Technical Brief

Removing Human Rights-related Barriers to TB Services

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Content

Overview

WHY – The imperative to remove human rights-related barriers to TB services

Human rights-related barriers (TB-related stigma and discrimination, harmful laws, policies and practices, gender inequality and gender-based violence) continue to keep people in need from gaining access to vital TB health services. These barriers can be overcome by implementing and scaling up recognized, well-defined, evidence-based programs that should be part of every national TB programme. These programs reduce stigma, give people knowledge about laws and policies and their rights, and provide legal and social support to prevent human rights violations and seek justice for discrimination and other abuse. Programs may also be designed to help health care workers to provide respectful, non-stigmatizing services. Programs especially must enable TB survivors and others affected by the disease to monitor and improve the provision of health care, to organize around health-related rights and to advocate for policies and practices that will increase access to health services.

HOW – Using the investment approach toward the goal of comprehensive programs to remove human rights-related barriers to services

Countries should take an investment approach in developing human rights programming. This requires that they:

- Assess and understand what the main human rights-related barriers to TB services are and who are affected by them.
- Design an evidence-based response to remove the existing barriers.
- Deliver programs to address human rights-related barriers at sufficient scale to make a difference.
- Monitor and implement evaluation programs to address human rights-related barriers, to inform quality and management; and
- Sustain the programs for the longer term, including by planning for government financing of donor-supported services.

WHAT –Effective programs to remove human rights-related barriers to services, including program essentials

Human rights-related barriers can be removed by implementing, as part of national TB programmes, interventions in some or all the following program areas:

- Eliminating TB-related stigma and discrimination.
- Reducing TB-related gender discrimination, harmful gender norms and violence.
- Improving legal literacy (“know your rights”).
- Increasing access to justice.
- Monitoring and reforming policies, regulations and laws.
- Ensuring people-centered and rights-based TB services at health facilities.

- Ensuring people-centered and rights-based law enforcement practices.
- Supporting community mobilization and advocacy, including community-led monitoring.
- Addressing the needs of people in prisons and other closed settings

The Global Fund has also recognized a subset of **program essentials** include in these program areas. Ideally, human rights-related barriers should be **comprehensively** addressed with interventions in all program areas. However, **at a minimum**, the Global Fund expects national TB programmes to include these **program essentials.** All TB programming are required to:

- Be human rights-based and gender-responsive.
- Be informed by and respond to analysis of inequities.
- Include stigma and discrimination reduction activities for people with TB and TB-affected populations.
- Include legal literacy and access to justice activities; and
- Include support for community mobilization and advocacy and community-led monitoring for social accountability.

In the sections on program areas, this technical brief integrates lessons learned and case studies from the Global Fund's Breaking Down Barriers initiative. Since 2017, Breaking Down Barriers has supported 20 countries to scale up programs that remove human rights-related barriers to services. Assessments of the work undertaken have demonstrated the importance of investing in such activities to ensure effective TB responses, and further progress assessments under way in 2022-2023 will continue to evaluate their impact.

1. Human Rights Commitments in the TB Response

The Global Fund to Fight AIDS, Tuberculosis and Malaria is committed to supporting efforts of governments and civil society to remove human rights-related barriers to prevention and treatment services for the three diseases.[i] It seeks to achieve this objective by supporting national TB programmes to implement and scale up evidence-based programs that remove stigma, discrimination and violence, in turn increasing access to prevention and treatment. These programs help to ensure that all people in need of TB prevention, testing and treatment have access to good-quality services. In addition to intensifying action to remove human rights barriers to health services, the Global Fund **requires that all grants be human rights-based, gender-responsive and informed by an analysis of inequalities and inequities**. Norms and principles of human rights, gender equality and equity should be integrated into the design, implementation, monitoring and evaluation of all TB activities. This includes non-discrimination, transparency, participation, fairness and accountability. [ii]

Box 1. Global Fund's human rights standards for all grant recipients

- Grant non-discriminatory access to services for all, including people in detention.
- Employ only scientifically sound and approved medicines or medical practices.
- Do not employ methods that constitute torture or cruel, inhumane or degrading treatment.
- Respect and protect informed consent, confidentiality and the right to privacy concerning medical testing, treatment or health services rendered.
- Avoid medical detention and involuntary isolation which, consistent with WHO guidance, are to be used only as a last resort.

The Global Fund Framework "promote enabling environments, in collaboration with partners and affected communities, to reduce TB-related stigma, discrimination, human rights and gender-related barriers to care, and advance approaches to address catastrophic cost due to TB."

This brief describes activities eligible for Global Fund support to contribute to realizing this goal.

In all countries, the Global Fund seeks to support meaningful participation of people with or having survived TB to address injustices that impede people's access to TB prevention, diagnosis and care. Confronting injustices such as TB-related stigma and discrimination that stand in the way of health services is crucial to an effective TB response. Confronting gender-related barriers to care entails pursuing **gender-transformative** programs – those that seek to turn harmful gender norms and practices into positive ones.

Human rights and gender equality are squarely on the global agenda for ending tuberculosis. At the 2018 TB High-Level Meeting, United Nations member states committed to end TB-related stigma and discrimination, implement accessible community-based TB services that promote equity, gender equality and human rights and ensure the meaningful involvement of affected communities in the TB response. In 2019 a "Declaration of the Rights of People Affected by

Tuberculosis"[iii] was developed by TB survivors and others affected by the disease. It emphasizes the right of all people to access TB services that reflect the "highest attainable standard" of prevention and care, delivered respectfully and without discrimination.

