Technical Brief

Tuberculosis, Gender and Human Rights

April 2017
Geneva, Switzerland

The Global Fund

Contents

I. Introduction 3

II. Barriers to ensuring gender-responsive and rights-based TB programming 4

01 Reducing stigma and discrimination 7

02 Reducing gender-related barriers to TB services 8

03 TB-related legal services 8

04 Monitoring and reforming policies, regulations and laws that impede TB services 9

05 Knowing your TB-related rights 11

06 Sensitization of law-makers, judicial officials and law enforcement agents 11

07 Training of health care providers on human rights and ethics related to TB 11

08 Ensuring confidentiality and privacy 12

09 Mobilizing and empowering patient and community groups 12

IV. A rights-based and gender-responsive approach to TB responses 13

VI. Further reading 14

I. Introduction

The purpose of this Technical Brief is to assist Global Fund applicants to consider how to include programs to remove human rights and gender-related barriers to tuberculosis (TB) prevention, diagnosis and treatment services within funding requests and to help all stakeholders ensure that TB programs promote and protect human rights and gender equality.

"Promoting and protecting human rights and gender equality" is Strategic Objective 3 (SO3) in the Global Fund's new Strategy 2017-2022: Investing to End Epidemics.[1] With regards to TB, this objective commits the Global Fund to:

- Scale up programs to support women and girls, including programs to advance sexual and reproductive health and rights;
- Invest to reduce health inequities, including gender- and age-related disparities;
- Introduce and scale up programs that remove human rights barriers to accessing services;
- Integrate human rights considerations throughout the grant cycle and in policies and policy-making processes;
- Support the meaningful engagement of key and vulnerable populations and networks in Global Fund-related processes.

To fulfill SO3, the Global Fund requires that all funding requests (formerly 'Concept Notes') "must include, as appropriate, interventions that respond to key and vulnerable populations, human rights and gender related barriers and vulnerabilities in access to services."[2]

The new Strategy has elevated the Global Fund's commitment to gender equality, recognizing the urgent need to eliminate health disparities among men, women, adolescent girls and boys, and transgender people. Programs to remove human rights and gender-related barriers aim to address stigmatizing, discriminatory and punitive attitudes, practices, regulations, policies and laws that impede people's access to health services, and to protect and promote the realization of related human rights, such as the right to be free from cruel, inhuman or degrading treatment, and the right to redress, should rights be violated. Human rights and gender-related barriers to access to TB services have been identified in a number of TB concept notes, but few grants include programs to remove these barriers, or if they do include them, none go on to implement them to a significant scale. As highlighted in the Global Fund Tuberculosis Information Note, addressing gender inequality and human rights barriers with concrete programs and gender-responsive, human rights-based programming and implementation is essential to ensuring that quality TB services are available and accessible to all, in particular key and vulnerable populations.[3]

[1] *The Global Fund Strategy 2017-2022: Investing to End Epidemics*. GF/B35/02 – Revision 1, p.3. Available online.
[2] *The Global Fund Sustainability, Transition and Co-financing Policy.* GF/B35/04 – Revision 1, pp.6, 11-13. Available online.
[3] The Global Fund to fight AIDS, TB and Malaria: *TB Information Note*. Geneva, 2016, pp.14-15. Available online.

II. Barriers to ensuring gender-responsive and rights-based TB programming

Tuberculosis (TB) is among the world's leading cause of death among infectious diseases.[4] It is also a leading killer of people living with HIV, responsible for 35% of deaths in this population in 2015;[5] TB and HIV, and the gender and human rights-related challenges in addressing them, are thus closely intertwined. TB is a disease of poverty and inequality. A number of factors related to human rights and gender can hinder the effectiveness, accessibility and sustainability of TB programs and services, as explained in this section.

Underlying poverty and economic inequality: The realization of human rights is challenged in the lives of many people living with and at risk of TB. People who live in conditions of overcrowding, inadequate ventilation and poor nutrition are vulnerable to the disease and likely also to be disadvantaged in not having sound information about TB or access to good-quality TB services. While TB services themselves may be free, such factors as transportation to services and attaining good nutrition to support good treatment outcomes may be impeded by poverty. TB incidence and prevalence reflect poverty and inequality from community to community, as well as globally. While TB-related mortality overall declined 40% from 1990 to 2015, over 95% of TB-related deaths are in low- and middle-income countries,[6] with 86% of deaths in Africa and South and Southeast Asia.[7] Sub-Saharan Africa, with only 11% of the world's population, accounts for about 26% of new TB cases and about three quarters of new cases of HIV-TB co-infection.[8]

TB and HIV: People living with HIV and others with compromised immunity face high TB risk. TB was estimated to cause about one third of all deaths among people living with HIV in 2015.[9] It is well understood that HIV risk is also heightened by a wide range of human rights violations, including gender inequality and inequity. The stigma, discrimination and exclusion associated with HIV can amplify and be amplified by TB-related stigma.[10] Stop TB Partnership suggests tackling HIV and TB barriers in an integrated way with special outreach, integration of TB and HIV services at the facility level with health workers trained to understand the stigma and human rights concerns inherent to both diseases, peer support and community support for sustaining treatment, and support to government and community entities that can document human rights abuses in this doubly affected population and ensure functioning mechanisms of complaint and redress.[11]

