB in 2007. When infection is diagnosed and drugs are available, TB is curable. Because people living with HIV are more likely than non-HIV-infected persons to have extrapulmonary or smear-negative pulmonary TB, the disease is often inaccurately diagnosed, and this—along with diagnostic delays caused by poverty, the expense of transport to a facility to diagnose TB, alongside HIV related comorbidty—is a significant cause of the higher TB-related mortality among people with HIV.

TB/HIV is a leading reason why TB control is failing worldwide. In response to the impact of TB/HIV and learning from the contribution that HIV activists have made in mobilizing political will behind HIV care programs, the WHO's Stop TB Department revised its TB control strategy in 2006 to include policies that recommend national TB programs and their partners to address TB/HIV coinfection as well as empower TB patients and their communities to improve TB/HIV collaborative policies and mobilize resources and political will for TB.

Earlier, in 2004, the WHO had issued the *Policy on Collaborative TB/HIV Activities* that outlined three goals to confront the dual epidemic: establishing country mechanisms for collaboration, decreasing the burden of TB in people living with HIV/AIDS and decreasing the burden of HIV in TB patients. As part of the first goal, the policy strongly recommended establishing local TB/HIV advocacy, communication, and social mobilization (ACSM) programs. The TB/HIV interventions, known as the Three I's (*intensified* TB case finding among people with HIV, *isoniazid*

preventive therapy, and TB *infection* control), are a component of the policy framework that aims to reduce the burden of TB among people with HIV. In 2008 the WHO focused its recommendations on National AIDS Programs to implement the Three I's.

WHO has reported that there has been progress in some TB/HIV collaborative services in the last two years. The WHO *TB/HIV Fact Sheet 2009* reports that in 2007, 135 countries reported on the implementation of some TB/HIV activities, up from just seven countries in 2003. Globally in 2007, nearly a million TB patients were tested for HIV and accessed HIV prevention, treatment, and care, up from 22,000 in 2002. However, the number of people with HIV tested and treated for TB is lagging behind the targets set by *The Global Plan to Stop TB 2006–2015*. In 2007, only 27 percent of people living with HIV accessed TB services. Even more discouraging is the fact that less than 1 percent of eligible people diagnosed as both TB- and HIV-positive received isoniazid preventive treatment in 2007. Only 16 of the 63 high-burden TB/HIV countries (HBCs) have any ACSM activities, and only seven reported involving patient-centered organizations or networks in advocacy activities.

The TAG-ICW TB/HIV advocacy project documents how HIV activists' capacity can be built and strengthened to advocate for TB/HIV detection, treatment, and cure, and how this leads to strengthening TB programs to better achieve the targets currently being missed.

III. The TAG-ICW Model for Building the Capacity of HIV Advocates to Take On TB

A. A History of TAG-ICW Collaboration

In 2007, Treatment Action Group (TAG) received a four-year grant from the Bill and Melinda Gates Foundation to foster increased international advocacy on TB/HIV research and treatment. TAG's TB/HIV Project has the following objectives:

1. To coordinate global TB/HIV community advocacy to improve TB policy and scale up collaborative TB/HIV activities, with a particular focus on activist involvement on the global Stop TB Partnership.

2. To empower, train, and support African TB/HIV advocates to participate fully and effectively in supporting scale-up of TB and TB/HIV activities at the national and regional levels.

3. To coordinate advocacy to educate U.S. leaders about the need to triple funding commitments to TB and TB/HIV control and research.

4. To strengthen global TB research advocacy among HIV community networks for increased funding for new tools and operational research, and to integrate affected communities into TB research.

The second objective focuses on building the advocacy capacity of African AIDS activists to take on TB advocacy. Though TB is the leading cause of death among people living with HIV, TB is not a major advocacy priority for many HIV advocates

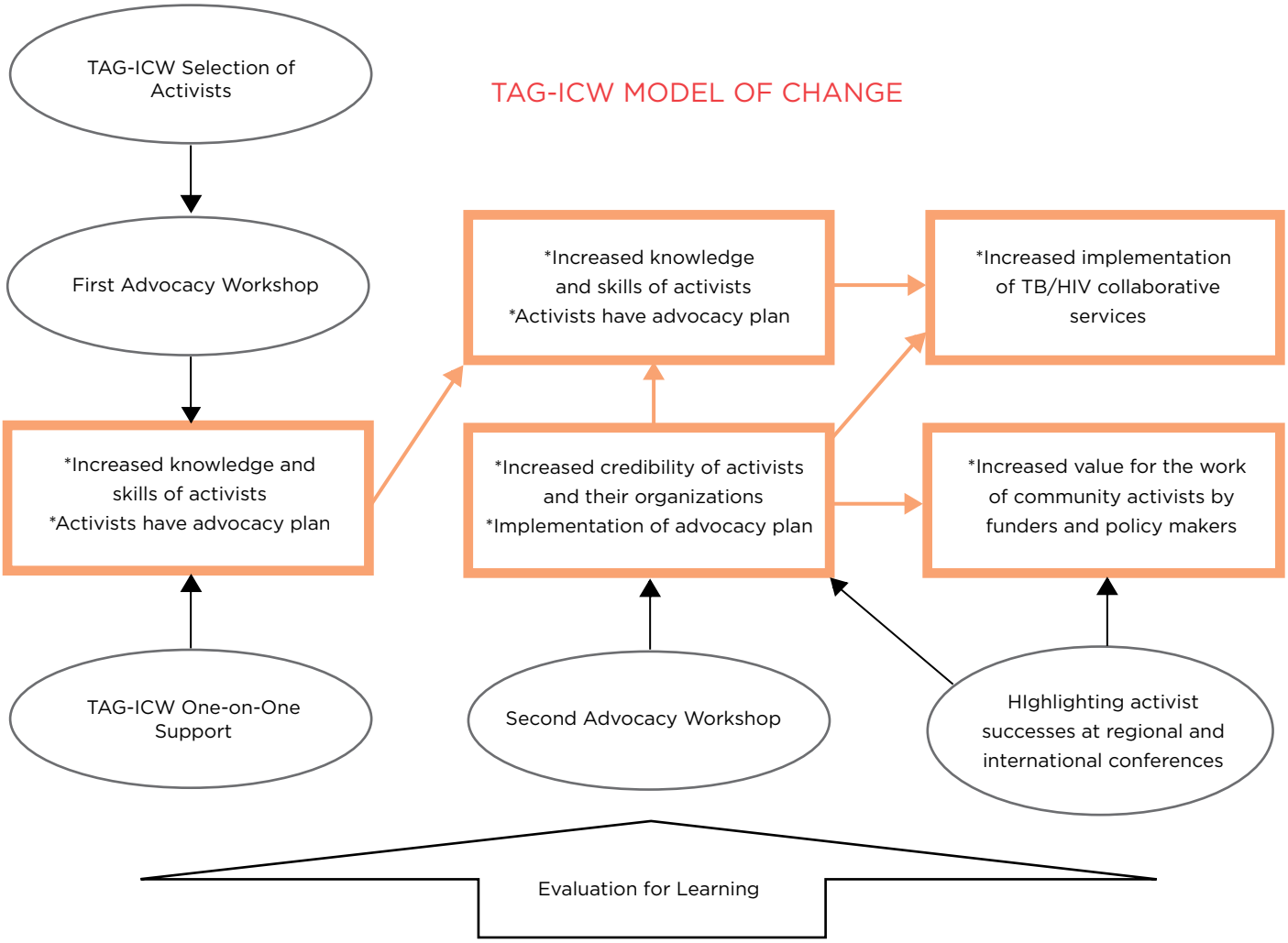
in Africa. TAG's project builds upon the rich history of HIV treatment activism to help an already organized and politicized HIV advocacy movement take on TB and HIV together.