Stop TB Partnership's Global Plan to End TB 2023-2030 notes that it is essential that national TB programmes and their civil society partners work together to "remove legal, cultural human rights- and gender-related barriers to prevention, care and support".[iv] The Global Plan emphasizes the call of TB-affected communities for a global TB response that is based on rights and is "equitable and stigma-free, with communities at the center."[v] It highlights the crucial importance to national TB programmes of strengthening community systems, including ensuring that communities have the capacity to be leaders in monitoring the national TB response.

The purpose of this technical brief is to assist Global Fund applicants to develop strong funding requests for the module **Removing Human Rights and Gender-related Barriers to TB Services**, as well as for human rights-related activities in other modules. It describes human rights-related barriers to TB services, an investment approach to programming to remove those barriers and examples of programs that have been shown to reduce them, including examples of program essentials. It is hoped that the examples of existing programs from many countries provided here will inspire applicants' ideas about TB responses that promote and protect human rights and gender equality.[vi]

2. Human Rights and Gender-related Barriers to TB Services

TB is one of the world's leading causes of death among infectious diseases. Millions of people who become ill with TB are not diagnosed, and only about a third of those with drug-resistant TB have access to treatment.[vii] Human rights-related factors contribute to these problems. TB is a leading cause of death among people living with HIV. Depending on the context, the human rights-related challenges to addressing TB and HIV are closely related. TB is a disease of poverty and inequality. Many factors related to human rights can hinder the effectiveness, accessibility and sustainability of TB programs and services, as explained in this section.

Underlying poverty and economic inequality: Living in conditions of overcrowding, inadequate ventilation and poor nutrition, often associated with poverty, are TB risk factors. Even if TB medicines are free, people living in poverty may not be able to afford diagnostic tests or the cost of reaching a health facility or may face other economic and social barriers. As of 2022, over 80% of TB-related deaths occur in low- and middle-income countries.[viii]

TB and HIV co-infection: People living with HIV face high TB risk. They are 18 times more likely than those without HIV to develop active TB.[ix] The stigma, discrimination and exclusion associated with HIV can amplify and be amplified by TB-related stigma. **This close link between these two diseases means that HIV and TB services should be planned and implemented in close coordination.**

Gender-related risks: In 2020, 56% of TB cases were among adult men, 33% among women and 11% among children.[x] Men are usually more likely than women to face TB risk in occupations such as mining or blasting and because of risky behaviors such as smoking, alcohol consumption and drug use. Men's feelings of not needing regular health care or of seeing primary care facilities as being for women and children may result in delayed TB diagnosis and less successful treatment adherence.[xi,xii] Where men are often perceived as main breadwinners, the fear of losing work or economic opportunities by being perceived as ill also affects men's health seeking behavior. Women often have earlier access to TB and HIV diagnosis and care because of their engagement with reproductive health services. On the other hand, women may also have less autonomy and access to household resources for seeking TB diagnosis and care. Women may face particularly severe TB stigma, which was found to be a cause of women's delay in seeking treatment in Bangladesh, for example.[xiii] In some places cultural norms may make women hesitant to undergo sputum tests. Being known to have had TB has been reported to undermine the marriage prospects of women in some settings.[xiv] Failure to integrate TB services with reproductive care can also disadvantage women.

Stigma and discrimination. People with TB have a right to be free from discrimination in health care, employment, housing, education and other settings. But they face stigma and discrimination often because of TB's association with poverty and poor living conditions or because of misinformation and myths about the disease. Stigma may be worsened by the failure to protect the confidentiality and privacy of people affected by TB, particularly in health care, employment and education. Women, men and young people may all be affected.

People in state custody and people who use drugs. People in prison and pretrial detention are at high TB risk because these settings are often overcrowded and poorly ventilated. Prisoners are often systematically excluded from TB services, either through denial of access or because they do not know how to seek services, and women in prison are often less likely to have access to TB treatment than men.[xv] People who use drugs may face high TB risk not only because of shared drug-using equipment but also because they may live in conditions of poverty and are likely to be in state custody in their lifetime.

Mobile populations: In many circumstances, migrants, refugees, nomads and displaced persons are at high risk of TB and may be excluded from services and information. Barriers to services may include ethnic, cultural, linguistic, legal or other discriminatory attitudes and practices, illegal status, fear of deportation or lack of required documentation.

Occupational risks without protection. People in certain lines of work such as mining, health care, prisons and other closed settings, construction, and certain industrial settings, may be heavily exposed to TB-related risk factors without adequate workplace protections. In many places, mining, blasting and construction rely on poorly paid workers in remote locations where employers are not held to account for inadequate workplace safety.

Involuntary isolation. Laws or health regulations may allow for compulsory detention, isolation or other punishment for people with TB who refuse or do not complete treatment. Such practices may constitute human rights violations. When people with TB are treated respectfully, unwillingness to undergo treatment is rare. WHO notes that involuntary isolation "should never be a routine component" of TB programs.[xvi] Only in the rare case when a person is contagious with TB and all reasonable efforts have been made to initiate treatment and resisted, involuntary isolation may be justified as a last resort. In such rare cases, the least restrictive isolation possible must be used in a medically appropriate setting with good-quality care and only for the period of contagion. In addition, there must be mechanisms of appeal and redress for those who have been treated unjustly. Forced TB treatment, whether during involuntary isolation or otherwise, is never permissible.

Punitive laws and policies: In addition to laws that enable isolation practices without regard to the norms noted above, laws and policies that may constitute barriers to TB services include those that provide inadequate protection of:

- Privacy with respect to TB status.
- The right to be free of mandatory TB testing without informed consent.
- The rights of migrants and displaced persons to equal access to TB care.
- Workers exposed to TB and TB risk factors.
- The rights of employees not to be dismissed or punished during TB treatment or because of TB status.
- Equitable access to TB interventions and innovations for adults and children.[xvii]

In some countries, the rare instances of involuntary isolation for the purpose of TB treatment may make use of prisons or other criminal detention facilities, which is contrary to WHO guidance, as noted above.

