

---

# Tuberculosis, Gender and Human Rights Technical Brief

---

14 NOVEMBER 2019

GENEVA, SWITZERLAND

# Table of Contents

1. Introduction	3
2. Gender- and human rights-related risk of TB transmission and barriers to TB services	4
3. A rights-based and gender-responsive approach to TB responses	7
3.1 Knowing the epidemic	
3.2 Integrating TB into broader community and health systems	
4. Programs to address gender and human rights-related barriers in the TB response	9
4.1 Reducing stigma and discrimination	
4.2 Addressing gender-related risks to TB and barriers to services	
4.3 TB-related legal services	
4.4 Monitoring and reforming policies, regulations and laws that impede TB services	
4.5 Knowing your TB-related rights	
4.6 Sensitization of law-makers, judicial officials and law enforcement agents	
4.7 Training of health care providers on human rights and ethics related to TB	
4.8 Ensuring confidentiality and privacy	
4.9 Mobilizing and empowering groups of people affected by TB and community groups	
4.10 Programs in prisons and other closed settings	
5. Further Reading	19

# 1. Introduction

The purpose of this technical brief is: (1) 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 (2) to help all stakeholders ensure that TB programs promote and protect human rights and gender equality.

Through the Political Declaration of the United Nations High Level Meeting on TB, Member States have committed to:<sup>1</sup>

- Affirm that all people affected by TB access people-centered prevention, diagnosis, treatment, management of side effects and care, as well as psychosocial, nutritional and socioeconomic support for successful treatment.
- Commit to involve affected communities and civil society in the TB response.
- Commit to recognize the various sociocultural barriers to TB prevention, diagnosis and treatment services, especially for those who are most vulnerable.
- Commit to promote and support an end to TB-related stigma and all forms of discrimination, including by removing discriminatory laws, policies and programs.
- Commit to enacting measures to prevent tuberculosis transmission in workplaces, schools, transportation systems, incarceration systems and other congregate settings.
- Commit to developing community-based health services through approaches that protect and promote equity, ethics, gender equality and human rights.

The global TB survivor community has worked to articulate these rights further with the Declaration of the rights of people affected by tuberculosis.<sup>2</sup>

The Global Fund's strategy includes an objective about "Promoting and protecting human rights and gender equality", recognizing the urgent need to eliminate health disparities among men, women, adolescent girls and boys, and transgender people.<sup>3</sup> With regards to TB, this objective describes the need 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.

Funding requests to the Global Fund should include, as appropriate, interventions that respond to key and vulnerable populations, human rights and gender-related barriers and vulnerabilities in access to services.<sup>4</sup>

---

<sup>1</sup> UN General Assembly. Political declaration of the high-level meeting of the General Assembly on the fight against tuberculosis. UN doc. A/RES/73/3, 18 October 2018, [https://www.un.org/en/ga/search/view\\_doc.asp?symbol=A/RES/73/3](https://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/73/3)

<sup>2</sup> Stop TB Partnership and TB People. Declaration of the Rights of People Affected by Tuberculosis <http://www.stoptb.org/assets/documents/communities/Declaration%20of%20the%20rights%20of%20people%20affected%20by%20TB%20-%20A5%20english%20version.pdf>

<sup>3</sup> *The Global Fund Strategy 2017-2022: Investing to End Epidemics*. GF/B35/02 – Revision 1, p.3. Available [online](#).

<sup>4</sup> *The Global Fund Sustainability, Transition and Co-financing Policy*. GF/B35/04 – Revision 1, pp.6, 11-13. Available [online](#).

Addressing gender and human rights barriers with concrete programs and gender-responsive human rights-based programming is essential to ensuring that quality TB services are available and accessible to all, in particular key and vulnerable populations.<sup>5</sup>

Programs aim to work at the individual, community and provider levels to promote better access to critical TB prevention and treatment services. This includes addressing stigmatizing, discriminatory and punitive attitudes, practices, regulations, policies and laws that impede people's access to health services. Further, programs and approaches should be adopted that recognize differences in risk and access to services based on gender, age, work status, and other factors.

Applicants can refer to the Global Fund's Technical Brief: *Gender Equity*<sup>6</sup> for further information on the Global Fund commitment to address gender and age-based inequities in the context of HIV, TB and malaria.

## 2. Gender- and human rights-related risk of TB transmission and barriers to TB services

TB is one of the world's leading causes of death among infectious diseases.<sup>7</sup> It is also a leading killer of people living with HIV, responsible for an estimated 300,000 deaths in this population in 2017.<sup>8</sup> 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. Many 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.** People who live in conditions of overcrowding, inadequate ventilation and poor nutrition are at higher risk of contracting TB infection and developing TB disease, and they are likely to lack access to good-quality TB services and information about the disease. People affected by TB have the right to access good-quality TB prevention, testing, treatment and care services as part of the right to health. While TB medicines themselves may be free, such factors as transportation, good nutrition to optimize treatment outcomes, and initial diagnostic costs may be impeded by poverty. TB incidence and prevalence reflect poverty and inequality. While TB-related mortality overall declined 42% from 2000 to 2017, over 82% of TB-related deaths among HIV-negative people occurred in Africa and South and Southeast Asia.<sup>9</sup> However, most TB deaths can be prevented with early diagnosis and good-quality treatment. In high-income countries, less than 5% of people with TB die from TB-related death.<sup>10</sup> Sub-Saharan Africa, with only 11% of the world's population, accounts for about 25% of new TB cases and about three quarters of new cases of HIV-TB co-infection.<sup>11</sup>