To achieve this objective, TAG partnered with ICW. Since September 2007, through TB/HIV advocacy workshops and support, TAG and ICW have worked to build the advocacy capacity of 49 community activists throughout Africa.

Over the past two years, TAG and ICW have developed a model that involves five components: activist selection, advocacy workshops, one-on-one support, highlighting the work and leadership of activists at regional and international conferences, and using ongoing evaluation to refine and strengthen the model. The TAG-ICW model provides a pathway to build a stronger movement for TB advocacy that can increase political support for TB policies, programs, and research and ultimately contribute to the improvement in TB and TB/HIV program implementation.

The TAG-ICW advocacy model recognizes the importance of building community support and a knowledge base through intensive advocacy training, education workshops and ongoing support. The model seeks to strengthen activist capacity to engage in broader advocacy by influencing decision makers at all levels. Advocacy as TAG-ICW defines it through our TB/HIV workshops and support requires activists to attempt to influence decision makers to choose courses of action that benefit people at risk from the overlapping TB/HIV co-epidemics, in line with the activists' community priorities. These decision makers include policy makers; health officials, such as national TB and AIDS program managers; researchers; and members of the media.

TAG-ICW MODEL OF CHANGE



B. Components of the TAG-ICW TB/HIV Advocacy Capacity-Building Model

TAG-ICW's model involves working with a selected group of activists over the course of a year. During that year, TAG and ICW provide the activists with the following support:

- An initial TB/HIV advocacy workshop focused on TB/HIV basic science, advocacy strategies, and development of organizational advocacy plans.
- A second TB/HIV advocacy workshop focused on gaps in skills/knowledge identified by activists, emerging issues, and peer sharing on advocacy plans.
- One-on-one support for each activist via monthly telephone calls throughout the year.
- Highlighting activist successes at regional and international conferences to build additional support for TB advocacy and to enhance the visibility and credibility of activists.
- Ongoing evaluation to refine and strengthen the TAG-ICW model.

i. Selection of Activists

While it is TAG and ICW's belief that social change requires strong collective action as well as individual leadership, we only had the capacity to work with individual activists who acted as representatives of their organizations. In order to ensure greater collective action, activists that TAG-ICW interfaced with were given the responsibility of building the capacity of their organization and activist networks to take on TB advocacy issues.

Activists who became part of the TAG-ICW process were required to submit a letter of support from their organization stating that it backed their involvement with the project. The host organization also had to express a commitment to taking on TB advocacy in the future. TAG-ICW recruited activists in leadership positions within their agencies who were well placed to influence and sustain their organizations' commitment to TB advocacy.

The application to participate in TAG-ICW's capacity-building efforts was circulated through activist listservs. Activist groups that received funding to take on TB advocacy through the Tides–International Treatment Preparedness Coalition Collaborative Fund or from the Open Society Institute's Public Health Watch TB/HIV Advocacy and Monitoring Project were invited to apply. Applications were also sought from activist networks or organizations recommended by partner agencies involved in HIV and TB/HIV advocacy, such as the Treatment Action Campaign and AIDS Rights Alliance of Southern Africa.

ii. The TAG-ICW TB/HIV Advocacy Workshops

Since 2007, TAG and ICW have held six comprehensive workshops for two cohorts of selected activists. The workshops were conducted in eastern, western, and southern Africa, with sessions held in Abidjan, Addis Ababa, Dar es Salaam, Entebbe, and Johannesburg. The four-day advocacy workshops were structured to include technical sessions as well as time for networking and interactive/group activities.

The Curriculum for the First Workshop

The goal of the initial workshop was to build a strong science-based understanding of TB and TB/HIV. Sessions in the first workshop included:

- The basic science of TB.
- Global surveillance/trends regarding TB/HIV including the epidemiological spread of multidrug-resistant (MDR) and extensively drug-resistant (XDR) TB and implementation of collaborative policies.
- Global/national commitments and opportunities for advocacy.
- TB transmission and prevention.
- TB diagnostics and the challenges they present for people living with HIV as well as new diagnostics that are being developed to address these challenges.
- TB treatment, and the challenges of TB/HIV co-treatment.
- Existing TB vaccines and their limitations, and new vaccines that are being developed.
- The basics of the research process for developing TB drugs and vaccines.
- The policy making process.
- Developing an advocacy plan.

After the first workshop, TAG-ICW staff provided phone support to the activists in order to further develop their advocacy plans and discuss their challenges and successes. TAG and ICW used the information they gathered through these ongoing interactions, as well as issues identified by activists, to develop the curriculum for the second workshop.

The Curriculum for the Second Workshop

The second workshop was typically held six months after the first workshop. This workshop reinforced the science and policy literacy provided during the first workshop and responded to gaps in knowledge and needs identified by activists while implementing their advocacy plans. The second workshop also served to highlight the successes of peer activists.

The sessions in the second workshop included:

- The review of the basic science of TB, including transmission, diagnostics, treatment, and issues specific to those living with HIV/AIDS.
- Working with the media.
- Setting goals and objectives.
- Evaluating success in advocacy.
- Human rights issues regarding MDR and XDR TB.
- Sharing promising practices in advocacy.