Box 2. TB key and vulnerable populations

The Stop TB Partnership identifies several types of key and vulnerable populations with respect to TB.[xviii] These include:

- Those facing significant TB exposure because of where they live or work, including prisoners, sex workers, miners, hospital visitors, health care workers, those who live in urban slums or dwellings with poor ventilation, those who work with livestock.
- Those who have limited access to good-quality TB services, including migrant workers, women in settings with gender disparities, children, refugees and internally displaced persons, illegal miners, unhoused persons, and those with mental and physical disabilities; and
- Those at increased TB risk because of biological or behavioral factors that compromise immunity, including people who live with HIV, use tobacco, are undernourished, suffer from alcohol-use disorders, inject drugs or have diabetes or silicosis.

3. Investment Approach to Addressing Human Rights-related Barriers

This section uses the investment approach framework (understand/assess, design, deliver and sustain) to describe how programs to remove rights-related barriers should be planned, designed, implemented and scaled up. Programs to remove human rights-related barriers are a core part of the TB grant and the national response, as they are needed to increase access to services. The Global Fund aims to support countries to achieve **comprehensive** human rights programming (see Box 2).

Box 3. Comprehensive programs to remove human-rights related barriers:

a) Are a set of interlocking human rights activities that mutually reinforce each other to reduce barriers (see section 4 on program areas).

b) Are aligned to where the key and vulnerable populations are located and most affected by the barriers.

c) Cover the majority of the estimated numbers of those key and vulnerable populations; and

d) Are adequately resourced to move from one-off or small-scale activities to a level of implementation likely to significantly reduce human rights-related barriers to services.

3.1 Promoting meaningful participation of affected populations

It is part of Global Fund **program essentials** (see section 4.1 below) that programs to address human rights-related barriers to TB services be "informed by and respond to analysis of inequities". That is, programs should be based on a substantial assessment and analysis of where human rights barriers and gender inequality exist and whom they affect. Assessment of rights-related barriers to TB services should be conducted with the meaningful participation and leadership of people affected by TB and key populations, as well as other key stakeholders.

TB-related human rights and gender barriers were assessed in 13 countries in the Global Fund's Breaking Down Barriers (BDB) initiative.[xix,xx] The baseline assessments for TB identified the barriers noted in section 2, especially in their common finding that TB stigma and combined HIV and TB-related stigma are widespread.[xxi] They also revealed the intersectionality of rights-related barriers – that is, for example, people affected by TB faced gender-based discrimination and also stigma related to having been in prison or having used drugs. Baseline assessments helped to shape national plans to overcome these barriers in a comprehensive way. Midterm assessments were also conducted in BDB countries, showing development and in many cases significant expansion of programs to address rights-related barriers to TB services. Many of the program examples in this brief come from those assessments. At this writing, assessments of further progress in these countries are getting under way.

A number of countries have assessed TB-related human rights and gender barriers using the Communities, Rights and Gender (CRG) Assessment of the Stop TB Partnership, which was developed with the participation of people affected by TB.[xxii] It focuses on why and how people affected by TB, especially key and vulnerable populations, may be excluded from TB services. It also raises the issues of gender-related barriers and the legal and policy environment for TB services.[xxiii] For example, CRG assessments conducted in 13 countries found that explicit legal

protection from TB-related discrimination is commonly lacking, and migrants and formerly incarcerated persons are often excluded from services.[xxiv] Key populations not recognized in national TB programmes were identified through these assessments in almost all countries. Assessments using this tool yielded results that can be captured under seven dimensions of the right to health, namely: availability, accessibility, acceptability and quality (AAAQ) of programs; nondiscrimination; health-related freedoms; gender perspective; vulnerable and marginalized groups, participation and remedies and accountability.

Countries that do not have a recent assessment of human rights-related barriers and corresponding programs to address them should, whenever possible, use the Global Fund's new rapid assessment tool.

In addition to special assessments, it is useful for national health information systems to maintain age- and sex-specific data in their reporting of TB cases, as many countries do. Regular collection of data on treatment initiation and completion by sex and age, which is less frequently done, can help to identify barriers to care in specific sub-populations.

3.2 Design an evidence-based, comprehensive response to remove barriers

Once the barriers are understood and the location of the populations that are experiencing them are known, countries should put in place programs to remove those barriers. At a minimum, the countries' response should include the four program essentials (see section 4.1); but countries should design and plan for a **comprehensive response,** which will involve scaling up programming in all human rights program areas.

The following elements are important in the design of an effective response to removing human rights-related barriers to services:

- **Develop a theory of change** that clearly lays out the pathway to removing identified barriers. As noted above, many tools have been developed and used to assess gender-related and other human rights-related barriers to TB health services. Results of these assessments as well as emerging evaluations of existing programs can inform a theory of change aiming to guide development and expansion of efforts to address human rights-related barriers.
- **Involve those affected and those already working on TB-related human rights issues in program design.** Involve key and vulnerable populations meaningfully to select and design the human rights interventions that are included in funding requests. Many countries have human rights working groups that are familiar with TB issues and can help engage key populations. Where such working groups do not exist, it should be a priority to set one up or to expand the mandate of an existing working group. It should also be resourced appropriately in order to meet regularly and provide oversight to programs to reduce TB-related human rights-related barriers.
- **Provide support for community-centered and community-led programs.** Civil society entities, particularly community-led organizations, are societal enablers of the TB response. Communities should be at the center in designing and delivering programs to remove human rights-related barriers and be supported by investments to build and sustain their programming capacity.
- **Design for scale-up to comprehensive levels.** Applicants should plan, fund and implement programs at the scale necessary to have a significant, positive impact on access to services. Efforts to scale up programs should be strategic and aligned with national TB strategies,

investments cases and national human rights plans. To ensure sustainability, national TB programmes should have concrete plans for transition to government funding for donor-supported actions to reduce human rights-related barriers to TB services, as well as other elements of national TB efforts.