**TB and HIV co-infection.** 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 2017.<sup>12</sup> It is well understood that HIV risk is also heightened by a wide range of human rights violations, including gender inequality. The stigma, discrimination and exclusion associated with HIV can amplify and be amplified by TB-related stigma.<sup>13</sup> In settings where women are disproportionately affected by HIV, they may also face a higher burden of TB than their male

<sup>5</sup> The Global Fund to fight AIDS, TB and Malaria: *TB Information Note*. Geneva, 2016, pp.14-15. Available [online](#).

<sup>6</sup> [https://www.theglobalfund.org/media/5728/core\\_gender\\_infonote\\_en.pdf](https://www.theglobalfund.org/media/5728/core_gender_infonote_en.pdf)

<sup>7</sup> 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.

<sup>8</sup> WHO Global TB Report 2018, [https://www.who.int/tb/publications/global\\_report/tb18\\_ExecSum\\_web\\_4Oct18.pdf?ua=1](https://www.who.int/tb/publications/global_report/tb18_ExecSum_web_4Oct18.pdf?ua=1)

<sup>9</sup> WHO *Global Tuberculosis Report 2018*, op.cit.

<sup>10</sup> Ibid.

<sup>11</sup> Ibid.

<sup>12</sup> World Health Organization. HIV-associated tuberculosis (fact sheet). Geneva, 2016. At:

[http://www.who.int/tb/publications/tbhiv\\_factsheet.pdf?ua=1](http://www.who.int/tb/publications/tbhiv_factsheet.pdf?ua=1)

<sup>13</sup> Daftary A. HIV and tuberculosis: The construction and management of double stigma. *Social Science & Medicine* 2012; 74: 1512–19.

counterparts. This is the case in areas of sub-Saharan Africa where young women especially (18-24 years) may face 2 to 3 times higher rates of new HIV infections than men of the same age.<sup>14</sup>

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.<sup>15</sup>

**Gender-related risks.** Globally, men and boys account for 64% of TB cases. This means that approximately two men become infected with TB for everyone woman or girl.<sup>16</sup> Men also are less likely to have their TB detected and reported than women, and men account for 63% of TB deaths among HIV-negative people.<sup>17</sup> However, gender-related risks and barriers to TB services take many forms, affecting everyone.

A growing body of literature highlights how notions of masculinity can negatively impact health-seeking behavior of men, which may be manifested as late or missing TB diagnoses and lower rates of TB treatment access and completion.<sup>18,19</sup> In many places, men are more likely to have employment, such as mining or blasting, that is associated with increased risk of TB. Men are more likely to engage in behavior with increased risk of TB, including smoking, alcohol consumption, and drug use.

On the other hand, women may have less access to TB treatment and prevention services than men due to cultural norms and inequalities. For women and girls, diagnostic delays and lower service efficiency may be due to increased stigma associated with having TB and the non-integration of TB services with other reproductive, maternal and child health services. Women may have difficulty 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.<sup>20</sup> 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.<sup>21</sup> In some settings, women have been less likely to undergo sputum smear examinations due to cultural norms and perceptions about femininity as well as gender dynamics of service provision.<sup>22,23</sup>

**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 because 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. Some research shows that that women may be significantly more vulnerable to stigma than men, with TB status

---

<sup>14</sup> Women and Girls – A Spotlight on Adolescent Girls and Young Women. Geneva, UNAIDS. 2019.

[https://www.unaids.org/sites/default/files/media\\_asset/2019\\_women-and-hiv\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/2019_women-and-hiv_en.pdf)

<sup>15</sup> Stop TB Partnership. People living with HIV: Key populations brief. Geneva, 2016.

<sup>16</sup> WHO *Global Tuberculosis Report 2018*

<sup>17</sup> WHO *Global Tuberculosis Report 2018*, op.cit.

<sup>18</sup> Chikovore et al. (2017). TB and HIV stigma compounded by threatened masculinity: implications for TB health-care seeking in Malawi, *International Journal of Tuberculosis and Lung Disease* 21(11):S26–S33.

<sup>19</sup> WHO, *Global Tuberculosis Report 2018*

<sup>20</sup> 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.

<sup>21</sup> 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.

<sup>22</sup> Cremers AL, de Laat MM, Kapata N, Gerrets R, Klipstein-Grobusch K, Grobusch MP (2015) Assessing the Consequences of Stigma for Tuberculosis Patients in Urban Zambia. *PLoS ONE* 10(3): e0119861. doi:10.1371/journal.pone.0119861

<sup>23</sup> 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.

undermining real or perceived marriage prospects.<sup>24,25</sup> 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.

Respect for the right to privacy and confidentiality of people with TB is key to combatting stigma and discrimination, particularly in health care, employment and education. This includes a right to privacy in their personal health data and to decide whether, how, when, with whom and to what extent their health information is shared or disclosed, including whether they have TB infection or TB disease.