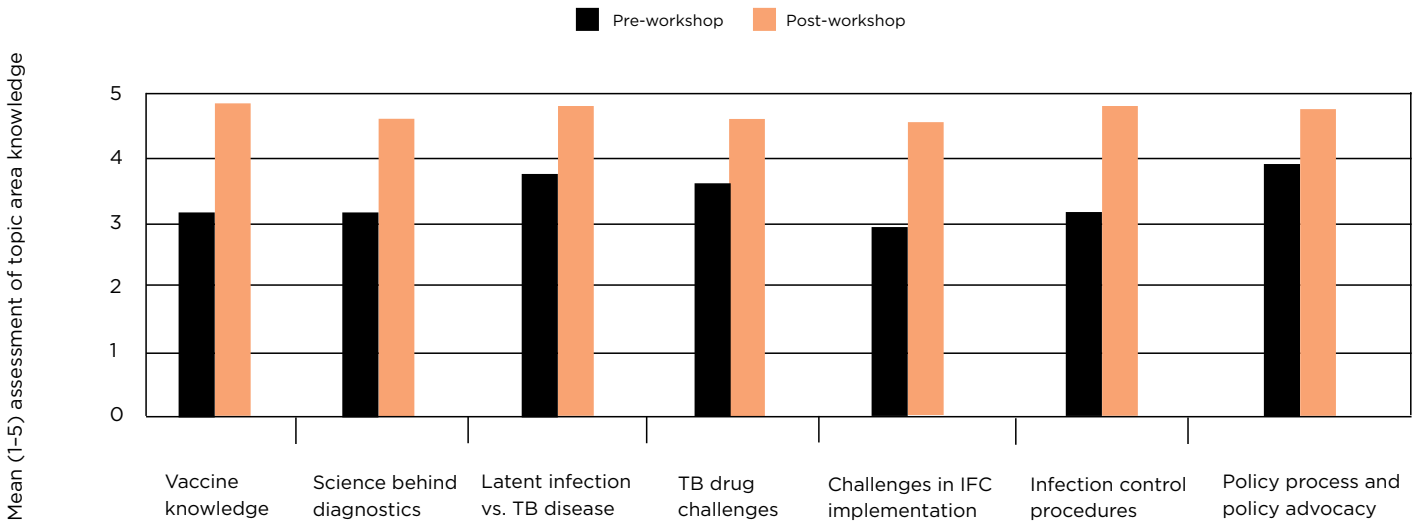
The second workshop allowed for further exploration of the advocacy plan, further peer-to-peer work, and additional support from TAG-ICW.

Outcomes from the TAG-ICW Advocacy Workshops

For each workshop, participants completed a pretest prior to the workshop and a posttest after each day of the workshop. The pre- and posttest analyses have consistently demonstrated a strong increase in self-reported skills and knowledge.

The following chart shows how participants' TB science and policy knowledge grew after attending the first 2008 workshop for new activists. All changes are statistically significant.

SAMPLE OF PRE- AND POST-WORKSHOP KNOWLEDGE ASSESSMENTS–ENTEBBE WORKSHOP 9/08



There is strong evidence that the impact of these workshops spread beyond just those who attended. In a survey of the first round of activists, over 90% of them reported developing educational tools for their communities based on content from the workshops. The structure of the workshops also allowed for participants to use the curriculum to conduct their own trainings for fellow activists.

TAG is currently writing up the curricula of the TAG-ICW TB/HIV advocacy workshops into an online toolkit that will be available on the TAG website by March 2010.

To be an effective activist, you need to have facts about issues you want to advocate for. Through the trainings I have acquired more knowledge on issues pertaining to TB, the coinfection and research around the same. Though I am a former TB patient, I did not take much note of the coinfection until after the trainings. I also did not have an understanding of the science of TB, TB diagnostics and treatment. I also did not have the full understanding of research, the stages, ethics, etc. It [the TAG-ICW workshop] has also helped me to recognize and take note when there are gaps in the national intervention plans around the two diseases and what can be done to fill in these gaps.

—**Carol Nawina Nyirenda,** CITAM+, Zambia

iii. The Structure of TAG-ICW One-on-One Support for Activists

The Advocacy Work Plan

By the end of the first advocacy workshop, each activist had developed a work plan with specific advocacy targets, strategies, and objectives. These work plans were developed to align with specific individual and organizational strengths and interests as well as the realities of the activists target countries or regions. After returning to their organizations, the activists discussed their advocacy work plans with their organizations' leadership. Through this process the plans evolved and developed deeper buy-in from the activists' organizations. These plans allowed for greater clarity and structure for advocacy activities and served as the bases for evaluation and support that TAG-ICW provided through monthly calls.

One-on-One Support

Each activist was assigned a primary and secondary TAG-ICW staff person to provide regular one-on-one support. Support ranged from structured monthly calls to informal, as-needed sessions. This allowed TAG and ICW staff to provide activists with further information on topics that they were still uncertain about, assist in problem solving, and identify resources to overcome challenges they faced in their advocacy efforts. For instance, if one activist was doing work that was relevant to another activists efforts, TAG and ICW staff connected the two so that they could share relevant information to enhance each other's advocacy.

TAG-ICW staff used a form called "Notes from the Field" to collect consistent information about each of the activists' advocacy efforts; this form also provided structure for monthly phone calls. The structured documentation of what each of the activists was doing, and the struggles they faced, this helped TAG-ICW staff identify needs for additional assistance.

TAG-ICW also disseminated information about opportunities for funding, collaboration, and networking during these calls and when new resources became available. TAG and ICW staff used the information collected through "Notes From the Field" forms to keep the entire project TAG-ICW abreast of all the activists' efforts by sharing the forms with each other. Individual activists' needs were also discussed during regular staff conference calls to ensure consistent support for activists.

Participants at the TAG-ICW TB/HIV Advocacy Workshop in Johannesburg, April 2009

iv. Promoting the Work of Activists

From 2007 to 2009, TAG and ICW organized panels, satellite sessions, and produced documents to highlight activist efforts at regional and international conferences such as the Union World Conference on Lung Health, the Southern African TB Conference, the Stop TB Partnership's Partners Forum, and the International AIDS Conference. TB/HIV activist efforts were highlighted in these settings to increase awareness and support of TB and HIV funders, policy makers, and capacity builders for TB and TB/HIV advocacy efforts—both on the local and global levels. Previously, TB conferences had very little activist presence. As a result of the TAG-ICW efforts, there was now increased visibility of advocates at TB conferences and of TB/HIV activists at AIDS conferences. Highlighting activist efforts through global and regional conferences enhanced their credibility and enabled them to engage with TB and AIDS program managers more effectively at the national levels.

v. Ongoing Evaluation of the TAG-ICW Model and Activist Accomplishments

In September 2007, TAG contracted with an outside evaluator, the TCC Group, to provide ongoing evaluation services for the TAG-ICW TB/HIV project. TAG and ICW were most interested in formative evaluation to inform the model and be responsive to activist needs identified through the evaluation process. Specifically related to the TAG-ICW capacity-building work, the TCC Group conducted pre- and post-workshop knowledge assessments and reported back to TAG-ICW on what areas were most and least successfully impacted by the advocacy workshops. TCC also regularly collected data directly form the activists to track progress on their goals and objectives and to document what was working well. Finally, TCC facilitated sessions for the activists on development of goals and objectives and measuring advocacy successes.