For more information on these elements, see the Global Fund's guidance on Achieving Quality in Programs to Remove Human Rights and Gender-related Barriers to HIV, TB and Malaria.

3.3 Deliver high-quality interventions to address human rights barriers

The following components are crucial to ensuring the delivery of programs to address human rights-related barriers to TB services. Further information and examples are found in section 4 below.

- **One-off activities are not enough:** Activities that involve a single, isolated or limited output, such as a training session or the one-time production of human rights materials, are not in and of themselves sufficient to reduce rights-related barriers. Rather they should be part of a larger strategy that ensures that attitudes and behaviors are changed and that those changes are sustained.
- **Combine programs for greater impact:** Programs from the different program areas should be combined to create the greatest impact. For instance, to change attitudes in health care delivery, combine training of health care workers and patient rights materials and rights literacy with community-led monitoring of health services. Programs aimed at different age groups may also be combined when practicable.
- **Build local expertise for sustainability:** Build a cadre of expertise among service providers and affected populations for longer-term capacity and sustainability. This can include (a) institutionalizing human rights education into pre- and in-service curricula for health care workers, social workers and law enforcement; (b) training outreach workers to act as peer human rights educators and paralegals; and (c) funding human resources to ensure that capacity to address human rights-related barriers can be sustained as part of national TB programmes.
- **Ensure human resources are adequate:** Implementation of programs to reduce human rights-related barriers can be delayed or hampered by the lack of dedicated human resources to oversee and coordinate these programs. For example, thanks to USAID and Global Fund support, many of the grants made in the Stop TB Partnership Challenge Facility for Civil Society, have explicitly supported building capacity of organizations led by TB survivors to design, implement and evaluate programs to reduce rights-related barriers.
- **Monitor and evaluate results:** Effective programming requires a robust system of monitoring, evaluating and learning from the inception of a program: this will allow implementers to measure progress, learn from results, conduct quality assurance and redesign activities for more impact. Examples in section 4 include some illustrations of monitoring and evaluation activities.
- **Transition from donor funding**: Throughout the process of implementation and scale-up, applicants should consider how to sustain the delivery of programs to remove human rights-related barriers. Countries should consider the financial, programmatic, governance and political dimensions of sustainability. From a financial perspective, countries should track progress towards sustainable funding and support for programs to reduce human rights-related barriers.

For more information on the sustainability of programs to remove rights-related barriers, see the Guidance Note on Sustainability, Transition and Co-Financing.

4. Programs to Address Gender- and Human Rights-related Barriers

4.1 Program essentials for national TB Programmes

The sub-sections below offer concrete examples from many countries of programs to address human rights-related barriers in nine program areas. Included in these program areas, the Global Fund has recognized a subset of **program essentials**. Ideally, human rights-related barriers should be **comprehensively** addressed with interventions in all program areas. However**, at a minimum**, the Global Fund expects national programmes to include these **program essentials** by ensuring that all TB programming must:

- Be human rights-based, gender-responsive and gender-transformative.
- Be informed by and respond to analysis of inequities.
- Include stigma and discrimination reduction activities for people with TB and TB-affected populations.
- Include legal literacy and access to justice activities; and
- Include support for community mobilization and advocacy and community-led monitoring for social accountability.

The program examples below fit into these essential areas, as noted in the subsections below.

It is also important to note with respect to **all** programs that rights-based, gender-responsive TB responses are built on well-tested human rights norms and principles. These include:

- Non-discrimination – whatever level of services are available, it should be offered without discrimination of any kind.
- Transparency, including ready access to health information.
- Accountability, including means of complaint and redress for those experiencing injustices.
- Progressive efforts to ensure affordable, accessible, culturally appropriate and scientifically sound services for all; and
- Meaningful participation of people affected by TB, including key populations and persons of all genders, in program and policy decision-making that affects them.

Gender-transformative human rights-based TB programming – that is, programming that seeks to turn harmful gender norms and practices into protective and beneficial ones – **can never be an afterthought.** It is central to ensuring that high-quality TB services are available and accessible to all. The planning, implementation and evaluation of Global Fund-supported TB programs are opportunities to contribute to gender-transformative TB responses.

Actions to address human rights and gender-related barriers to TB services, with examples from many countries, are described below. The program areas on this list align with recommendations from technical partners, including WHO and the Stop TB Partnership. Program types noted in the Global Fund Modular Framework Handbook[xxv] are noted as a reminder.

Some of the examples noted here of programs to reduce human rights-related barriers to TB health services are relatively new activities. Many have not been fully evaluated or have not been implemented long enough for their medium-term or long-term impact to be completely known. Rigorous evaluation of impact in all program areas is encouraged and is eligible for Global Fund support. In addition, further progress assessments in all BDB countries will be completed in 2023 and will undoubtedly yield more information on impact and lessons learned. Based on the emerging evidence from many settings, the program areas noted below should be included in national TB programmes.[xxvi]

Countries should choose the interventions that are indicated by the epidemic they face and the populations most affected. Though the examples here are presented in distinct program categories, these categories overlap to some degree. Additional resources to guide programs can be found in the Annex. Examples for which no other reference is provided are from the Breaking Down Barriers midterm assessments (see link to all assessments in Annex).

