# **Biographies of Public Health Watch TB Monitoring Project Researchers**

## **Olayide Akanni**

Olayide Akanni, Public Health Watch researcher from Nigeria, began her career as a health correspondent for *Punch Newspaper*, the most widely read newspaper in the country. "My scientific background [in biochemistry] was particularly useful because I could speak with scientists and medical doctors at their level," she notes.

As a journalist, she became especially interested in the "huge divide between the medical personnel and the laymen on the street." For Akanni, the challenge was: "how to bridge this divide—how do you make technical, health information simple?" Akanni believes the media can serve as a purveyor of vital information:

"The media has a critical role to play in communicating truths to people so people can make informed decisions about their health. The layman on the street will believe what he reads about his health. They just say 'yes' to the doctor but sometimes they don't really understand what the doctor is saying... That has always been a driving force."

Raising public awareness about major health issues has become a central theme of Akanni's career. Now a Senior Programme Officer with Journalists Against AIDS (JAAIDS), Akanni oversees the organization's activities within Nigeria's Federal Capital Territory and coordinates TB and HIV/AIDS advocacy projects. JAAIDS aims to contribute to the prevention, care, and control of HIV/AIDS in Nigeria by providing innovative communication interventions to facilitate positive behavior change and ultimately, to reduce the spread of TB and HIV/AIDS.

When Akanni joined JAAIDS in 2002, she admits that she and most of her journalism colleagues did not realize TB was an issue in Nigeria. But in their efforts to coordinate a series of treatment literacy workshops to educate civil society groups on HIV/AIDS, they realized that "if we're talking about care for people living with HIV, we should also include information on TB."

Through her research for Public Health Watch, Akanni learned that TB is a major health concern in its own right. HIV/AIDS is fueling the TB epidemic in Nigeria, the nation with the largest number of new TB cases in Africa, contributing to a 6 percent annual increase in TB prevalence and a four-fold increase in HIV rates among people living with TB between 1991 and 2001.

As a health advocate, Akanni has identified stigma as a major barrier to diagnosis and treatment for people living with TB. She found that many TB patients abandon their jobs due to blatant forms of discrimination, including stigmatization from fellow workers who fear infection, as well as despair that their employers will fire them.

By raising awareness about TB and emphasizing its curability, Akanni believes that stigma and discrimination can be reduced:

"The most pressing issue is making the public realize that TB is a problem. You know you have a problem on your hands when there is a problem and people don't realize there is a problem! There is a kind of silence around TB and it's an unhealthy silence. HIV/AIDS is constantly in your face—people know the signs and symptoms. TB doesn't have that even though it's a major killer. How do we raise the profile of TB and give it the much-needed attention? If it's not in the news, then it's not an issue."

Olayide has become a major voice on TB and HIV/AIDS, especially on treatment access, in Nigeria and Africa.

# **Afsan Chowdhury**

Public Health Watch researcher Afsan Chowdhury of Dhaka, Bangladesh, is an advocacy, communications and social mobilization specialist and former journalist who has worked on TB issues for the past decade. He says his background in health and development have often come together; he uses his journalism experiences to "sell issues of public health" to the media and general public.

Chowdhury has experience as a reporter for *The Daily Star*, the most widely circulated English daily newspaper in Bangladesh, and as a correspondent for the British Broadcasting Corporation (BBC). In the early 1990s, he convinced the BBC to allow him to produce a 20-part series on TB. The BBC is now "very proud to have done something on TB from so many years back," he says. "The sense of emergency wasn't there at all—I felt extremely concerned about the lack of emergency around TB. That was a tough period in the early 1990s because there were so many competing priorities. I think TB has been the largest killer at any given period of time."

Chowdhury worked for UNICEF from 1986 to 1993 and was very active in the organization's child immunization campaign in Bangladesh, widely considered the most successful public health campaign in the country to date. "The government feels very proud about [this campaign]," Chowdhury notes.

"We got people involved... It could not have been successful without the participation of the people. And by people participating, I mean people lending their homes to use as outreach sites... The people were stronger than the public health planners. Every village cooperated. People's homes were the immunization centers—they were not government property. Public participation is what made this program move. It gave a great push to the whole public health business. It gave legitimacy to social mobilization."