The Stop TB Partnership Stigma Measurement Assessment<sup>26</sup> is a new tool that will help national TB programs and TB affected communities to measure the stigma that is faced by people affected by TB. The Global Fund Core List of indicators for TB<sup>27</sup> includes new indicators aim to measure the impact of stigma in accessing TB services over time. The Stigma Measurement Assessment and other efforts to measure the level and impact of the TB-related stigma are important ways to demonstrate the impact of the evidence-based and quality stigma reduction programs on accessing TB services.

**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. Moreover, 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.<sup>28</sup> Women in prison are generally less likely to have access to TB treatment than incarcerated men.<sup>29</sup> 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.<sup>30</sup>

**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.<sup>31</sup>

**Occupational risks without protection.** 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.<sup>32</sup> 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.<sup>33</sup>

**Involuntary isolation.** In a number of countries, laws or public health regulations allow for compulsory detention, isolation or other punishment for people with TB who are lost to follow-up.<sup>34</sup> Such policies or practices create barriers to seeking and using health services and may constitute human rights violations. When people with TB are engaged respectfully and their informed

---

<sup>24</sup> Miller et.al.(2017). 'It makes the patient's spirit weaker': tuberculosis stigma and gender interaction in Dar es Salaam, Tanzania, *International Journal of Tuberculosis and Lung Disease* 21(11):S42–S48.

<sup>25</sup> Cremers, Anne Lia, 1,2, Myrthe Manon de Laat1 , Nathan Kapata1,3,4, Rene Gerrets2 , Kerstin Klipstein-Grobusch5,6, Martin Peter Grobusch1

<sup>26</sup> <http://www.stoptb.org/communities/>

<sup>27</sup> Global Fund Modular Framework Handbook, Tuberculosis Core list of indicators includes: TB O-7 percentage of people with TB who experienced self-stigma due to their TB status that inhibited them from seeking and accessing TB services; TB O-8 percentage of people with TB who experienced stigma in health care settings due to their TB status that inhibited them from seeking and accessing TB services; and TB O-9 percentage of people with TB who experienced stigma in community settings due to their TB status that inhibited them from seeking and accessing TB services.

[https://www.theglobalfund.org/media/4309/fundingmodel\\_modularframework\\_handbook\\_en.pdf](https://www.theglobalfund.org/media/4309/fundingmodel_modularframework_handbook_en.pdf)

<sup>28</sup> Stop TB Partnership. Key populations brief: Prisoners. Geneva, 2016.

<sup>29</sup> UN Development Programme. Gender and tuberculosis. New York, Dec. 2015.

<sup>30</sup> 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.

<sup>31</sup> Stop TB Partnership. Key populations brief: Mobile populations. Geneva, 2016.

<sup>32</sup> Stop TB Partnership. Tuberculosis and human rights (briefing note). Geneva, undated.

<sup>33</sup> Stop TB Partnership. Key populations brief: Miners. Geneva, 2016.

<sup>34</sup> 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.

consent is respected, unwillingness to undergo treatment is rare. As noted in WHO's *Ethics Guidance for the Implementation of the End TB Strategy*, involuntary isolation should never be a routine component" of TB programs.<sup>35</sup> In all cases, involuntary confinement is an infringement of the right to liberty and security of person. In the rare case when a person is contagious with TB and poses a danger to others, after all reasonable efforts have been made to initiate treatment and implement infection control measures, involuntary isolation, as a last resort, may be justified using the least restrictive means possible and only for the period when the person remains contagious.<sup>36</sup> Isolation must be administered in a medically appropriate setting with provision of treatment and testing services, as well as nutritious food and other basic necessities. Isolation may not be administered as a form of punishment, and any person subjected to it must have been informed in advance of its possibility.<sup>37</sup> In addition, there must be mechanisms of appeal, complaint and redress for those wishing to assert unjust practices. Forced treatment, whether during involuntary isolation or not, is never permissible.<sup>38</sup> Forcibly treating a person with TB is unethical and a violation of human rights.

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

A human rights-based and gender-responsive approach to TB and other health problems entails integrating human rights and gender equality norms and principles – including non-discrimination, the right to health, 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 that 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. 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.

#### 3.1 Knowing the epidemic

Countries need sex- and age-disaggregated data on treatment initiation and completion to understand their TB epidemics and program according to who is most at risk. Currently most

---

<sup>35</sup> World Health Organization. *Ethics Guidance for the Implementation of the End TB Strategy*. Geneva, 2017.

<sup>36</sup> Ibid.

<sup>37</sup> Ibid.

<sup>38</sup> Ibid.

countries routinely collect case notification data (the number of new or relapse TB cases reported to health authorities) with a breakdown by sex and age. Collecting other key indicators such as treatment initiation and completion data by sex would allow countries to understand how gender and age interact with the epidemic, and which sub-populations are at higher risk of not being reached with quality services.

These data should be complemented with an understanding of the reasons populations are disproportionately affected by TB. Some countries are starting to conduct routine gender and human rights assessments of their TB responses to identify barriers to services and design more community-responsive programs. To facilitate this activity, the Stop TB Partnership has developed a Community, Rights and Gender (CRG) Assessment tool, which will support countries in understanding why people aren't being reached and how to respond appropriately.<sup>39</sup> For example, in Tanzania, the Eastern Africa Network of AIDS Services Organizations (EANNASO) supported the national program to carry out a CRG assessment. One of the outcomes was a review of the gender policy and how the findings from the assessment could inform more concrete responses to address differences in care driven by gender-related risks or barriers. Further, a new electronic TB register to track individual cases captures vulnerable populations and disaggregates data by age and sex to better inform programming. National TB plans and strategies should be based on this profound understanding and inclusion of programming to address gender and human rights-related barriers.