4.2 Examples from programs areas of demonstrated effectiveness

Certain types of programs have been shown or are beginning to be shown to be effective in reducing human rights-related barriers to TB services. These are:

- Eliminating TB-related stigma and discrimination.
- Reducing TB-related gender discrimination, harmful gender norms and violence.
- Improving legal literacy ("know your rights").
- Increasing access to justice.
- Monitoring and reforming policies, regulations and laws.
- Ensuring people-centered and rights-based TB services at health facilities.
- Ensuring people- centered and rights-based law enforcement practices.
- Community mobilization and advocacy, including community-led monitoring.
- Addressing the needs of people in prisons and other closed settings.

These are discussed in turn below.

➔ **Note:** Similar program areas are essential in Global Fund-supported HIV programs. **It is very important that those involved in the design, implementation and evaluation of all programs to reduce TB-related human rights barriers be aware of analogous HIV programs and coordinate with them to the greatest degree possible.** See also the Global Fund's Removing Human Rights-related Barriers to HIV technical brief.

a) Eliminating stigma and discrimination

Addressing TB-related stigma and discrimination is a **program essential** for TB funding requests. The Global Fund Modular Framework Handbook provides an illustrative list of several types of activities that can address TB-related stigma and discrimination, including:

- Situational analysis and assessments, for example, Stop TB-CRG Assessment, and TB Stigma Assessment.

- Programs to reduce all forms of internalized stigma among TB-affected communities**.**
- Engagement with religious and community leaders and celebrities.
- Peer mobilization and support developed for and by people with TB and affected communities, aimed at promoting well-being and human rights**.**
- Training of journalists and media professionals on TB and stigma, including the use of non-stigmatizing language in TB communication materials, media shows**.**
- On-going community-led and community-based monitoring of service quality, including stigma, discrimination, and other rights-violations.

Examples of these and other types of programs are discussed below.

Assessing stigma and discrimination: If the nature and extent of TB-related stigma and discrimination are not well known, assessing them is a priority. Periodic assessments using replicable and comparable methods are also useful to assess the impact of anti-stigma programs over time. The Global Fund Modular Framework includes indicators on TB-related self-stigma, stigma in health settings, and stigma in community settings that inhibit access to TB services. (Stigma in health settings is discussed in section F below.) includes indicators on TB-related self-stigma, stigma in health settings, and stigma in community settings that inhibit access to TB services (stigma in health settings is discussed in section F below).

The Stop TB Partnership stigma assessment tool[xxvii] lays out a six-month protocol to measure TB-related stigma. It covers stigma experienced by people affected by TB (anticipated, enacted and self-stigma), that experienced by families and caregivers of people affected diagnosed with TB, stigma in the community, stigma in health settings, and structural stigma (from policies, laws and law enforcement practices).

Supported by the Global Fund, **Ghana** is one of the first countries to have used the TB stigma tool in a large-scale study.[xxviii] The NGO TB Voice Network, led by TB survivors, helped conduct the study. In 8 of Ghana's 16 administrative regions, some 1,025 people with TB, 975 family members of affected people, 4,261 persons in the community, and 295 health workers were among the respondents, with about 100 persons tapped for in-depth interviews. The assessment detailed the many ways in which stigma and fear of discrimination undermine TB health-seeking and treatment adherence. Many suggestions for community-based awareness-raising were derived from the results, in addition to a recommendation for a law that would explicitly prohibit TB-related discrimination. The central role of TB Voice in the assessment was crucial to its credibility and ability to recruit members of the affected community.

Researchers in several countries recently reported on TB stigma studies that were designed before the Stop TB Partnership stigma assessment tool was available. They based their work on earlier WHO and Stop TB Partnership guidance on assessing TB-related knowledge, attitude and practice (KAP).[xxix] Much of their data collection was similar to the methods in the new assessment tool – for example:

- In an urban area of **Uganda,** it was found that TB-related stigma among about half of the persons affected by TB who were surveyed was linked to misperceptions about the disease, including that it was directly caused by alcohol consumption rather than by a bacterium. TB was also linked in the minds of many people to HIV, whether there was underlying coinfection

or not.[xxx] The authors suggested that both these factors should inform awareness-raising campaigns for the public.

- Fear of facing discrimination was found to discourage people with or at risk of TB in **Cambodia** from seeking diagnosis and care. About half of a sample of 730 persons with TB agreed that fear of being seen in the community as having TB was a barrier to seeking care. But people reported that encouragement from family, friends and especially TB survivors could overcome this fear. This result indicates the need to support survivor organizations as advocates and educators.[xxxi]

A number of countries have also included a TB stigma element in their HIV Stigma Index exercises. This strategy can yield useful information but only as relates to persons coinfected with HIV and TB.