Chowdhury is now trying to use these lessons on social mobilization in his advocacy efforts around TB. Since 2003, Chowdhury has served as the Director of Advocacy at BRAC (Bangladesh Rural Advancement Committee), the largest nongovernmental organization in the world.

Over the past few years, he has noticed a paradigm shift in the way TB is addressed in Bangladesh:

"The whole strategy has to be taken from the medical to the social sphere. We are now finally seeing this—we are making the cart move a little bit. We have had more journalists than ever working on TB—there has been more coverage in the last one year than in the last 35 years! And this is not including the World TB Day. Now it is it not forgotten...There are ads now. Announcements, activities, plays, newspaper ads, editorials, there are statements, comments, everything. I don't have to push as much now."

Although TB is still widely considered "a disease of the poor," there appears to be less stigmatization around TB today compared to ten years ago. He attributes this to the fact that treatment is free and the fact that "top-notch social leaders—journalists, government officials—are coming out." BRAC has "had sessions where senior journalists talk about how they've had TB. This creates an enabling environment," he says. "Now you can approach any government officer and ask what is happening on the TB front. That is very satisfying; no, it's not satisfying—that is what it should be," Chowdhury explains.

Yet, Chowdhury still believes his job is not done; there is still significant work ahead to increase social mobilization around TB:

"Public pressure is still not felt by the National TB Programme; it's still a specialist program, and we're still telling the public what to do; that we know best. We need to show that the right belongs to the people [and the] provision of TB services has . . . to be seen as an obligation. Until we do this, [TB control] is not sustainable, and we won't reach the targets."

Chowdhury edited the book, <u>Stopping a Killer: Combating Tuberculosis in South & South East Asia</u> and has worked as a consultant on health advocacy, including on <u>HIV/AIDS</u> issues, in Nigeria, Uganda, Nepal, and India, among other countries.

### Jamillah Mwanjisi

Public Health Watch researcher Jamillah Mwanjisi grew up in Mbeya, a small town in the southern highlands of Tanzania. After attending a college for journalism in the capital city of Dar es Salaam, she became a reporter for *The Express*, an English newspaper, covering parliamentary issues and HIV/AIDS when the epidemic "was still an issue we could not really talk about in the media." As one of the few privately-owned papers during a time of transition from socialism to open economy, *The Express* had more freedom of expression than most papers.

In 2002, Mwanjisi and seven other media, communication, and advocacy professionals founded Media Bank to help health and human rights organizations to conduct media-based advocacy. She has continued to work with Media Bank on a part-time basis for the past four years.

Mwanjisi admits she did not realize TB was a major health issue until she began her research with Public Health Watch. "I truly believed TB affected the older generation more and not as much the younger people," she says.

"In Mbeya, where I grew up, TB was discussed as a disease of the past—there might have been cases, but people did not talk about it ... As a journalist in Dar es Salaam, I would have assumed that I would have had information. If people like me who live in the big city and work with the media don't know about TB, then what do the people in the rural communities know? It was very frustrating... When we started doing the initial interviews with government officials, it was very hard to get information on TB."

Mwanjisi reports that available information on TB is overly technical and full of jargon, especially in comparison to resources on HIV/AIDS, and that government officials make little attempt to communicate the basic, essential information that people need in language they can understand. Mwanjisi also found the lack of available information on the linkages between TB and HIV/AIDS "shocking." Over 50 percent of people living with HIV/AIDS are coinfected with TB in Tanzania.

This lack of information can lead to delays in accessing treatment for people living with TB, increasing the potential for transmission of the disease. One recent study in Tanzania found that the median duration between onset of TB symptoms and visiting a health facility was about eight months.

Mwanjisi found that women are especially vulnerable to TB:

"Access to care is more limited for women compared to men. They cannot access treatment in time and for TB, accessing care in time is very important. TB is yet another threat for women. I haven't seen any interventions that are specifically targeting women. There should be extra efforts to target women."

She notes that Tanzanian women often have to "choose between traveling [to a clinic] and getting their medications or buying food for the family"—and often opt against accessing TB care. Patients from rural areas in particular may spend several hours traveling to and from health facilities and one to six hours in the clinic waiting to receive medications—every day for the first two months of treatment."