#### **Stop TB Partnership Community, Rights and Gender Assessment**

The Global Fund has supported Community, Rights, and Gender (CRG) assessments in key countries through its TB Strategic Initiative 'Finding the missing people with TB' implemented by the Stop TB Partnership. These assessments are meant to investigate the extent to which national responses to TB (and HIV) take into account the critical aspects of gender equality and human rights. The assessments aim to enable countries to improve the planning, implementation, monitoring and evaluation of human rights-based TB programming and gender-transformative TB approaches. Key results from some of the first assessments revealed too few supportive laws and policies to protect human rights and ensure gender-transformative approaches (Philippines and Pakistan). TB-related stigma was also found to be high (South Africa), and further meaningful engagement of vulnerable and marginalized TB key populations\* in TB policy and programming was recommended (Indonesia).

\* Stop TB categorizes key populations as prisoners, miners, people who use drugs, PLHIV, healthcare workers, mobile populations, children under 5 years, rural and urban poor and indigenous people.

### **3.2 Integrating TB into broader community and health systems**

Efficient and effective delivery of TB services should be based on where and how people can most easily access services. Community responses are needed as part of the paradigm shift from top-down efforts to control the epidemic to multisectoral collaboration to end TB. Collaboration with communities and civil society organizations is a pillar of both WHO's End TB Strategy<sup>40</sup> and the Stop TB Partnership's Global Plan to End TB.<sup>41</sup>

Gender is one component that drives people's ability to access services and their care preferences. In many contexts, TB services may reach more men if delivered through private

<sup>39</sup> These assessments are country owned, led by civil society in partnership with National TB Programs. These assessments have now been undertaken in Bangladesh, Cambodia, Democratic Republic of the Congo, Indonesia, Kenya, Mozambique, Nigeria, Pakistan, Philippines, South Africa, Tanzania and Ukraine and several more countries are underway.

<sup>40</sup> World Health Organization. *The End TB Strategy*. Geneva, 2014.

<sup>41</sup> Stop TB Partnership. *The Global Plan to End TB – The Paradigm Shift, 2016-2020*. Geneva, 2015.



providers and workplace-based programs. On the other hand, strategies to reach women may rely on initial contact through maternal or child services. UNDP recommends systematic collaboration among TB, HIV and maternal and child health service providers to optimize women's access to TB services and information.<sup>42</sup> This recommendation is particularly pertinent in settings with high HIV burden among adolescent girls and women of reproductive age (15-49), where integration into large-scale prevention and PMTCT programs is a key strategy for reaching women and their children with TB diagnosis and treatment.<sup>43</sup> A recent CRG assessment in Ukraine recommended the referral of people with TB to social services providers, such as centers of social services for family, children and youth, social services institutions and NGOs, to receive support for both them and their families.<sup>44</sup>

In Kenya, the 2018 CRG assessment noted a lack of interventions focused on men, who are disproportionately affected by TB in the country. As a result, men affected by TB built upon outreach efforts to target specific populations through Community Health Volunteers (CHVs). TB screening programs were set up in settings where most of the workers are men, such as quarries and *matatu* (minibus communal taxis) and *boda boda* (motorcycle and bicycle taxis) enterprises. The town of Busia on the Ugandan border has a clinic that targets truck drivers and offers screening for TB and HIV. Once screened, truck drivers are advised on TB treatment as needed. The clinic staff also provides TB medicines to drivers who may have forgotten theirs.

## 4. Programs to address gender and human rights-related barriers in the TB response

The following descriptions of interventions— with examples of real experiences – intend to support Global Fund applicants and implementers to identify ways to improve TB programs' health outcomes by reducing human rights and gender-related barriers to services. The program areas on this list align with recommendations from technical partners, including WHO and the Stop TB Partnership. The following descriptions 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. Additional resources can be found at the end of this document.

### 4.1 Reducing stigma and discrimination

The following programs can address TB-related stigma and discrimination:

- **Assessing stigma and discrimination.** Stigma indexes and other tools provided in the “further reading” section of this technical brief can support applicants and implementers to assess the type and level of TB-related stigma in a given population, such as healthcare settings, communities or others. This assessment can also show if stigma is more pronounced

---

<sup>42</sup> UNDP, op.cit.

<sup>43</sup> Needham DM, Foster SD, Tomlinson G, Godfrey-Faussett P. Socio-economic, gender and health services factors affecting diagnostic delay for tuberculosis patients in urban Zambia. *TM & IH*. 2001; 6: 256–259.

<sup>44</sup> Ukraine Stop TB CRG Assessment

in some locations or groups. The information collected is key to designing programs that include anti-stigma measures.