Addressing TB-related stigma and discrimination in the community: Assessments such as those described above can help identify gaps in knowledge and misinformation about the disease, which can shape the content of anti-stigma information and advocacy. Lessons from extensive experience with stigma and discrimination reduction programs in the community underscore both the need to ensure user-friendliness of information and the need to choose and mobilize the right messengers. For example:

- The NGO TB People in **Kyrgyzstan** developed TB anti-stigma materials for madrassas and Islamic community centers, as noted in the BDB midterm review.[xxxii] The organization reached over 2,000 Muslim clerics, urging them to encourage their followers to learn about TB, counter misinformation and seek services when needed. Religious leaders also participated in a city-wide day declaring Bishkek a “Zero TB City” and urging people to be supportive of those affected by the disease.
- The organization REACH in **India** mobilizes TB survivors to be “TB champions” who work with communities and families of people affected by TB to reduce stigma and become mentors or allies to people with TB. REACH also sponsored an art workshop in which TB survivors expressed aspects of their experiences of stigma in original art works.[xxxiii]
- TB Proof, an NGO led by TB survivors in **South Africa**, participates in the global “Unmask Stigma” campaign, which is based on sharing the experiences of TB survivors especially on social media. Though the campaign has not been fully evaluated, it has generated thousands of “likes” on Facebook and drawn the participation of celebrities and academic experts. TB Proof has also developed films and written materials to share in the community, with all materials reviewed by WHO and university experts.[xxxiv] TB Proof also advocates for eliminating stigmatizing language in government documents, such as referring to people only as “cases” and calling people who do not complete treatment “defaulters”.
- In addition to social media, the NGO **Nepal** Anti-TB Association (NATA) produced an anti-stigma video drama that aired for 36 days on a national television network, according to the BDB midterm assessment. Radio spots in five languages had an audience of thousands, and a campaign based on SMS on mobile phones was estimated to reach 20,000 people.

Some general lessons from this TB-related anti-stigma work in the community include the following:

- The meaningful participation of people who are or have been affected by TB in anti-stigma efforts is indispensable. TB survivors sharing their stories and their solidarity can influence community perceptions and encourage those newly affected by TB.
- Choose people known and respected in the community to be "TB champions".
- Anti-stigma messaging should take advantage of whatever medium reaches people. It is most effective if it is based on the experiences of local people and on formative assessments of circulating misinformation that needs to be countered.
- Many anti-stigma activities await rigorous evaluation, which may be eligible for Global Fund support. As noted above, many existing tools are available for assessing changes especially in community- and family-level stigma.

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. Ensuring confidentiality and privacy of people with TB, including for their personal health data, is an important part of stigma reduction in health facilities. There are more details and lessons learned on these programs in section F below.

Addressing TB-related discrimination: Though closely related, stigma and discrimination are not the same. Addressing discrimination is likely to involve challenging laws and policies or the way they are enforced. These issues are discussed in section E below.

Box 4: TB and COVID-19

In its annual TB report for 2022, WHO underscored that COVID-19 has continued to halt the progress seen in the global TB response before 2019. This development is related in some places to a shift in resources to deal with COVID-19, but it may also be that people with TB feared seeking health care because they would be assumed to have COVID-19 and would be caught up in the stigma of COVID-19 or in lockdowns or other COVID-19 response measures. In Ghana, for example, where it was clear that COVID-19-related stigma was impeding access to TB services, the NGO TB Voice Network produced an animated video that reached at least 100,000 people to urge welcoming and non-stigmatized care for people with either disease. Global Fund applicants may seek support for activities to prevent COVID-19 from being a barrier to TB care and support.

b) Reducing TB-related gender discrimination, harmful gender norms and violence

It is a Global Fund **program essential** that TB programs be gender-responsive – that is, "programs where gender inequities, norms, roles and inequalities have been considered, and measures have been taken to address them."[xxxv] Ideally, as already noted, programs should strive to be gender-transformative, where programs seek to change harm gender norms and practices into protective or beneficial ones. Gender-responsive and gender-transformative programs should

benefit persons of all gender identities. Discrimination against transgender persons in many settings may be an important barrier to seeking and gaining access to TB services.

TB programs should be informed by and respond to the location-specific ways in which gender-related factors affect TB risk and people's ability to seek and adhere to treatment. The Stop TB-CRG assessment includes a gender assessment component. Stop TB Partnership and UNAIDS also developed a specialized HIV and TB gender assessment tool.[xxxvi] Both these instruments cover a broad range of gender-related barriers based on documented experiences from many countries.

The Global Fund Modular Framework provides an illustrative list of several types of programs that can address TB-related gender discrimination and harmful gender norms and violence, including an illustrative list of several types of programs that can address TB-related gender discrimination and harmful gender norms and violence, including:

- Communities, Rights and Gender (CRG) assessment (as noted above).
- Sensitization and engagement of community, religious and opinion leaders on gender-based violence, harmful gender norms and traditional practices.
- Creating champions among religious and community leaders to promote elimination of gender-based violence and harmful gender norms and traditional practices.
- Community consultations to identify specific gender-related barriers to accessing HIV/TB services.
- Empowering women's groups to raise awareness of TB-related rights and monitor violations.
- Monitoring of TB-related violations against women and young people.

Examples of existing programs addressing gender-related barriers in a number of countries include the following:

- Mining can pose high TB risks, which largely affect men. The Global Fund and the World Bank have supported user-friendly TB services for mineworkers through a regional effort in **southern Africa**. Activities include providing diagnostic and treatment services at accessible hours and helping men to know how to prevent TB transmission in their families and communities. In **South Africa**, the Justice for Miners (JFM) Campaign, South Africa Resource Watch and others in civil society have advocated for thousands of mineworkers to receive compensation for TB contracted on the job.[xxxvii] In 2022, JFM was registered as an NGO, enabling it to establish chapters in several mining communities around the country.[xxxviii]
- The problem of men's reluctance to use primary health care facilities, even if they regularly face TB risks, has been addressed in a number of countries in several ways:
    - Establishing clinic hours that enable men to seek care without losing their jobs or other employment repercussions.
    - Establishing service hours for men only.
    - Ensuring health workers are trained to be aware of men's problems and attitudes; and
    - Mobilizing men's groups and leaders as well as TB champions in the community to encourage men to seek the care they need.[xxxix]
- In **Kenya**, with Global Fund support, the NGO North Star Alliance is reaching long-haul truckers, almost all men, to ensure that they can pick up TB medicine anywhere on their routes

and get easy access to information on how not to spread the disease.[xl] In 2019, about 30% of North Star's 108,000 patients were truckers.[xli]