The march led by Mrs. Nabillah Sempala, Member of Parliament for Kisenyi in Kampala at the launch of "Stock Out Campaign" in Uganda, 17 March, 2009.

Mrs. Nabillah Sempala (left) who officiated at the launch of the "Stock Out Campaign" and Robert Kyagulanyi Sentamu a.k.a Bobi Wine (center), a renowned Ugandan artist who participated in the launch, at the health care facility in Kisenyi, Kampala, listening to testimonies of people who had experienced the drug stock outs.

IV. Activist profiles

a. The Community Working Group on Health: **Albert Makone**, Zimbabwe

Albert Makone is an activist based in Zimbabwe who has become one of the leading TB/HIV activists working for TB/HIV collaborative services working domestically and globally. He currently works at the Community Working Group on Health (CWGH), a network of civic and community organizations focused on increasing community participation in health in Zimbabwe.

Taking on TB/HIV Advocacy

Albert initiated CWGH's work to address the impact of TB on people living with HIV based on feedback from community members participating in CWGH's support groups in 2008. While attending his first TAG-ICW TB/HIV workshop, Albert developed an action plan framing the CWGH's advocacy strategy for reducing the burden of TB among people living with HIV. After the workshop, his advocacy plan was refined based on conversations between Albert, CWGH staff, and TAG-ICW staff. The plan prioritized the uptake of intensified case finding (ICF) in HIV care settings.

One of the main challenges Albert and his CWGH colleagues faced in expanding TB and HIV service integration in Zimbabwe is the fact that there are few organizations advocating for improved TB and collaborative TB/HIV polices and services. The lack of a coordinating mechanism between the few nongovernmental organizations (NGOs) addressing TB has required CWGH to take on a leadership role in pushing the TB/HIV advocacy agenda in Zimbabwe.

TB/HIV Advocacy Strategies

Albert cites his good working relationship with the Ministry of Health (MoH) as a key factor in his success. Instead of focusing on what is not being done by government programs, CWGH acknowledges the challenges faced by the National Tuberculosis Program and other government programs implementing services and tries to problem solve by positioning themselves as a partner. Albert has found that the Ministry of Health has come to view CWGH as a resource invested in its success rather than simply a critic, and has come to appreciate the fact that partnering with NGOs will ultimately benefit both the TB and AIDS programs as well as communities impacted by the disease.

TB/HIV Advocacy Successes

Albert's advocacy approach has yielded many successes. He organized a national policy dialogue in collaboration with the Zimbabwe National Network of People Living with HIV/AIDS, which brought together the NTP, the National AIDS Program, health care providers, advocates, and people living with HIV to discuss the need for integrated TB/HIV services. After this meeting Albert was asked to participate on the writing team that drafted the TB/HIV Collaborative guidelines for Zimbabwe.

In response to nationwide stock-outs of essential medicines, Albert and the CWGH team convened another national policy dialogue meeting attended by representatives from government, civil society, funders, the health care sector, and affected communities to discuss treatment access, with a focus on HIV and TB medications in Zimbabwe. Albert and the team were tasked with monitoring the availability of essential medications and developing recommendations on how to address root causes of stock-outs.

In addition to his work on the national level, Albert has worked in close partnership with the management of two rural health centers to implement ICF and improved infection control measures (e.g., patients presenting with a cough should queue up in a different line for treatment). As a result of his advocacy for TB/HIV collaborative services, a quarter of the AIDS service organizations in two districts are now offering TB screening to their clients and referring clients for diagnosis and treatment of TB. Through Albert's efforts, CWGH has been able to secure funding from the Open Society Institute–South Africa, Oxfam, and the UK Department for International Development (DFID) to support their work on drug stock-outs and to further strengthen and expand their ICF work.

For more information, please visit www.cwgh.co.zw
or email Albert at albertmako@gmail.com

b. Hope Care Foundation: **Ben Dzivenu**, Ghana

Ben is an activist in Ghana, where he works to improve the lives of people living with or at risk of contracting TB and HIV by building the capacity of fellow activists. He works at Hope Care Foundation, an organization whose mission is to improve the health status of people living in Ghana.

Taking on TB/HIV Advocacy

Ben has been involved in TB/HIV advocacy work since 2004 through his former position at the Vital International Foundation. After moving to work for the Hope Care Foundation, Ben has continued his TB/HIV advocacy.

In Ghana, people with TB are highly stigmatized, and the spread of HIV in the country has worsened the stigma, particularly for people who are coinfected with TB and HIV. Ben has found that education has been an effective tool to overcome the stigma of coinfection.

TB/HIV Advocacy Strategies

After attending his first TAG-ICW TB/HIV advocacy workshop in November 2008, Ben did some research to gather data on the impact of TB among people with HIV in Ghana. From the available data, Ben came to realize that there was a serious problem in Ghana regarding the implementation of isoniazid preventive therapy (IPT), one of the strategic cornerstones of reducing the burden of TB among people with HIV. Through his research Ben found that Ghana was working on infection control and intensified case finding, but IPT was not part of the national TB policy. As an executive member of the well-respected Ghana NGO Coalition on Health, Ben conducted a workshop to share the information he had just received to make the NGO Coalition

aware of the Three I's. After being equipped with this new information, the NGO Coalition organized a workshop with media houses, followed by a press conference on IPT. The media picked up the need for IPT and the incoming minister of health, who was going through his confirmation hearing, was asked in the Ghanaian parliament why Ghana was not implementing IPT. Following his confirmation the Health Minister—who is himself a medical doctor—called a meeting with the national TB and AIDS program managers and the leadership of the Ghana NGO Coalition on Health to discuss the need for the implementation of IPT to reduce the burden of TB among people living with HIV.

Ben continues to build the knowledge of other activists and NGOs regarding TB/HIV and to support the development of other activists. Ben has been able to effectively disseminate the knowledge he gained through the TAG-ICW TB/HIV advocacy workshops to his networks in Ghana. Through his leadership Ben has catalyzed action amongst his advocacy networks to further their common goal of reducing the burden of TB/HIV and improving the health of all Ghanaians.