Gender inequality and gender norms: Gender-related barriers to TB services may take many forms, affecting both men and women. Overall, men face higher risk of developing TB than women,[12] and there are more TB deaths among men. Men are generally less likely to have their TB detected and reported than women.[13] Men are also more vulnerable to TB due to gender-specific occupations. In many places, men are more likely to have jobs, such as mining or blasting, with exposure to particulates. Men may be more likely to migrate for work, which may cause interruptions in TB treatment. Men may also be more likely to smoke or use drugs in many societies, both independent risk factors for TB.

---

[4] World Health Organization. *Global Tuberculosis Report 2016.* Geneva, 2016, p 5. WHO estimates that in 2015 there were 1.4 million deaths from TB, another 0.4 million deaths from TB among people living with HIV, and 1.1 million deaths from HIV/AIDS.
[5] WHO TB fact sheet at http://www.who.int/mediacentre/factsheets/fs104/en/
[6] World Health Organization. Tuberculosis (fact sheet no. 104). March 2016, at: http://www.who.int/mediacentre/factsheets/fs104/en/.
[7] WHO *Global Tuberculosis Report 2016*, op.cit.
[8] Ibid.
[9] World Health Organization. HIV-associated tuberculosis (fact sheet). Geneva, 2016. At: http://www.who.int/tb/publications/tbhiv_factsheet.pdf?ua=1
[10] Daftary A. HIV and tuberculosis: The construction and management of double stigma. *Social Science & Medicine* 2012: 74: 1512–19.
[11] Stop TB Partnership. People living with HIV: Key populations brief. Geneva, 2016.
[12] Dodd PJ, Looker C, Plumb ID, et al. Age-and sex-specific social contact patterns and incidence of Mycobacterium tuberculosis infection. *American Journal of Epidemiology* 2016; 183(2):156-166
[13] Onozaki I, Law I, Sismanidis C et al. National tuberculosis prevalence surveys in Asia, 1990-2012: an overview of results and lessons learned. *Tropical Medicine and International Health* 2015; 20:1128–45

On the other hand, women may have less access to TB treatment and prevention services than men, and in some settings, have been less likely to undergo sputum smear examinations.[14] Women may have difficultly gaining access to TB services because male family members are unwilling to pay for these services, women's health may not be considered as important as that of male family members, or because TB in women is more stigmatized than in men.[15] Women generally wait longer than men for diagnosis and treatment, and may be discouraged from seeking care by a lack of privacy or child-care facilities in health care settings.[16] Women in prison are generally less likely to have access to TB treatment than incarcerated men.[17]

Stigma and discrimination: People with TB have a right to be free from discrimination in all settings, including health care, employment, housing, education and migration. Despite this right, they often face stigma and discrimination as a result of their TB status or TB history. As TB is often associated with poverty and other socially "undesirable" behaviors and living conditions, people with TB, or suspected of having TB, may be stigmatized and discriminated against based on their perceived socio-economic status and behaviors, as well as because of TB. Stigma and discrimination discourage the seeking and uptake of TB testing and treatment services. For people with HIV-TB co-infection, TB-related stigma may be exacerbated by HIV-related stigma.

People in state custody and people who use drugs: People in prison and pretrial detention are at high TB risk because of the conditions found in closed settings, which often include overcrowding, poor ventilation and poor sanitation. However, prisoners are often systematically excluded from TB prevention, diagnosis and care services, either through denial of access or because they do not know how or where to seek services.[18] People who use drugs in many settings face high TB risk not only because of shared drug-using equipment but also because they may live in conditions of poverty and they are likely to be in state custody in their lifetime.[19]

Mobile populations: In many circumstances, migrants, refugees, nomads and displaced persons are at particularly high risk of TB but may be excluded from services and information because of ethnic, cultural, linguistic or other discriminatory barriers, stigmatizing attitudes, illegal status, and fear of deportation or lack of required documentation.[20]

Occupational risks without protections: People in certain lines of work -- mining, health care, prisons, and certain industrial settings – may face particular risks of exposure to TB or to TB-related risk factors without adequate workplace protections.[21] In many places, mining relies on poorly paid workers in remote locations where state regulatory mechanisms do not hold mining companies to account for inadequate workplace safety.[22]