- **Addressing stigma and discrimination in the community and workplace.** Lessons learned from program experiences show that provision of basic non-judgmental, gender-responsive information on TB, accessible to the lay public and to employers and employees, can counter stigma and discrimination.<sup>45</sup> Such information can help de-stigmatize people vulnerable to or affected by the disease, empower people with TB and their communities to know their rights, and ensure access to services for all. Recognition and respect for the rights to privacy and confidentiality of people with TB is also critical to combatting stigma and discrimination in the community and workplace. 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 support groups for people with TB, 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 potential employers at construction sites, factories and hotels.<sup>46</sup> Information included the importance and location of MDR-TB prevention and treatment services. All workplace information programs should emphasize that people with TB 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 people with TB.<sup>47</sup> Ensuring confidentiality and privacy of people with TB, including for their personal health data, is an important part of stigma reduction in health facilities and increases uptake of health services by those who need them.<sup>48</sup> See point 6 in this brief.
- **Addressing stigma and discrimination in education.** TB-related stigma can lead to discrimination and exclusion in education,<sup>49</sup> and it has been demonstrated that school-based information programs have been effective in some settings.<sup>50</sup>

---

<sup>45</sup> See “Further reading” section at the end of this brief.

<sup>46</sup> Humana People to People China. TB Kunming: 2014 Year Report. At: [www.uffnorge.org](http://www.uffnorge.org).

<sup>47</sup> International HIV/AIDS Alliance, 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.

<sup>48</sup> Stop TB Partnership. Key populations brief: Health Care Workers. Geneva, 2016.

<sup>49</sup> 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.

<sup>50</sup> 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 generated community support for people in need of TB services and helped contribute to reduction of stigma.<sup>51</sup> 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, people with TB 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 the NGOs that spearheaded the work was also seen to be a crucial determinant of its positive outcome.

### 4.2 Addressing gender-related risks to TB and barriers to services

Gender has a profound impact on risk of TB exposure, transmission, access to and delivery of TB services. TB prevention programs should be informed by and respond to the ways in which gender impacts on individual, household and community practices that increase risk of TB. 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 as workers exposed to particulates, or are more likely to use drugs,<sup>52</sup> advocacy and targeted extension of male-friendly services can help. Women face more financial barriers to care than men. Countries may consider programs to address this barrier through free TB treatment and diagnosis for female-headed households, changing clinic hours and/or diagnostic spaces, training health care workers on gender-responsive approaches to care, and work-place testing and treatment approaches.

In some settings, women are less likely to undergo sputum smear examinations due to cultural norms and perceptions about femininity as well as gender dynamics of service provision. Experiences from Malawi and Ethiopia suggest that cultural barriers to sputum tests interact with logistic and cost barriers faced by women. Adjusting protocols – for instance, to allow for home collection of sputum or to eliminate having to return to a health facility solely for the purpose of sputum sampling – may help overcome these barriers.<sup>53</sup>

### 4.3 TB-related legal services

Even if people know their rights, they may not be able to assert them 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, 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 in Mozambique mobilizes lawyers and trains paralegals to work with community leaders and health committees to improve access to health services, including TB services. This approach has brought legal remedies to people with HIV and TB facing delays in receiving their medications, as well as rectifying poor sanitation conditions in health facilities, helping to establish mobile services for remote populations, and cutting wait times for severely ill

<sup>51</sup> 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.

<sup>52</sup> Ibid.

<sup>53</sup> Kumwenda M, Nyang/wa B-T, Chikuse B et al. The second sputum sample complicates tuberculosis diagnosis for women: A qualitative study from Malawi. *International Journal of Tuberculosis and Lung Disease* 2017; 21(12):1258-1263; Yassin MA, Datiko DG, Tulloch O et al. Innovative community-based approaches doubled tuberculosis case notification and improve treatment outcome in southern Ethiopia. *PLoS One* 2013; 8: e63174.

persons.<sup>54</sup> Programs aiming to improve access to justice should be attentive to barriers to legal services faced by women as a result of unequal household-level decision-making power and resource control as well as inequality under the law.

With access to legal services, people with TB, those at risk and their advocates have in many instances used litigation to challenge human rights-related barriers to TB services. A 2017 compendium of TB-related case law by the TB, Human Rights and the Law Consortium shows that litigation has been used in a number of countries spanning several regions in areas such as TB-related employment discrimination; compulsory isolation, treatment or testing; practices in prison; insurance and compensation issues; barriers faced by immigrants and asylum-seekers; and poor-quality care.<sup>55</sup> Details of successful legal arguments in these cases may inform future legal action.

#### 4.4 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. For example, through advocacy, community mobilization, awareness-raising and litigation. Some examples of actions that can be taken to change policies and laws that undermine the uptake and effectiveness of TB programs are:

- **Actions to combat involuntary isolation, coerced or compulsory treatment.** Forced treatment is never permissible. In all cases, treatment for TB must be provided on a voluntarily basis with the individual's informed consent and cooperation. Global Fund applicants may, for example, request support for: (a) assessments 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 people with TB or the general public. Funding requests may also include measures to strengthen mechanisms of complaint and redress for persons in TB care who believe their rights are violated. They might also include resources to establish exemplary community-based treatment and monitoring in order to show alternatives to involuntary isolation.<sup>56</sup> An example can be found in Box 2.
- **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.<sup>57</sup> Facing a similar challenge with respect to hepatitis C medicines, the 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 future treatment costs.<sup>58</sup> 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.

<sup>54</sup> Feinglass E. Spring 2015 program update: Realizing the right to health. *Health Namati News*, June 2015.