TB/HIV Advocacy Accomplishments

As a result of Ben's activism, the NTP has included plans for IPT in *The National Tuberculosis Health Sector Strategic Plan for Ghana 2009–2013*. This plan acknowledges that the effectiveness of IPT has been well documented and states that the Ghanaian NTP is planning to scale up IPT by initiating pilot projects to demonstrate how best to implement IPT in a manner that ensures high rates of treatment completion. Ben and the NTP have identified two districts in Ghana where the IPT projects will be initiated in the upcoming year. The commitment to IPT is expected to be further solidified in November 2009 through the National Health Bill that will make IPT part of Ghana's response to TB/HIV.

After reflecting on his partnership with the Ghana NGO Coalition on Health, Ben believes that working with the media was central in generating political pressure to push for the implementation of IPT. He also credits the leadership of the health minister, Dr. Sipa-Yanky, who brought together the TB and AIDS program managers to catalyze action for the integration of IPT into Ghana's national policy and practice.

Though he was able to get support from his organization to implement his advocacy workplan, Ben is fully aware of the lack of funding available for advocacy work. TB programs may be willing to fund education but have not been willing to give money to those doing advocacy.

For more information, please email Ben at bdzivenu@yahoo.com

c. The Community Initiative for Tuberculosis, HIV/AIDS and Malaria: **Carol Nawina Nyirenda**, Zambia

Carol Nawina Nyirenda is an HIV/AIDS activist who has channeled her personal experience as a person living with HIV and a TB treatment survivor into her domestic and global activism. She works for the Community Initiative for Tuberculosis, HIV/AIDS and Malaria (CITAM+), an organization that advocates for national access to information, treatment, care and support for people living with HIV/AIDS, TB, and malaria, with a special focus on for MDR TB in Zambia.

Taking on TB/HIV Advocacy

A longtime HIV activist, Carol began incorporating TB into her HIV advocacy work in 2004 after the Treatment Advocacy and Literacy Campaign (TALC), the organization she was then part of, was awarded funding by the Open Society Institute's (OSI's) Public Health Watch TB/HIV Monitoring and Advocacy Small Grants Project. Through this project, OSI provided organizational grants to support monitoring of and advocacy for collaborative activities while TAG conducted workshops to build the capacity of funded activists to advocate for TB/HIV collaborative services. It was in this setting that Carol learned that TB was not just another opportunistic infection but in fact the leading cause of death amongst people with HIV. Through her initial engagement with OSI and TAG, Carol also recognized that there were many opportunities to advocate for collaborative policies to reduce the burden and spread of TB. Since becoming a strong advocate for TB and TB/HIV, Carol has been sharing resources and information with fellow activists and people living with TB and/or HIV and has worked to reduce the overall stigma of TB disease.

TB/HIV Advocacy Strategies

Previously, as a leader in TALC, Carol helped set up support groups for persons with TB/HIV. She quickly realized that having the leadership of the support groups primarily be people who had TB and HIV meant that many HIV-negative TB patients were not comfortable attending due to stigma. To address this, Carol invited HIV-negative people with TB to start leading the groups. This resulted in more people with TB attending the groups which continue to be an important source of treatment literacy and support for persons undergoing TB treatment, including those who are coinfected with HIV.

Carol's domestic advocacy is centered on her role as a community representative to the Ministry of Health's Joint Coordinating Board for Affected Communities. Her work on the national level is grounded in the key role she plays in building the capacity of HIV/AIDS organizations to take on TB/HIV advocacy and community treatment literacy.

In terms of her global advocacy Carol is a community representative on the Stop TB Partnership's coordinating board, and has also represented communities of people living with TB, HIV, and malaria on the UNITAID board. While serving on the UNITAID board Carol successfully lobbied for the provision of resources for diagnostics for TB drug resistance testing. Subsequently, in July 2008, UNITAID committed over US$26 million to address the diagnostics gap for MDR TB.

TB/HIV Advocacy Accomplishments

Carol has been a strong advocate for improving TB/HIV collaborative services in her native Zambia as well as globally. Her knowledge and skills in advocacy have made her a credible and trusted resource, both at home and around the world. Carol has received global recognition for her activism and has served as a panelist at the April 2008 meeting in Thailand of the UNAIDS Program Coordinating Board (PCB) where she addressed the issue of MDR TB among people living with HIV. In part, due to her advocacy, the UNAIDS PCB decided to monitor TB/HIV mortality numbers as a measure of the impact of the implementation of the collaborative activities recommended by the WHO policy to reduce the burden of TB/HIV.

Through her monitoring of collaborative services in Zambia, Carol discovered that Zambia did not have infection control guidelines in place. This was alarming because Carol found HIV clinic staff and patients lacked knowledge regarding the risk of TB transmission. Since its establishment in 2008, CITAM+ has brought this issue to the Ministry of Health and the NTP. As a result the NTP has invited two CITAM+ representatives to serve on the committee to work on IC guidelines.

Carol was also instrumental in setting up TB information desks at HIV antiretroviral (ARV) public clinics. Many of these clinics already had HIV information desks staffed by volunteers. CITAM+ trained these volunteers on issues related to TB/HIV. These volunteers would then impart this information to persons visiting the ARV clinics. CITAM+ obtained funding from the Zambian National AIDS Network (ZNAN) to provide food supplements such as beans and cooking oil as incentives for the volunteers.

Recently, Carol left TALC to take a position as the National Coordinator for CITAM+ because she wanted to concentrate more on advocacy around TB/HIV coinfection. In her new position, Carol has provided leadership in assisting fellow HIV-focused NGOs to integrate TB into their work. Carol organized a workshop with help from TAG and the Consortium to Effectively Respond to AIDS/TB Epidemic (CREATE) to increase the knowledge, skills, and advocacy capacity of NGOs across Zambia. This workshop led to a formation of a civil society network that is focused on TB.

Carol identifies the lack of funding for TB/HIV advocacy as a major barrier to expand and strengthen the voice of organizations led by people infected or affected by TB.

For more information, please e-mail Carol at carolnawina@yahoo.com

d. The Southern Africa HIV and AIDS Information Dissemination Service: **Joshua Chigodora**, Zimbabwe

Joshua is an activist from Zimbabwe who is working with numerous government organizations to advocate for the integration of TB and HIV programs as part of the national response to curb the spread of HIV. The Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS) is the primary organization that Joshua works with. SAfAIDS is a regional nonprofit organization based in Pretoria, South Africa, that promotes effective and ethical development responses to the epidemic, and works to reduce the impact of HIV through knowledge management, capacity development, advocacy, policy analysis, and documentation.