[14] Begum VP, de Colombani S, Das Gupta AH et al. Tuberculosis and patient gender in Bangladesh: sex differences in diagnosis and treatment outcome. *International Journal of Tuberculosis and Lung Disease* 2001; 5: 604–610.
[15] Country Coordinating Mechanism (HIV and TB), Niger. Evaluation de la prise en compte du genre dans les ripostes nationales au VIH et à la tuberculose au Niger : rapport définitif. Niamey, 2015.
[16] Begum et al., op.cit.; Thorson A, Diwan VK. Gender inequalities in tuberculosis: aspects of infection, notification rates, and compliance. *Current Opinion in Pulmonary Medicine* 2001; 7:165–169; see also Karim F, Akramul Islam M, Chowdhury AMR et al. Gender differences in delays in diagnosis and treatment of tuberculosis, *Health Policy and Planning* 2007; 22:329–334.
[17] UN Development Programme. Gender and tuberculosis. New York, Dec. 2015.
[18] Stop TB Partnership. Key populations brief: Prisoners. Geneva, 2016.
[19] Getahun H, Baddeley A, Raviglione M. Managing tuberculosis in people who use and inject illicit drugs. *Bulletin of the World Health Organization* 2013; 91(2):154-6.
[20] Stop TB Partnership. Key populations brief: Mobile populations. Geneva, 2016.
[21] Stop TB Partnership. Tuberculosis and human rights (briefing note). Geneva, undated.
[22] Stop TB Partnership. Key populations brief: Miners. Geneva, 2016.

Involuntary isolation: In a number of countries, laws or public health regulations allow for compulsory detention, isolation or other punishment for those who refuse TB treatment or are lost to care.[23] Such policies or practices create barriers to seeking and using health services and may constitute human rights violations. WHO suggests that, where patients are engaged respectfully and with their informed consent, unwillingness to undergo treatment is rare. In any case, as noted in WHO's *Guidance on the Ethics of TB Prevention, Care and Control*, detention "should never be a routine component" of TB programs.[24] In the rare case when, after all "reasonable efforts" have been made, a patient refuses care or continuation of care, a "carefully limited" involuntary isolation, using the least restrictive means possible, may be justified as a last resort.[25] Isolation must not be administered as a form of punishment, and any person subjected to it must have been informed in advance of the possibility of it.[26]

III. Programs to address gender inequality and remove human rights barriers in the TB response

The following descriptions of types of programs – with examples of real experiences – will help Global Fund applicants and implementers to identify ways to improve TB programs' health outcomes by reducing human rights barriers present in their specific TB epidemics. Most of the program areas on this list align with the program areas to reduce human rights barriers to HIV services that are recognized by the Global Fund and UNAIDS, and are as important for ensuring the effectiveness of TB services, as they are for HIV services. The following description of program areas and the examples are not exhaustive. Countries should choose the interventions that are clearly indicated by the epidemic they face and the populations particularly affected. The resources listed at the end of this paper may be consulted for more information.

[23] Mburu G, Restoy E, Kibuchi E, Holland P, Harries AD. Detention of people lost to follow-up on TB treatment in Kenya: the need for human rights-based alternatives. *Health and Human Rights* 2016; 18(1):43-54.
[24] World Health Organization. *Guidance on ethics of tuberculosis prevention, care and control*. Geneva, 2010.
[25] Ibid.
[26] Ibid.

01 Reducing stigma and discrimination

Many kinds of programs can address TB-related stigma and discrimination, for example:

- Assessing stigma and discrimination: Many stigma indexes and other tools have been developed to help assess the type and level of TB-related stigma in a given population, e.g. in health care settings, in communities, and whether stigma is worse in some locations or some population groups than in others. This information can be crucial for designing effective anti-stigma measures. (See references to some tools in "Further reading".)
- Addressing stigma and discrimination in the community and workplace: There are many lessons learned from program experiences in the provision of basic non-judgmental information on TB, accessible to the lay public and to employers and employees, to counter stigma and discrimination. (See "Further reading".) Such information can help de-stigmatize people vulnerable to or affected by the disease, empower patients and their communities to know their rights, and ensure access to services for all. Mass media or other awareness-raising activities can help address stigma in the community or workplace, especially if they are informed by an understanding of the origins of stigma and the nature of misconceptions that may feed stigma. (See Box 1.) Experiences from a number of countries indicate that stigma can also be reduced through such strategies as patient support groups, clubs or "buddy" programs in the workplace, and mobilizing and informing anti-stigma champions among political, religious, cultural or thought leaders. In Kunming, China, where migrant workers are a particularly vulnerable population, the Global Fund supported information campaigns with workers and also with potential employers of migrant workers at construction sites, factories and hotels.[27] Information included the importance and location of MDR-TB prevention and treatment services. All workplace information programs should emphasize that TB patients should not be fired when they are ill.
- Addressing stigma in health care settings**:** Many programs have been designed to help health workers understand and address their own concerns about TB risk on the job, as well as stigmatizing attitudes toward patients.[28] Ensuring confidentiality and privacy of patients with TB is an important part of stigma reduction in health facilities and increases uptake of health services by those who need them.[29] (See also point 6 below.)
- Addressing stigma and discrimination in education**:** TB-related stigma can lead to discrimination and exclusion in education;[30] and it has been demonstrated that school-based information programs have been effective in some settings.[31]