- Discreet home-based sputum collection may help in places where women are reluctant to participate. In **Malawi**, with Global Fund support, making sputum collection a community event, often led by women volunteers, has helped to normalize it for women and others.[xlii] On TB Day in 2019, the Ministry of Health publicly recognized the importance of the work of volunteers organized by ActionAid to increase sputum collection in many locations.
- The TB gender assessment in **Kyrgyzstan** showed that women with TB face physical and emotional violence because of the disease.[xliii] With USAID support, the Red Crescent Society and the Republican Health Center trained hundreds of village health committee members, health workers, teachers and religious leaders in detecting and addressing the need for psychosocial services for women with TB. In 2022, the Red Crescent Society estimated that it had reached about 200,000 persons with this awareness-raising work.
- HIV and TB services and reproductive health services should ideally be integrated, with health personnel trained and supported to minimize both HIV- and TB-related stigma. Advocacy for this integration could be a program priority.

Lessons from work in this area include:

- Gender-related barriers to TB care vary from place to place. Programs will be most effective if they are based on an assessment of local barriers. Assessments should include the sharing of experiences of local persons affected by TB.
- There is a natural tendency to interpret "gender-sensitive" or "gender-transformative" as terms that refer to programs aiming to ensure equal access to services for women. With respect to TB, it should be remembered that men generally face higher TB risk, and some of the barriers to services they face, as noted above, are clearly gender-related. Gender-transformative programs in this area can seek to improve access to services for men, women or persons of other genders, depending on assessed needs.

c) Legal literacy ("know your rights")

Legal literacy programs are part of the Global Fund's TB **program essentials.** People need to know their rights to be able to assert and claim them. Rights or legal literacy is especially crucial for marginalized populations already prone to discrimination 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 (sections D and E below). Legal literacy activities can also be combined with health literacy efforts – that is, activities to raise awareness of the basic facts of TB diagnosis, transmission, treatment and support.

The Global Fund Modular Framework Handbook provides an illustrative list of types of activities that can improve TB-related rights literacy, including: provides an illustrative list of types of activities that can improve TB-related rights literacy, including:

- Integration of human rights and legal literacy as part of the TB champion/peer educator trainings (e.g., "Right to Breathe" training).

- Development and dissemination of communication materials on patient rights and other human rights materials.

Many existing programs and tools address TB rights literacy, for example:

- The 2019 the Declaration of the Rights of People Affected by TB is a proclamation of human rights by people affected by TB published by Stop TB Partnership and the NGO TB People.[xliv] In plain language, drawing on widely ratified human rights laws, the Declaration is a comprehensive set of norms on which to base TB rights literacy efforts.
- Another tool, the Nairobi Strategy on TB and Human Rights provides a roadmap to develop a human rights-based response to TB at all levels. The Nairobi Strategy covers elements such as:
    - Building diverse advocacy strategies for key audiences with the meaningful participation of TB survivors and other affected persons whose organizations should always be supported.
    - Meaningful engagement of affected populations with international organizations and experts; and
    - Building toward a legal and policy environment conducive to a rights-based TB response.
- Drawing on international norms, some countries have created patient rights charters for their own settings. The TB patient charter developed in **Ghana** covers TB service norms, the right to be treated with dignity and supported in the community, and the right to user-friendly information and confidentiality of medical records.[xlv] It also outlines the responsibilities of TB patients to adhere to treatment and of survivors to aid in community solidarity with those affected. A 2016 study in one peri-urban hospital in Ghana concluded that the charter was helpful in raising awareness among health care providers, but more needed to be done to raise patients' awareness of it.[xlvi] The goal around a similar charter in **Côte d'Ivoire**, according to the BDB midterm review, is to distribute it to every new TB patient. Posting these charters in health facilities is also a good strategy.
- The NGO KELIN in **Kenya** has conducted rights literacy sessions in informal settlements in Nairobi where people face TB risk because of living conditions. Rights literacy efforts were linked to a temporary legal aid clinic in the same locations. Hundreds of people in each location were reached in a few days, indicating to KELIN the need for expansion of this service. TB champions trained by KELIN in four large counties also conducted community forums to help people demand the good-quality TB services to which they have a right.

d) Increasing access to justice

Interventions to address access to justice are part of the Global Fund's TB **program essentials**. 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.

The Modular Framework Handbook suggests that the following types of activities can be part of increasing access to justice in TB responses:

- Community-led and community-based monitoring of health service quality, including stigma, discrimination and other rights violations.
- Hotlines and other rapid response mechanisms in cases of TB-related rights violations.
- Linkage of community-led monitoring (CLM) to legal counselling and support.
- Engagement of national legal aid board/agencies, and human rights/legal organizations to expand pro bono legal services and/or legal aid clinics to include TB-related legal services.
- Alternative and community forms of resolution of TB-related disputes.
- Engagement of religious or traditional leaders and traditional legal systems (e.g., village courts) with a view to resolving disputes and changing harmful traditional norms.
- Strategic litigation to reform harmful laws and policies, including those related to involuntary detention for TB treatment, workplace safety, and rights of employees with TB.
- Trainings in justice settings, particularly on issues noted in the previous point.