<sup>55</sup> University of Chicago Law School, International Human Rights Clinic. *Tuberculosis, human rights and the law: A compendium of case law (1<sup>st</sup> ed.)*. Chicago, 2017.

<sup>56</sup> World Health Organization. *Guidance on ethics of tuberculosis prevention, care and control*. Geneva, 2010.

<sup>57</sup> 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-access>

<sup>58</sup> Maistat L, Alliance for Public Health – Ukraine. Rolling up HCV treatment programs for PWID in Ukraine. Presentation to VHPB meeting, Ljubljana, March 2016.

But in many countries, access to health services is conditional 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.<sup>59</sup> Global Fund requests for funding, including in challenging operating environments where refugee and IDP movements may be intense, can include support for advocacy in favor of health regulations and policies that keep borders or movement from becoming barriers to essential services. In addition, these measures may help to establish an environment conducive to policy change. For example: (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.<sup>60</sup>

- **Enabling legal and policy framework.** When criminal sanctions, especially imprisonment, are applied to drug use, minor drug possession and possession of drug-using equipment, 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 be reluctant to use health services for fear of their drug-use becoming known.<sup>61</sup> The funding application to the Global Fund could include advocacy for creating an enabling environment to ensure access to TB diagnosis, treatment, care and support for people who use drugs, including advocacy to review punitive legal and policy frameworks hindering people who use drugs from accessing TB services, or for developing health policies that enable integration of TB services with methadone clinics or other facilities that are 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, 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.<sup>62</sup> 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, such as blasting or mining, or on women in health care provision. Women who are domestic workers or in other informal-sector jobs are in many countries unlikely to be included in national insurance schemes or face other systematic barriers to TB care. 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.** Applications to the Global Fund may include activities to assess and/or address prison conditions with respect to TB risk – overcrowding, poor ventilation, drug injection with contaminated equipment, and others – and to establish policies and practices that minimize TB risk and optimize access to care. Advocacy for less use of pretrial detention and incarceration where non-custodial sanctions are possible is an intervention that countries should consider including in Global Fund grants.<sup>63</sup>

---

<sup>59</sup> Stop TB Partnership. Mobile populations: Stop TP Partnership key populations brief. Geneva, 2016.

<sup>60</sup> 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](http://www.who.int/tb/publications/WHOIOM_TBmigration.pdf)

<sup>61</sup> Getahun et al., op.cit.

<sup>62</sup> International Labour Organization. *Tuberculosis: Guidelines for workplace control activities*. Geneva, 2003.

<sup>63</sup> Csete J. Consequences of injustice: pretrial detention and health. *International Journal of Prison Health* 2010; 6(1):3-14.

### Using the courts to challenge TB-related imprisonment

In 2010 in Nandi County, Kenya, in a case initiated by a public health officer, two men were convicted and sentenced to eight months in prison for non-compliance with TB treatment.<sup>64</sup> 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 prison. Detention is meant to be for treatment, not punishment.<sup>65</sup> 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.<sup>66</sup>

#### 4.5 Knowing your TB-related rights

Even if people know their rights, they may not be able to assert them without assistance from legal or paralegal professionals.

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 – either 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). Patient rights programs can also be effectively combined with training of health care workers in non-discrimination, 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.

The *Nairobi Strategy on TB and Human Rights: A Human Rights-based Response to TB* provides a detailed roadmap to develop and implement a human rights-based response to TB at the global, regional, national and local levels.<sup>67</sup> The strategy includes elements of enhancing human rights literacy as well as other program areas described in this brief. The box below summarizes the elements of the Nairobi strategy.

Launched in 2019, the *Declaration of the Rights of People Affected by TB* is a proclamation of human rights by people affected by TB around the world.<sup>68</sup> The Declaration provides a comprehensive set of human rights norms related to TB that are derived from international and regional human rights law and can serve as a key document on which to base human rights literacy efforts for people affected by TB.

<sup>64</sup> 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.

<sup>65</sup> Ibid.

<sup>66</sup> 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>

<sup>67</sup> Available at [http://www.stoptb.org/assets/documents/communities/Nairobi\\_Strategy\\_WEB.PDF](http://www.stoptb.org/assets/documents/communities/Nairobi_Strategy_WEB.PDF).

<sup>68</sup> Stop TB Partnership and TB People. Declaration of the Rights of People Affected by Tuberculosis. Geneva, 2019.

<http://www.stoptb.org/assets/documents/communities/FINAL%20Declaration%20on%20the%20Right%20of%20People%20Affected%20by%20TB%2013.05.2019.pdf>.

## **The Nairobi Strategy on Tuberculosis and Human Rights: A Human Rights-based Response to Tuberculosis**

### **Overall objective:**

To develop and implement a human rights-based response to TB at global, regional, national and local levels.

Sub-objective 1: Implement a human rights-based approach to TB through diverse advocacy strategies:

- Support networks of affected communities of people with TB, TB survivors and civil society at global, regional, national and local levels.
- Enhance judiciary and legal communities' awareness on implementation of a human rights-based approach to TB.
- Expand legislators' and policymakers' capacity to incorporate human rights-based approaches to TB in laws and policies.
- Engage and advise international organizations and experts on the implementation of human rights-based approaches to TB in global policies and programs
- Sensitize health care workers in public and private sectors on the need to incorporate a human rights-based approach to TB in their work.