[27] Humana People to People China. TB Kunming: 2014 Year Report. At: ww.uffnorge.org.
[28] International HIV/AIDS Allliance, Zambart Project and STAMPP-EU. *Understanding and challenging TB stigma: toolkit for action.* Brighton, UK, 2009; Stop TB Partnership. Good practice: Stop TB Partnership challenge facility for civil society – financial support to community initiatives for positive change. Geneva, undated.
[29] Stop TB Partnership. Key populations brief: Health Care Workers. Geneva, 2016.
[30] See, e.g., Cremers AL, de Laat MM, Kapata N, et al. Assessing the consequences of stigma for tuberculosis patients in urban Zambia. *PLoS ONE* 2015; 10(3):e0119861.
[31] Gothankar JS. Tuberculosis awareness program and associated changes in knowledge levels of school students. *International Journal of Preventive Medicine* 2013; 4(2):153-7.

Reducing TB-related stigma and raising awareness in India

A major communication and community mobilization initiative in the Indian state of Odisha was meant to generate community support for people in need of TB services and to contribute to reduction of stigma.[32] Specially trained "interface NGOs" worked with community groups and local leaders to raise awareness of the availability of free services and to dispel misinformation about TB using language, illustrations and examples to which everyone could relate. In the qualitative evaluation that followed, TB patients reported experiencing less stigma in health services, and both government health workers and traditional healers said they understood the disease better and were less wary of helping people with TB. The presence of former patients in community-level awareness-raising was found to be especially helpful. Adequate financial support to NGOs which spearheaded the work was also seen to be a crucial determinant of its positive outcome.

02 Reducing gender-related barriers to TB services

A number of gender-related barriers or potential barriers to TB services are mentioned above. Countries need to understand their populations at risk of TB and living with TB who may likely comprise groups of men at risk. Assessments of gender-related barriers to services in a given community and systematic collection of gender-disaggregated data on incidence, prevalence and services can inform targeted outreach to men and women, training of health workers and other health system strengthening. As suggested in the Global Fund's TB Information Note, gender-focused assessments can highlight regulations, laws and policies as well as program practices that fail to take into account gender-related drivers of risk. If men's (or women's) working hours impede seeking health services, useful measures may include mobile services, increasing budgets to allow for longer hours of service at fixed facilities, and advocacy with community leaders, men's and women's groups and others on the importance of access to services for all. If men tend not to use primary health care facilities because they are perceived to be for women and children, for example, targeted awareness-raising may change attitudes. If men are disadvantaged as migrant workers or workers exposed to particulates or are more likely to use drugs,[33] advocacy and targeted extension of male-friendly services can help. In HIV-endemic areas, TB services and information should be available to women seeking HIV care and assistance in preventing vertical transmission of HIV. UNDP recommends systematic collaboration among TB, HIV and maternal and child health service providers to optimize women's access to TB services and information.[34]

03 TB-related legal services

Even if people know their rights, they may not be able to assert their rights without assistance from legal or paralegal professionals. In some circumstances, access to legal assistance may be the most direct and effective way for marginalized persons to get access to TB services or to be protected from compulsory treatment or involuntary isolation or to address stigma and discrimination. Community-based and peer-led legal counselling or services may be particularly effective. For example, the NGO *Namati* mobilizes lawyers and trains paralegals to work with community leaders and health committees to improve access to health services, including TB services. In Mozambique, this approach brought legal remedies to HIV and TB patients facing delays in receiving their medications, as well as rectifying poor sanitation conditions in health facilities, helping to establish mobile services for some remote populations, and cutting wait times for severely ill patients.[35]

[32] Kamineni VV, Turk T, Wilson N, Satyanarayana S, Chauhan LS. A rapid assessment and response approach to review and enhance advocacy, communication and social mobilisation for tuberculosis control in Odisha state, India. *BMC Public Health* 2011; 11:463.
[33] Ibid.
[34] UNDP, op.cit.
[35] Feinglass E. Spring 2015 program update: Realizing the right to health. *Health Namati News*, June 2015.

04 Monitoring and reforming policies, regulations and laws that impede TB services

Policies and laws can impede access to TB services and can be challenged in many ways, depending on the nature of the policy or law, e.g. through advocacy, community mobilization and awareness-raising, and litigation. Some examples are noted below of actions that can be taken to change policies and laws that undermine the uptake and effectiveness of TB programs:

- Actions to combat involuntary isolation, coerced or compulsory treatment: Global Fund applicants may, for example, request support for: (a) assessment of current policies and laws regarding isolation and compulsory treatment (including whether migrants, minorities, people who use drugs or other disfavored populations are disproportionately isolated); (b) advocacy for practices and laws that conform to international standards; (c) support for training of health workers or judges; or (d) "know your rights" efforts for patients or the general public. Funding requests may also include measures to strengthen mechanisms of complaint and redress for patients who believe their rights are violated. They might also include resources to establish exemplary community-based treatment and monitoring to show alternatives to involuntary isolation.[36] (See Box 2 below for an example of the use of litigation in this regard.)
- Reforming intellectual property regulations and laws and regulatory frameworks for medicine registration: Médecins Sans Frontières (MSF) estimates that only 2% of people who need the newer medicines that can treat MDR and XDR TB have access to them, partly because of the high prices of these medicines which are protected by patents, and partly because these medicines are not yet registered for therapeutic use in some countries.[37] Facing a similar challenge with respect to hepatitis C medicines, a principal recipient of a Global Fund grant in Ukraine used the leverage of Global Fund support to negotiate a concessionary price with the manufacturer of the medicines and to push the government to agree to speed up registration and assume more of the treatment costs down the road.[38] The lessons from this experience may be relevant to TB.
- Improving policies, practices and laws affecting care for mobile populations such as refugees and other migrants: In the interest of public health and human rights, migrant workers, refugees and displaced people should have access to the TB services that they need. But in many countries, access to health services is conditioned on proof of citizenship or residency. Even internally displaced persons (IDP) may not be able to gain access to health services outside their home province or region.[39] Global Fund funding proposals, including in challenging operating environments where refugee and IDP movements may be intense, may request support for advocacy in favor of health regulations and policies that keep borders or movement from becoming barriers to essential services. In addition, measures such as the following may help to establish an environment conducive to policy change: (a) health worker training or sensitization on the situation of migrants, refugees and internally displaced people; (b) cross-border referral systems and other collaboration to open discussions for cross-border policies and practice standards; and (c) operations research on social determinants of TB in migrant, refugee and displaced populations.[40]

[36] World Health Organization. *Guidance on ethics of tuberculosis prevention, care and control*. Geneva, 2010.
[37] Médecins Sans Frontières. Just 2% of people with the severest cases of drug-resistant TB currently have access to new, more effective treatments (online statement), 21 March 2016, at: http://msfaccess.org/about-us/media-room/press-releases/just-2-people-severest-cases-drug-resistant-tb-currently-have-acc#
[38] Maistat L, Alliance for Public Health – Ukraine. Rolling up HCV treatment programs for PWID in Ukraine. Presentation to VHPB meeting, Ljubjana, March 2016.
[39] Stop TB Partnership. Mobile populations: Stop TP Partnership key populations brief. Geneva, 2016.
[40] International Organization for Migration and World Health Organization. Tuberculosis prevention and care for migrants. Geneva, 2014, at: http://www.who.int/tb/publications/WHOIOM_TBmigration.pdf

- Enabling legal and policy framework: When criminal sanctions, especially imprisonment, are applied to drug use, minor drug possession and possession of drug-using equipment, as is the case in many countries, it is likely that a large percentage of people who use drugs will be in prison or pretrial detention at some time in their lives and also that they will be reluctant to use health services for fear of exposure of their drug use.[41] The Global Fund funding application could include advocacy for creating an enabling environment to ensure access to TB diagnosis, treatment, care and support to people who use drugs, including advocacy to review punitive legal and policy framework hindering people who use drugs from accessing TB services or developing health policies that enable integration of TB services with methadone clinics or other facilities that may be trusted by people who use drugs.
- Improving workplace/occupational policies and laws: Global Fund applicants may request support for assessments of or challenges to employment-related laws and practices that undermine the rights of workers who have TB or have had TB or who are put at risk of TB on the job, including failing to give them time off for treatment without loss of their job or seniority and failing to ensure confidentiality of workers' TB status.[42] These problems can be addressed by advocacy, litigation, education of employers, TB workplace policies and worker empowerment activities. As noted above, depending on the nature of the epidemic and the locale, occupational risks may fall disproportionately on men who engage in occupations where TB related risks are high, e.g. blasting or mining, or on women who do likewise, e.g. health provision. In either case, efforts to improve workplace policies should be informed by an assessment of men's and women's attitudes toward seeking and utilizing TB services and should encourage access to male-friendly/women-friendly information on TB in the workplace.
- Improving prison conditions and policies: Global Fund funding requests may include activities to assess and/or address prison conditions with respect to TB risk – overcrowding, poor ventilation, drug injection with contaminated equipment, etc. – and to establish policies and practices that minimize TB risk and optimize access to care. One of the most important actions to support in Global Fund grants may be advocacy for less use of pretrial detention and incarceration where non-custodial sanctions are possible.[43]

Using the courts to challenge TB-related imprisonment

In 2010 in Nandi County, Kenya, in a case initiated by the public health officer, two men were convicted and sentenced to eight months in prison for non-compliance with TB treatment.[44] In prison, they endured conditions that could only exacerbate their illness, including overcrowding and poor diet. They were released with the help of civil society organizations after 46 days. The Kenyan NGO KELIN filed a petition with the high court to challenge the practice of imprisonment as punishment in such cases. The ruling of the High Court on World TB Day in March 2016 recognized that detention may be justified to protect the public's health, but that detention should not be in a prison because, among other things, it is meant to be for treatment, not punishment.[45] The court declined to award damages to the plaintiffs for their time in prison, but it ordered the development of a policy on health-related confinement. The court's decision was hailed as a "game-changer" by KELIN and a milestone toward more rights-based and patient-centered practices related to isolation linked to TB.[46]