Taking on TB/HIV Advocacy

Joshua's involvement with TAG and ICW was well timed given the increased awareness of the problem of TB and HIV coinfection both in his organization and in Zimbabwe. SAfAIDS was already very interested in taking on TB/HIV advocacy at the time Joshua was selected to participate in the TAG-ICW advocacy project. He has been able to draw upon SAfAIDS's excellent reputation with the Ministry of Health and Child Welfare (MoH&CW) to further his activism.

TB/HIV Advocacy Strategies

Joshua has focused on education and advocacy for integration of TB/HIV collaborative services. SAfAIDS has a strong media presence, and Joshua has appeared on national television four times in 2009 to provide TB education and the need to minimize the impact of TB in people living with HIV. These appearances led to Joshua being engaged by the Public Service Commission, the body that employs civil servants in Zimbabwe, to carry out their program to provide TB and HIV education in the workplace.

Joshua has also worked with MoH&CW and other stakeholders to advocate for integration of TB and HIV programs as part of the national response to curbing the spread of TB in Zimbabwe. To do this, SAfAIDS convened policy dialogues that included the Ministry of Health, civil society, and private sector stakeholders. The main goal was to change the standard opt-in/opt-out arrangement for TB screening for people living with HIV/AIDS and to have health care providers at all levels of service advise people with HIV to be screened for TB, and vice versa.

TB/HIV Advocacy Accomplishments

As described above, SAfAIDS was engaged by the Public Service Commission to carry out its TB and HIV workplace program. Joshua conducted six awareness sessions with government ministries. The topics he covers included general TB education, how TB is linked with HIV, and the need for integration of TB and HIV services. SAfAIDS specifically advocates for service integration because of the long distances that many Zimbabweans must travel for health care.

SAfAIDS's work with the MoH&CW and other policy makers has contributed to an official government policy that requires people seeking HIV testing and counseling to also be offered a TB test, and vice versa. SAfAIDS has provided ongoing advice in the implementation of this policy but is not yet involved in implementation or monitoring of this policy.

For more information, please visit www.safaids.net
or email Joshua at joshua@safaids.org.zw

e. The Coalition for Health Promotion and Social Development: **Prima Kazoora**, Uganda

Prima Kazoora is a community activist who works for the Coalition for Health Promotion and Social Development (HEPS-Uganda), a health consumers' organization advocating for health rights and responsibilities. Prima's work in the arena of monitoring the accessibility of essential medicines started in 2006 through a World Health Organization (WHO) and Health Action International (HAI) project. The WHO-HAI project was implemented in partnership with the Ugandan Ministry of Health, which had defined a list of essential medicines. However, this list of essential medicines did not include any HIV antiretroviral therapies (ARTs) or TB medications. HEPS was the civil society representative of the advisory committee that provided input into the WHO-HAI project. After that project, in 2009 HEPS monitored the accessibility of essential medicines through the DFID-funded Medicines Transparency Alliance (MeTA), which is a multistakeholder alliance working to improve access and affordability of medicines for populations that are unable to access essential medicines due to cost and/or accessibility.

Taking on TB/HIV Advocacy

In 2006 Prima and other activists from HEPS built on their experience with the WHO-HAI project to begin monitoring the availability of HIV medications for the Missing the Target report that was a project of the International Treatment Preparedness Coalition (ITPC), a global network of HIV treatment activists. After attending the TAG-ICW workshop in September 2007, Prima realized the impact of TB on people with HIV and wanted to integrate TB into HEPS's monitoring work. Because the Ministry of Health had already defined the list of essential medicines and because her fellow activists were less familiar with TB, she had a difficult time

getting support for the integration of TB medications into HEPS's monitoring efforts. However funding from the Dutch nongovernmental organization, the Humanist Institute for Development Cooperation (HIVOS), made it possible for HEPS to conduct a parallel monitoring effort to include TB and HIV drugs and diagnostics. Furthermore, through their preexisting relationship through the WHO-HAI project, HEPS also got support and input from the Ministry of Health, the National Drug Authority of Uganda, the Uganda AIDS Commission, as well as members of civil society, to ensure that the monitoring tools that they used covered all relevant topics and to gain buy-in of government agencies. The Ministry of Health provided introductory letters that were critical in allowing HEPS to conduct the monitoring exercise effectively.

TB/HIV Advocacy Strategies

HEPS's partnership with the MoH, as well as its own experience in monitoring the availability of essential medicines, has brought credibility to HEPS's report that identifies stock-outs of TB drugs in many regions of Uganda. Prima's work shows how activists can not only provide community perspective to governmental bodies but also serve as a critical source of data that can be used to address gaps in government services.

Beyond her monitoring work, Prima has joined a nationwide coalition of activists to educate fellow HIV and human rights organizations about the need to advocate for increased involvement of affected communities in TB programs. Their main focus has been to influence the national TB program leadership to increase TB/HIV collaborative services through partnerships with civil society organizations. The coalition has collected its own data on the availability of TB and TB/HIV services in Kampala to use as a basis for its advocacy with the national TB and AIDS programs.

TB/HIV Advocacy Accomplishments

Prima's work has allowed TB/HIV activists to be recognized as crucial partners in the fight against TB in Uganda. She was selected to serve on the Technical Working Group on Medicines that advises the Ugandan government on policies related to purchase and accessibility of essential medicines.

HEPS has also been chosen to be the civil society coordinator in MeTA's Uganda pilot project. Prima, through HEPS, continues to play a leadership role in the civil society network that is committed to building fellow HIV and human rights organizations' capacity to take on TB advocacy. She is currently working to expand the national TB network, leading the development of a networkwide advocacy plan.

For more information, please visit www.heps.org
or e-mail Prima at pmkazoora@yahoo.com

f. The Tikondane Women's PLWHA Support Group: **Thokozile Phiri-Nkhoma**, Malawi

Thoko is an activist who works for the Tikondane Women's PLWHA Support Group (TIPOWOSU), whose mission is to eliminate suffering among women living with HIV through advocacy, capacity building, empowerment, and civic education.

Taking on TB/HIV Advocacy

Thoko and TIPOWOSU had taken on some TB/HIV work prior to her participation in the TAG-ICW advocacy project, mainly in support of the provision of DOTS, the WHO-recommended five-pronged strategy to combat TB that was expanded in 2006. After Thoko participated in the TAG-ICW advocacy workshop, she realized that TIPOWOSU had been taking on TB without adequate education. Thoko shared the knowledge she gained from the TAG-ICW trainings with her fellow activists and has expanded TIPOWOSU's capacity to do informed TB advocacy work.