#### Ezio Távora dos Santos Filho

Ezio Távora dos Santos Filho, Brazilian researcher for Public Health Watch, has been living with HIV since the early 1980s, and worked for many years as a leading member of *Grupo Pela Vida*, the first organization for people living with HIV and AIDS in Brazil. He has also survived two cases of TB infection, the second a complex extra-pulmonary case which was diagnosed and treated while he was researching his Public Health Watch report. He comments:

"At present, only an individual with good connections and access to top-quality medical assistance (including rapid TB diagnostic tests) can survive a complex TB/HIV coinfection in Brazil."

Santos Filho has degrees in law and political science, and has been particularly interested in exploring the impact of international assistance on the design and implementation of Brazilian health policies and on HIV/AIDS and TB in particular.

As noted in the Public Health Watch report, the differences between the Brazilian AIDS and TB programs are striking. The AIDS program is extremely well funded and successful; it has been held up as a model of world-class, equitable service provision and AIDS health workers enjoy a high level of prestige.

By contrast, the Brazilian TB program is under-funded, poorly-organized and out of step with international TB control standards. At the same time, Brazil has more TB cases than any other country in Latin America and is the only country in the region to be designated a "high-burden country" by the WHO (one of the 22 countries that carries over 80 percent of the total global TB burden). Public awareness of the threat of TB, even among high-risk populations such as people living with HIV/AIDS, is extremely low, and stigmatization of people with TB is a serious issue. Santos Filho notes:

"People find it very strange when I speak openly about having TB – even very prominent and well-educated people often feel ashamed of admitting they have the disease."

Santos Filho believes the presence or absence of social mobilization is responsible for the difference between the quality of HIV/AIDS and TB policies and services: civil society groups have been extremely well-organized and effective in pressing for increased attention and funding for HIV/AIDS, but until recently there has been almost no public engagement around TB. He asserts that waiting for the kind of "bottom-up" engagement and activism on TB that was undertaken by the well-educated and politically connected constituencies first affected by HIV/AIDS may not be realistic when so many of those affected by TB are from the poorest and most marginalized communities. For Santos Filho, social mobilization is necessary, but will not occur without participation and support from donors, policymakers, and community activists (particularly HIV/AIDS activists).

#### Amara Soonthorndhada

The Public Health Watch researcher from Thailand, Amara Soonthorndhada, is a well-respected scholar in reproductive health and gender studies. Soonthorndhada has a Ph.D. from the School of Development Studies in University of East Anglia, England and two masters degrees: one in Sociology from the Banaras Hindu University in India and another in Applied Population Research from the University of Exeter in England.

She has been an associate professor at the Mahidol University in Thailand for 32 years and is currently the deputy director of the University's Institute for Population and Social Research.

While most of her research has centered around adolescent sexuality, gender roles in health development, and women's empowerment, Soonthorndhada began to focus on TB five years ago, with funding from the British Consulate and Department for International Development (DFID) and most recently, from Public Health Watch.

In Thailand, "the general perception among political leaders as well as in Thai society is that TB has been completely eradicated," Soonthordhada says. In actuality, while TB incidence had fallen by 50 percent from 1985 to 1991, the number of new TB case rose again in the 1990s with the emergence of the HIV/AIDS epidemic in Thailand. Today Thailand has an incidence rate of 142 cases per 100,000 people, and is 18th on the World Health Organization's list of high-burden countries.

"One of the problems to eradicate TB in Thailand is that ... the policymakers, [including] the people working in the Ministry of Health, think there are more important diseases they have to deal with such as bird flu or dengue fever," she explains.

Soonthordhada believes in addition to the lack of political commitment to eradicate TB, stigmatization of people living with TB and TB/HIV, and of women in particular, is an issue of concern. In Thailand, TB is perceived as a "male" disease, associated with a high-risk lifestyle and behaviors such as drinking, smoking, and an active nightlife. Thus, women infected with TB are seen as being at odds with social norms and expectations of female behavior, intensifying the level of stigmatization they experience. As a result, Soonthordhada fears that women are more prone to "self-medicate" and to delay seeking treatment from medical clinics. She stresses that more research is needed on gender and TB.

#### **FOR THE MEDIA:**

To arrange an interview with Olayide Akanni, Afsan Chowdhury, Jamillah Mwanjisi, Ezio T. Santos, or Amara Soonthorndhada by telephone or in person, please contact: Rachel Guglielmo (rguglielmo@sorosny.org) or Emily Bell (ebell@sorosny.org).