[41] Getahun et al., op.cit.
[42] International Labour Organization. *Tuberculosis: Guidelines for workplace control activities.* Geneva, 2003.
[43] Csete J. Consequences of injustice: pretrial detention and health. *International Journal of Prison Health* 2010; 6(1):3-14.
[44] Maleche A, Were N. Petition 329: A legal challenge to the involuntary confinement of TB patients in Kenyan prisons. *Health and Human Rights Journal* 18(1):103-08.
[45] Ibid.
[46] Maleche A, Wafula T. Imprisonment of TB patients declared unconstitutional in Kenya. New York: Open Society Foundations, 2016, at: https://www.opensocietyfoundations.org/voices/imprisonment-tb-patients-declared-unconstitutional-kenya

05 Knowing your TB-related rights

TB-related rights literacy – helping people to know their rights under health regulations and national law as well as their human and patient rights with respect to TB -- can be part of larger information campaigns or community systems strengthening activities or can be more targeted. Rights literacy can be crucial, especially for marginalized populations already prone to discrimination and exclusion and without good access to mainstream information sources. It is best to combine rights literacy with measures that improve access to legal services or with measures to combat problematic policies and laws (see below). Patients' rights programs can also be effectively combined with training of health care workers in nondiscrimination, gender-responsiveness, confidentiality and informed consent. Health workers, mine workers, prison staff and others who may be exposed to TB on the job may also benefit from rights literacy programs.

06 Sensitization of law-makers, judicial officials and law enforcement agents

As suggested in the example from Kenya above, judges may also play important roles in protecting and fulfilling the rights of TB patients as well as caregivers. Training of police, judges, and other law enforcement and judicial personnel may be an essential activity to ensure the effectiveness and uptake of TB services. As with HIV, training of police is likely to be best received when it includes practical information on how police can protect themselves from TB on the job.

07 Training of health care providers on human rights and ethics related to TB

While health workers might be expected to be models for the community in respecting the rights of people affected by or at risk of TB, this is not always the case. Health workers may need support to overcome their own stigma and fears of acquiring TB, as well as to appreciate the importance of non-discriminatory provision of health care, informed consent, confidentiality and privacy, patient-centered care, patient rights and meaningful participation of patients in decision-making about their care. Training is one strategy for improving knowledge, attitudes and practices of health workers. It may be combined with integration of human rights and ethics elements in performance reviews or other incentives, as well as with patients' rights education. Training is unlikely to be effective if health workers perceive that they have inadequate supplies of medicines or diagnostics or otherwise poor workplace support, or if they feel their own privacy and confidentiality rights are inadequately protected.[47]

[47] Health and Development Networks, Stop TB Partnership, AIDS Care Watch, Development Cooperation Ireland. *Fighting TB on the front lines: Highlights and recommendations from the Stop-TB eForum 2005*. Dublin, 2005.

Improved health worker attitudes and practices in Tajikistan

Project Hope, a principal recipient of a Global Fund TB grant in Tajikistan, sought to address gaps in basic TB information for health workers and, at the same time, to address what it found in a baseline assessment to be patient-unfriendly practices and poor communication on the part of health workers.[48] A Tajikistan-specific program of basic TB information and interpersonal counselling/communication skills was designed for hospital nurses. In addition, hundreds of community volunteers were identified and trained to help improve TB knowledge in the general public. Because these activities occurred simultaneously, it is difficult to know which was responsible for the results, which included demonstrably better treatment outcomes and more effective community outreach. Project HOPE subsequently received major support from USAID to expand its TB work in Central Asia with an eye to improving the capacity of health personnel in the region to provide services to marginalized populations.[49]

08 Ensuring confidentiality and privacy

Not only with respect to the workplace but also in health care facilities, educational institutions and other settings, measures may be undertaken to reform policies, practices and laws that undermine confidentiality and privacy with respect to TB status. Funding requests to the Global Fund may include activities to assess practices in this area or to support the development of model policies and programs or undertake training of health workers.

09 Mobilizing and empowering patient and community groups

People's meaningful participation in decision-making about health policies and programs that affect them is an integral element of the right to health.[50] As is true for many health services, tuberculosis services have generally been delivered in a "top-down" fashion. The Global Fund, along with WHO, Stop TB Partnership and other experts, have emphasized, rather, that the best outcomes depend on empowering people to be meaningful participants in TB prevention, diagnosis and treatment, to know their rights as patients, and to play a "watchdog" role in monitoring the quality and reach of services.[51] Global Fund funding requests for TB can include community systems strengthening (CSS) activities that contribute to the empowerment of patients and the general public in interacting with TB service providers.[52] Some measures with successful outcomes in a number of countries include: (a) support to patient peer groups, (b) capacity-building to enable people, including men, women and young people, to take an active role in identifying and addressing TB risks in households, communities and workplaces, (c) creating platforms for formal participation of patients and patient groups in health decision-making, (d) building the policy advocacy capacity of current and former TB patients, and (e) building capacity and opportunity for community health committees or TB patient groups to monitor and report on the quality of TB services in their communities.[53]