TB/HIV Advocacy Strategies

Thoko's work has been focused on advocating for joint collaborative services and identifying gaps and missed opportunities to improve coordination between HIV and TB services. Thoko has built skills and support among infected and affected communities to advocate for their health needs. These activists also collect data to improve TIPOWOSU's understanding of the problems faced by the lack of implementation of collaborative services. In order to empower communities, TIPOWOSU developed its *TB/HIV Integrated Community Facilitators Manual* as a grassroots education tool.

To gather information to ground its data-driven strategy for advocacy, TIPO-

WOSU conducted a survey of health care workers and people living with TB and/or HIV to assess the gaps in the Malawian health system's provision of TB/HIV collaborative services. It subsequently formed a civil society coalition on TB and HIV to review the results of the survey that showed low knowledge of the need for TB and HIV collaborative services as well as poor understanding among the affected communities of TB/HIV. TIPOWOSU used this data to develop a position paper which was published in the *Daily Times* newspaper in Malawi. At the same time, TIPOWOSU worked directly with district health centers to help them identify ways to improve infection control and other collaborative services. TIPOWOSU is currently developing a statement of demand based on survey results that it will use as the basis of its advocacy for the improvement of TB/HIV collaborative services.

TB/HIV Advocacy Successes

At the time of the printing of this document TIPOWOSU is preparing its final report regarding the survey of health care workers, but has been able to begin training workers in health centers based on needs identified through its preliminary data analysis. For example, in two health centers, the survey data revealed that the health care workers didn't have proper information on infection control or intensified case finding. TIPOWOSU held a training for the workers, and now these health centers are referring HIV positive people for TB screening and have improved infection control by reducing the number of people in waiting rooms by having patients line up outside.

TIPOWOSU's mobilization of infected and affected communities has resulted in a civil society coalition that will allow for greater resource sharing among civil society organizations (CSOs) to improve coordination of their advocacy to monitor the implementation of TB/HIV collaborative policies. The CSOs in the network have also built each other's capacity to advocate for collaborative services.

For more information, email Thoko at tikondanewg@yahoo.com

V. Evolution of the TAG-ICW TB/HIV Advocacy Capacity-Building Model and Key Lessons

Though prior to September 2007 TAG had conducted many activist workshops to increase HIV advocates' awareness of TB/HIV coinfection, these workshops were one-off activities. TAG and ICW's current model for concerted capacity building of Africa-based HIV activists to take on TB advocacy has been developed in response to lessons learned, primarily over the past two years of this project. In September 2007 TAG and ICW held our first joint TB/HIV advocacy workshop, and since then we have continually sought feedback—from activists, through program evaluation, and through staff discussion—to make the program more effective in building and sustaining advocacy capacity.

Initially, the activist advocacy plans were developed as a group with all the activists being asked to focus on one of the five working groups (media; United Nations General Assembly Special Session on AIDS which monitored HIV universal access goals; TB/HIV implementation; research; and the Stop TB Partnership Community Task Force). Learning that these working group categories were too broad and did not address the specific strengths and contexts of the activist organizations, we changed our strategy and encouraged activists to devise workplans specific to the context of the epidemic and their organizations. Additionally, TAG-ICW asked the activists to focus on components of the Three I's in order to address the particular concern that this component of TB/HIV collaborative activities was lagging behind in its implementation.

In the first cohort of activists that TAG-ICW had trained, there was no formal structure for ongoing one-on-one support, such as regular conference calls, although TAG and ICW staff were available to provide support upon request. The first cohort that TAG-ICW worked with included monolingual francophone activists. After one year of providing bilingual workshops and follow up support TAG-ICW had to discontinue these efforts due to lack of sufficient bilingual staff capacity to provide adequate support to these advocates.

After reviewing the lessons learned from year one, TAG and ICW changed their selection process to exclude non-Anglophone activists. TAG-ICW also recruited activists in leadership positions in their organizations to ensure that after returning to their organizations they would be in a good position to influence the work of their institutions. After the first cohort, TAG-ICW also limited the size of subsequent group to 15 activists (down from 35) to allow for greater one-on-one support.

Key lessons learned from the past two years are detailed below:

a. Role of Local and National TB and AIDS Programs

- There is a vast difference between how national AIDS programs and national TB programs work with community activists. Many of the activists identified the lack of resources and coordination for TB advocacy as a major barrier for their work. There is a need for both AIDS and TB programs to include funding for community advocacy in their proposals and budgets. These resources can then be used to provide capacity building support similar to what TAG-ICW provided through this project to enhance TB advocacy.

A site visit by CITAM+ and partners to a TB/HIV information desk based at Kalingalinga Clinic during the Three I's Advocacy workshop held in Lusaka, Zambia in April, 2009. From left to right: Carol Nawina Nyirenda, Dorothy Chanda, Mr. Goma, Chisha Mwaba Phiri, Claire Wingfield and Foster Phiri.

b. Advocacy Training

- *Knowledge Reinforcement.* There is a dearth of TB information even in activists that are highly treatment literate about HIV and ARVs. Strong HIV activist history did not guarantee any significant knowledge about TB. This was true even though many of the activists had gone through TB treatment and recognized the impact of TB on their fellow community members. Consistent reinforcement of the TB/HIV "basics" is important; activists continue to show significant improvement in topics covered by previous workshops.

- *Interactive sessions* during the TB/HIV advocacy workshops are critical to allow for creative thinking on the part of activists, especially curricula that allow for role playing and sharing of experiences.

- *Sharing success stories* from other countries is vital in increasing confidence of fellow activists. The prevailing attitude was not "This wouldn't work in my country" but rather "How can I apply this to my own work?"

c. Advocacy Skills after the Workshop

- *Integrate IEC with community priorities*. There is a need to distinguish between IEC (Information, Education, and Communication) as not just an end unto itself, but as a critical component of building broader community support and engagement in advocacy efforts. Many activists were eager to take on IEC but were often not clear about how to plan to connect their IEC and community mobilization efforts with advocacy efforts aimed at convincing a decision maker (funder, program, or policy maker) to make changes in keeping with community priorities. Without a deliberate connection a lot of IEC might have been undertaken without ever leading to change in programs or policy.

- *Building and sustaining TB/HIV knowledge* and advocacy capacity is not a one-off effort. It is crucial to complement skill and knowledge building workshops with ongoing communication that provides an opportunity to clarify questions, problem solve and provide support on crucial issues, such as data collection methods to identify implementation gaps and strategies to engage national TB programs.