Sub-objective 2: Develop further the conceptual, legal and normative content and evidence base for a human rights-based response to TB through interdisciplinary research and scholarship and close collaboration with people affected by TB.

- Formulate and clarify the conceptual, legal and normative content of a human rights-based approach to TB.
- Conduct qualitative and quantitative research to generate an evidence base for the effectiveness of a human rights-based approach to TB.

### **4.6 Sensitization of law-makers, judicial officials and law enforcement agents**

As suggested in the above example from Kenya, judges, as well as caregivers, may also play important roles in protecting and fulfilling the rights of persons with TB. 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. The Southern Africa Litigation Centre (SALC), for example, has trained lawyers in 10 countries on criminalization of TB and HIV, among other health rights-related issues.<sup>69</sup>

### **4.7 Training of health care providers on human rights and ethics related to TB**

Whereas health workers are often models for the community when respecting the rights of people affected by or at risk of TB, there are exceptions. 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 people with TB 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

<sup>69</sup> V Divan. The Nairobi Strategy on Tuberculosis and Human Rights: 2016-2018 Progress Report. October 2018, at: <http://www.stoptb.org/assets/documents/communities/Progress%20Report%202016-18%20-%20Nairobi%20Strategy%20on%20TB%20and%20Human%20Rights.pdf>

or diagnostics or otherwise poor workplace support, or if they feel their own privacy and confidentiality rights are inadequately protected.<sup>70</sup>

### **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.<sup>71</sup> 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. These led to demonstratively better treatment outcomes and more effective community outreach. However, the activities occurred simultaneously, which makes it difficult to attribute the positive results to any one single activity. Project HOPE subsequently received support from USAID to expand its TB work in Central Asia to improve the capacity of health personnel in the region to provide services to marginalized populations.<sup>72</sup>

## **4.8 Ensuring confidentiality and privacy**

Measures to reform policies, practices and laws that undermine confidentiality and privacy with respect to TB status should be considered in health care facilities, educational institutions, and other settings. 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.

## **4.9 Mobilizing and empowering groups of people affected by TB 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.<sup>73</sup> As is true for many health services, tuberculosis services have generally been delivered in a "top-down" fashion. The Global Fund partnership, including WHO and Stop TB Partnership, civil society and community partners, along with other experts, has supported the notion that the best outcomes come from empowering people<sup>74</sup> 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.<sup>75</sup> Funding applications for TB to the Global Fund can include community systems strengthening (CSS) activities that contribute to the empowerment of people with TB and the general public in interacting with TB service providers.<sup>76</sup> Some measures with successful outcomes in a number of countries include: (a) support to peer groups of people in TB care, in particular for drug-resistant TB; (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 people with TB and their groups in health decision-making, (d) building the policy advocacy capacity of people with TB and those who previously lived with the disease, and (e) building capacity and opportunity for community health committees or

<sup>70</sup> 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.

<sup>71</sup> Stop TB Partnership and World Health Organization. *Advocacy, communication and social mobilization for tuberculosis control: Collection of country-level good practices*. Geneva, 2010.

<sup>72</sup> 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/>

<sup>73</sup> UN Committee on Economic, Social and Cultural Rights, General comment no. 14, op. cit.

<sup>74</sup> Stop TB created and strengthened networks in Africa, America, Europe, Eastern Europe and Central Asia, and Asia Pacific.

<sup>75</sup> Macq J. *Empowerment and involvement of tuberculosis patients in tuberculosis control: Documented experiences and interventions*. Geneva: World Health Organization and Stop TB Partnership, 2007.

<sup>76</sup> 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]*.



groups of people in TB care to monitor and report on the quality of TB services in their communities.<sup>77</sup>

Community-based measures are essential to ensure that TB programs are responsive and as comprehensive as possible, ensure coverage of basic services at the community level, and meet the needs of marginalized and excluded groups. Improving community-led and community-based responses can significantly contribute to achievement of better TB outcomes. In order for communities to be equal partners in the response, they require resources, technical assistance, tools and appropriate organizational, institutional and technical capacity-building. Community responses cover a wide range of activities that contribute to the detection, referral and successful treatment of people with TB, drug-resistant TB or HIV-associated TB by addressing human rights and gender-related barriers to accessing TB services from diagnosis to treatment adherence support. Examples of community-based TB activities<sup>78</sup> include:

- awareness-raising, behavior change communication and community mobilization;
- reducing stigma and discrimination;
- screening and testing for TB and TB-related morbidity (e.g. HIV counselling and testing, diabetes screening), including through home visits;
- facilitating access to diagnostic services (e.g. sputum or specimen collection and transport);
- initiation and provision of TB prevention measures (e.g. Isoniazid preventive therapy, TB infection control);
- referral of community members for diagnosis of TB and related diseases;
- treatment initiation, provision and observation for TB and co-morbidities;
- treatment adherence support through peer support and education and individual follow-up;
- social and livelihood support (e.g. food supplementation, income-generation activities);
- home-based palliative care for TB and related diseases;
- community-led local advocacy activities.