[48] Stop TB Partnership and World Health Organization. *Advocacy, communication and social mobilization for tuberculosis control: Collection of country-level good practices.* Geneva, 2010.
[49] Project Hope, "Project Hope awarded $24M USAID grant for Central Asian Republics regional TB program," 10 October 2014, at: http://www.projecthope.org/news-blogs/press-releases/2014/
[50] UN Committee on Economic, Social and Cultural Rights, General comment no. 14, op.cit.
[51] Macq J. *Empowerment and involvement of tuberculosis patients in tuberculosis control: Documented experiences and interventions*. Geneva: World Health Organization and Stop TB Partnership, 2007.
[52] Global Fund to Fight AIDS, TB and Malaria. Community systems strengthening: information note. Geneva, 2014; also Global Fund, Community systems strengthening: technical brief [when available].
[53] Macq, op.cit.

10 Programs in prisons and other closed settings

People in prison and pretrial detention have the right to health services that are the equivalent of those in the community.[54] It is well established that the course of TB epidemics in prison is an important determinant of TB epidemics in society,[55] which indicates that TB services in prison should be part of all national TB control efforts. But if CCMs and program managers perceive that there are particular barriers to establishing TB services in prison and pretrial detention equivalent to those in the community, it may be useful to request support to address those barriers. Training of prison medical personnel, as well as guards and other prison staff, on the basics of TB prevention and care can be effective. Establishing coordination of prison care among prisons and with post-release care in the community can be the key to enabling people in state custody to begin TB treatment without fear of interruption when they are transferred or released.[56] Peer-based, patient-centered approaches should be encouraged in prison as in other settings.[57]

IV. A rights-based and gender-responsive approach to TB responses

The previous section outlines programs that address particular human rights and gender-related barriers to TB program effectiveness. But there is more to rights-based health services than specific programs to address human rights barriers. A human rights-based and gender-responsive approach to addressing TB and other health problems means integrating human rights and gender equality norms and principles – including non-discrimination, transparency and accountability -- in the design, implementation, monitoring, and evaluation of programs. It also means empowering vulnerable groups and key populations, putting in place necessary programs to address their particular vulnerabilities and needs, ensuring their participation in decision-making processes which concern them, and ensuring that there are mechanisms for complaint and redress when rights are violated. Human rights-based services should be informed by a thorough assessment and analysis of where human rights barriers and gender inequality exist and whom they affect. In some cases, improved targeting of existing programs to ensure inclusion of marginalized persons can be an important human rights measure.

The planning, implementation, monitoring and evaluation of Global Fund-supported TB programs are opportunities to contribute to rights-based national TB responses. They can help ensure that users of health services and those most affected by TB are brought together in non-threatening and meaningful consultation with government, service providers, community leaders and others in civil society. The perspectives and voice of those affected by the disease are irreplaceable, including in determining priorities for reducing gender inequality and human rights barriers and in devising and implementing the most effective prevention and treatment services. Where there are established national human rights bodies or ombudspersons, those institutions may also play an important role in ensuring the respect, protection and fulfillment of the rights of people needing and using TB services.

[54] UN Commission on Crime Prevention and Criminal Justice. *United Nations Standard Minimum Rules for the Treatment of Prisoners (the Mandela Rules)*. UN doc. E/CN.15/2015/L.6/Rev.1, 21 May 2015 (see rule 24).
[55] Stuckler D, Basu S, McKee M, King L. Mass incarceration can explain population increases in TB and multidrug-resistant TB in European and central Asian countries. *Proceedings of the National Academy of Sciences* 2008;105(36):13280-5.
[56] Dara M, Acosta CD, Melchers NV, et al. Tuberculosis control in prisons: current situation and research gaps. *International Journal of Infectious Diseases* 2015; 32:111-7.
[57] Ibid.

V. Conclusion

Identifying and reducing human rights barriers to TB prevention, diagnosis and treatment may make the difference between programs that reach only the relatively privileged and programs that have broad and sustainable impact. In most cases, the programs described here to remove human rights and gender equality related barriers to TB services have a track record in some parts of the world. Their design, implementation and evaluation are the subject of international guidance and standards (see "Further reading" below). Building reduction of human rights barriers into Global Fund-supported TB programs will increase the effectiveness of national TB programs by making health services more effective and by increasing the reach of these services among highly marginalized and vulnerable groups. They will also serve to strengthen community and health services, leading to greater sustainability and equity.

VI. Further reading

The list below includes reports and guidelines available on the internet as well as articles from open-access scholarly journals.