- *Advocacy Planning*. There is a need to provide structure to plan for advocacy in a proactive way, with clear outcomes, strategies and targets. Though many of the activists had been engaged in advocacy, the proactive planning for advocacy was new for many.

d. Workshop logistics

- *Language proficiency support.* TAG-ICW had planned for one bilingual staff that could communicate in English and French to participate as part of the four-person team that was primarily tasked to build the capacity of TB/HIV advocates in Africa. After the first year, TAG-ICW realized that this level of staffing was insufficient to provide adequate organizational and on-going support for the Francophone activists. Staffing levels need to be carefully assessed to successfully provide support for activists.

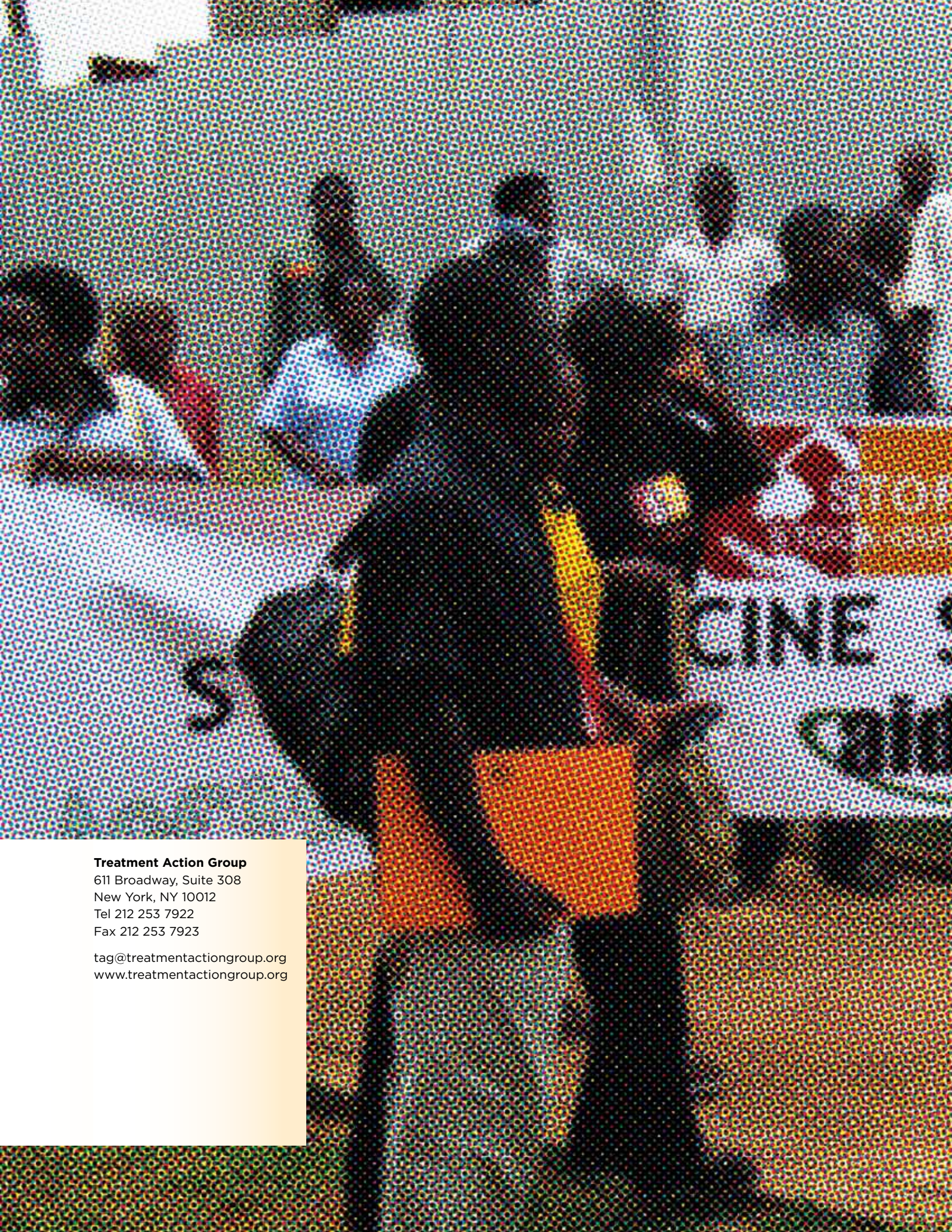
VI. Conclusion

This document shares the model that TAG-ICW developed to build the capacity of African HIV activists to take on TB and to document the outcomes of their advocacy in relation to TB and TB/HIV programs and policies. The capacity that TAG-ICW was able to build through workshops and the consistent follow-up support has strengthened activist voices on an international level as well as in their own countries; the impact of their work is growing rapidly.

Equipping activists with the knowledge of TB science and policy along with tools to analyze policy, collect data, and educate infected/affected communities allows activists to become a resource for strengthening TB programs, for policy makers, and for their fellow community members at risk for TB. All the activists TAG-ICW worked with have translated global TB and TB/HIV policy into local action, and are now in a unique position to identify the gaps in policy formulation and program implementation. Besides contributing to better understanding of advocacy needs, the activist case studies herein demonstrate how community advocacy can bring resources into resource-challenged areas for the betterment of TB programs.

Despite the WHO's revised TB control strategy, which now includes the need to empower TB patients and their communities, TB and TB/HIV activists are yet not fully engaged or empowered to participate in TB control and care efforts. The TAG-ICW experience over the last two years has highlighted the need for community-friendly TB science and policy literacy. The success of trained activists demonstrates the value of engaging advocates on national and global policy bodies. However, it is critical that national TB programs fund these efforts to fully benefit from the leadership that infected/affected activists can provide. The lack of available resources and funding to support the capacity building of activists as well as their subsequent advocacy efforts was consistently identified as a critical gap. National TB programs and both national and global health funders must increase funding to build an empowered community of infected and affected people and catalyze a social movement that can leverage attention, political will, resources, a sense of urgency and outrage to the response against TB, which despite being curable killed nearly 2 million people in 2007.

Elizabeth Mulenga , a member of CITAM+, making a presentation as a participant during the Three I's Advocacy workshop organized by CITAM+, TAG and CREATE in Lusaka, Zambia, April 2009.



Treatment Action Group
611 Broadway, Suite 308
New York, NY 10012
Tel 212 253 7922
Fax 212 253 7923

tag@treatmentactiongroup.org
www.treatmentactiongroup.org