In order to improve accessibility, responsiveness and quality of services, applicants are encouraged to explore the potential of allocating funds to community-based monitoring (CBM), “a process by which service users or local communities gather and use information on service provision or information on local conditions impacting on effective service provision.”<sup>79</sup> CBM increases community engagement and buy-in through collaborative processes identifying and addressing bottlenecks and gaps in service provision and the quality of the services, including human rights violations at the facilities and the communities against people affected by TB, in a collaborative manner and providing feedback using short local feedback loops.<sup>80</sup> For more information, refer to the Global Fund’s *RSSH Information Note*<sup>81</sup> and *Technical Brief on CSS*.<sup>82</sup>

---

<sup>77</sup> Macq, op.cit.

<sup>78</sup>ENGAGE-TB Approach (<https://www.who.int/tb/areas-of-work/community-engagement/background/en/>)

<sup>79</sup> EANNASO (2016). [Community Guide on Community-based Monitoring Mechanisms for Global Fund Grants](#).

<sup>80</sup> There are many CBM tools, such as the Stop TB OnImpact mobile application, which is being implemented in a number of countries, including DRC and Indonesia.

<sup>81</sup> Global Fund to Fight AIDS, TB and Malaria. *Building Resilient and Sustainable Systems for Health Information Note*. Geneva, 2019.

<sup>82</sup> Global Fund to Fight AIDS, TB and Malaria. *Technical Brief: Community Systems Strengthening*. Geneva, 2019.

#### 4.10 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 services received at the community level.<sup>83</sup> It is well established that the course of TB epidemics in prison is an important determinant of TB epidemics in society,<sup>84</sup> which indicates that TB services in prison should be part of all national TB control efforts. 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.<sup>85</sup> Peer-based, patient-centered approaches should be encouraged in prison as in other settings.<sup>86</sup>

In 2016, the South African NGO Sonke Gender Justice sued the government of South Africa over inhumane conditions of overcrowding and poor ventilation in Pollsmoor prison near Cape Town, citing TB risk to prisoners among other human rights violations in the facility. A decision in favor of Sonke Gender Justice and its co-litigants in this case resulted in a reduction in the prison population and changes in the regulations enabling incarcerated persons to have more access to outdoor exercise, among other improvements.<sup>87</sup>

---

<sup>83</sup> 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).

<sup>84</sup> 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.

<sup>85</sup> 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.

<sup>86</sup> *Ibid.*

<sup>87</sup> Keehn EN, Nevin A. Health, human rights, and the transformation of punishment: South African litigation to address HIV and tuberculosis in prisons. *Health and Human Rights Journal* 2018;20(1):213–224.

## 5. Further Reading

### **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/](http://www.who.int/tb/features_archive/ethics/en/)

Stop TB Partnership, KELIN, University of Chicago Law School. *The Nairobi Strategy: A human rights-based approach to TB*. Nairobi, 2016. <http://www.stoptb.org/assets/documents/communities/NairobiTBStrategyFINAL.pdf>

University of Chicago Law School, International Human Rights Clinic. *Tuberculosis, human rights and the law: A compendium of case law (1<sup>st</sup> ed.)*. Chicago, 2017. <http://www.stoptb.org/assets/documents/resources/publications/acsm/TB%20Human%20Rights%20and%20the%20Law%20Case%20Compendium%20FINAL.pdf>

Stop TB Partnership and TB People. Declaration on the Rights of People with Tuberculosis. Geneva, 2019.

<http://www.stoptb.org/assets/documents/communities/Declaration%20of%20the%20rights%20of%20people%20affected%20by%20TB%20-%20A5%20english%20version.pdf>

O'Neill Institute, Georgetown University. *Migration, Tuberculosis and the law: an urgent need for a rights-based approach*. Washington, DC, 2018.

<https://oneill.law.georgetown.edu/media/Migration-Tuberculosis-and-the-Law-An-Urgent-Need-for-a-Rights-Based-Approach.pdf>

Stop TB Partnership. UN high-level meeting on TB: Key targets and commitments for 2022. [http://www.stoptb.org/assets/documents/global/advocacy/unhlm/UNHLM\\_Targets&Commitments.pdf](http://www.stoptb.org/assets/documents/global/advocacy/unhlm/UNHLM_Targets&Commitments.pdf)

### 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 Alliance, 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](https://www.researchgate.net/publication/5311522_Gender_and_socio-cultural_determinants_of_TB-related_stigma_in_Bangladesh_India_Malawi_and_Colombia)

## **Stop TB CRG Assessment reports**

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](http://www.undp.org/content/dam/undp/library/HIV-AIDS/Gender%20HIV%20and%20Health/Gender%20and%20TB%20UNDP%20Discussion%20Paper%20(1).pdf)

Women and Girls – A Spotlight on Adolescent Girls and Young Women. Geneva, UNAIDS. 2019.

[https://www.unaids.org/sites/default/files/media\\_asset/2019\\_women-and-hiv\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/2019_women-and-hiv_en.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](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](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](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.ijdonline.com/article/S1201-9712\(14\)01747-0/pdf](http://www.ijdonline.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>

O'Neill Institute, Georgetown University. *Tuberculosis in prisons: a people's introduction to the law*. Washington, DC, 2019. <https://oneill.law.georgetown.edu/projects/tuberculosis-law-and-human-rights-project/tuberculosis-in-prisons-a-peoples-guide-to-the-law/>