TB, human rights and ethics: general

Citro B, Lyon E, Mankad M, Pandey KR, Gianella C. Developing a human rights-based approach to tuberculosis. *Health and Human Rights* 2016; 18(1):1-8. https://www.hhrjournal.org/

Slagle T, Ben Youssef M, Calonge G, Ben Amor Y. Lessons from Africa: developing a global human rights framework for tuberculosis control and prevention. *BMC International Health and Human Rights* 2014; 14:34. http://bmcinthealthhumrights.biomedcentral.com/articles/10.1186/s12914-014-0034-7

Stop TB Partnership. Tuberculosis and human rights (briefing note). Geneva, undated. http://www.stoptb.org/assets/documents/global/hrtf/Briefing%20note%20on%20TB%20and%20Human%20Rights.pdf

World Health Organization. *Guidance on ethics of tuberculosis prevention, care and control*. Geneva, 2010. http://www.who.int/tb/features_archive/ethics/en/

Communication and awareness-raising for TB

World Health Organization and Stop TB Partnership. *Advocacy, communication and social mobilization (ACSM) for tuberculosis control: A handbook for country programs*. Geneva, 2007.

World Health Organization and Stop TB Partnership. *Advocacy, communication and social mobilization to fight TB: A ten-year framework for action*. Geneva, 2006.

US Agency for International Development and Stop TB Partnership. *Guide to monitoring and evaluation of advocacy, communication and social mobilization to support TB prevention and care.* Washington, DC, 2013.

TB-related stigma

Courtwright A, Turner AN. Tuberculosis and stigmatization: pathways and interventions. *Public Health Reports* 2010; 125 Suppl 4:34-42. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2882973/

International HIV/AIDS Allliance, Zambart Project and STAMPP-EU. *Understanding and challenging TB stigma: toolkit for action*. Brighton, UK, 2009.

Macq J, Solis A, Martinez G, Martiny P. Tackling tuberculosis patients' internalized social stigma through patient centred care: an intervention study in rural Nicaragua. *BMC Public Health* 2008; 8:154.

Somma D, Thomas BE, Karim F et al. Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia. *International Journal of Tuberculosis and Lung Disease* 2008; 12(7):856-66. https://www.researchgate.net/publication/5311522_Gender_and_socio-cultural_determinants_of_TB-related_stigma_in_Bangladesh_India_Malawi_and_Colombia

Gender and TB
Stop TB Partnership, UNAIDS. *Gender assessment tool for national HIV and TB responses.* Geneva, 2016. http://www.stoptb.org/assets/documents/resources/publications/acsm/Gender_Assessment_Tool_TB_HIV_UNAIDS_FINAL_2016%20ENG.pdf

UN Development Programme. Gender and tuberculosis. New York, Dec. 2015. http://www.undp.org/content/dam/undp/library/HIV-AIDS/Gender%20HIV%20and%20Health/Gender%20and%20TB%20UNDP%20Discussion%20Paper%20(1).pdf

TB in the workplace
International Labour Organization. *Tuberculosis: Guidelines for workplace control activities.* Geneva, 2003. http://www.ilo.org/wcmsp5/groups/public/@ed_protect/@protrav/@ilo_aids/documents/publication/wcms_116660.pdf

World Health Organization and International Labour Organization. *Joint WHO/ILO policy guidelines on improving health worker access to prevention, treatment and care services for HIV and TB*. Geneva, 2014. http://apps.who.int/iris/bitstream/10665/44467/1/9789241500692_eng.pdf

TB and key populations
Stop TB Partnership series of monographs on key populations, including women, children, mobile populations, miners, people who use drugs, prisoners, rural populations and urban populations: http://www.stoptb.org/resources/publications/

Getahun H, Baddeley A, Raviglione M. Managing tuberculosis in people who use and inject illicit drugs. *Bulletin of the World Health Organization* 2013; 91(2):154-6.

International Organization for Migration and World Health Organization. Tuberculosis prevention and care for migrants. Geneva, 2014, at: http://www.who.int/tb/publications/WHOIOM_TBmigration.pdf

Patient and community empowerment
Macq J. *Empowerment and involvement of tuberculosis patients in tuberculosis control: Documented experiences and interventions*. Geneva: World Health Organization and Stop TB Partnership, 2007

Stop TB Partnership. *Good practice: Stop TB Partnership challenge facility for civil society – financial support to community initiatives for positive change*. Geneva, undated.

TB in prisons and pretrial detention
Dara M, Acosta CD, Melchers NV, et al. Tuberculosis control in prisons: current situation and research gaps. *International Journal of Infectious Diseases* 2015; 32:111-7. http://www.ijidonline.com/article/S1201-9712(14)01747-0/pdf

International Committee of the Red Cross. *Combating TB, HIV and malaria in detention – Uganda's experience*. Geneva, 2015. https://www.icrc.org/en/publication/av061a-combating-tb-hiv-and-malaria-detention-ugandas-experience

Penal Reform International and Royal Netherlands Tuberculosis Foundation. Human rights and health in prison: a review of strategy and practice. London, 2006. http://www.penalreform.org/resource/human-rights-health-prisons-review-strategy-practice/

World Health Organization Regional Office for Europe. *Prisons and health*. Copenhagen, 2014. http://www.euro.who.int/en/health-topics/health-determinants/prisons-and-health/publications/2014/prisons-and-health