Some examples of this kind of work are as follows:

- 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 persons.[xlvii]
- "Street lawyers" or community-based paralegals in **Kyrgyzstan** with Global Fund support have provided legal services to people with TB for such matters as obtaining the identity documents needed to obtain health care. In Kyrgyzstan, cases handled by paralegals are recorded in a database that enables trends in violations and case resolutions to be monitored. Though not all related to TB, from January 2020 through June 2022, the community-led monitoring system recorded almost 1,800 cases of human rights violations, which were referred to paralegal and legal services as needed.[xlviii]
- TB survivors from the NGO TB Voice were included among community-based peer paralegals in **Ghana**, trained and mobilized with Global Fund support. Ghana is one of relatively few countries that has evaluated its paralegal program by interviewing users of the paralegal services about a year after the paralegals were put in place.[xlix] Respondents were mostly sex workers and men who have sex with men. They had a generally high awareness of the paralegal services and the Patients Charter. They recounted instances of both successful resolutions of cases and cases that faced obstacles to resolution.
- The **Southern Africa** Litigation Centre (SALC) with UNAIDS, Stop TB Partnership and other partners conducted a training for both lawyers and journalists from 27 African countries in 2018. The danger of possible applications of criminal law against people with TB was among the topics covered. As with HIV, the legal experts in the training warned against the passage of TB-specific criminal law to punish people who refuse or do not adhere to treatment, for example.[l]

General lessons from this area of work include the following:

- Peer paralegals can resolve many TB-related cases and can gain the confidence of key and vulnerable populations. But back-up by lawyers is needed for more complicated cases. Monitoring the disposition of cases referred to lawyers is important. Paralegals need support to know how to judge whether a case requires the intervention of a lawyer. This topic should be part of orienting paralegals to the kinds of cases they are likely to confront.
- Paralegal training and support should include mediation and negotiation skills. Experience in these areas may eliminate the need for referral to lawyers in many cases.
- Community-based paralegal programs should be evaluated periodically from the perspective of the users of paralegal services.
- One-time paralegal training is not sufficient. Sustained support is needed for paralegals, ideally including opportunities to share experiences with other paralegals and receive refresher training. Establishing mentors for new paralegals has been important in some settings.
- Cases handled by paralegals should be recorded and monitored to inform advocacy and action to improve the policy environment and access to services.

e) Monitoring and reforming policies, regulations and laws

Advocacy to reform or repeal punitive or otherwise unjust policies, regulations, laws and practices is often important to establishing a rights-based TB response. Community-led monitoring (CLM) of laws, policies and practices can be a crucial means if empowering TB-affected people and their organizations. TB-related CLM is described in section H below.

The Global Fund Modular Framework notes several types of interventions to support monitoring and reform of laws and policies related to TB, including: types of interventions to support monitoring and reform of laws and policies related to TB, including:

- Development of advocacy/action plans based on the assessments for law and policy reform, especially for groups led by persons affected by TB.
- Engagement with parliamentarians and ministers of justice, interior, corrections, finance, industry, labor, education, immigration, housing, health and trade and religious and traditional leaders, among others, including community-led engagement.
- Community leadership and engagement in reviewing and drafting laws and policies related to TB and participating in legislative hearings.
- Training of parliamentarians on human rights and the role of protective legal framework in the TB response, including community-led trainings.

In addition to the CRG assessment described above, the Stop TB Partnership and UNDP have developed a legal assessment tool for TB.[li] It provides a checklist of laws and policies to be reviewed, including those related to issues noted in the section below. It provides guidance for both desk reviews and interviews with key stakeholders and offers suggestions for writing and

dissemination the assessment report. Examples of legal environment assessments are available on the Stop TB Partnership website.[1]

A key step in reforming punitive or rights-unfriendly laws and policies related to TB is to monitor TB-related human rights violations that occur. Numerous countries have established HIV-related human rights observatories – monitoring systems usually involving focal points on the ground to whom people living with HIV and key populations may turn to report stigma, discrimination and other violations of their rights. Some but not all of these systems include documentation of TB-related issues.

Examples of laws and policies related to TB that might be and have been targeted for advocacy activities are as follows:

Involuntary isolation or compulsory treatment: Global Fund applicants may request support for: (a) assessments of policies and laws regarding isolation and compulsory treatment (including whether certain populations are disproportionately affected); (b) advocacy for practices that conform to international standards; (c) support for training of health workers or judges; (d) "know your rights" efforts for people with TB or the general public, or (e) measures to strengthen mechanisms of complaint and redress for persons in TB care who believe their rights are violated.

Intellectual property and regulatory barriers: The high price of TB medicines, especially for MDR and XDR TB, is protected by patents. Non-registration of some newer medicines in government health systems may also impede access to them. In **South Africa**, for example, the "Fix the Patent Laws" campaign continues advocacy for measures to make patent-protected life-saving medicines affordable[2]. This campaign intersects with that of the Treatment Action Campaign urging the government to declare TB a national emergency, which would lead to urgent measures to ensure medicines for all.[lii]

Workplace/employment policies: Global Fund applicants may request support to assess or challenge employment-related laws and practices that may cause people affected by TB to lose their jobs if they take time for treatment or to face discrimination in the workplace. Workplaces that fail to provide adequate protection from TB risk factors or fail to ensure the confidentiality of TB status may also be advocacy targets. Other priorities might be awareness-raising programs for employers, rights literacy for workers, development of TB workplace policies and litigation where possible. The NGO Section 27 and other NGOs in **South Africa** helped to win a settlement for damages paid to miners suffering from silicosis and the families of those who died.[liii]

Catastrophic costs: Global Fund applicants may seek support for advocacy to ensure that TB diagnosis and treatment does not incur catastrophic costs to patients. Advocacy to improve legal and policy framework around the social protection measures or policy and legal literacy around social protection for communities can also be supported.

Mobile populations: Global Fund applicants may request support for measures to ensure equal access to TB services for refugees, internally displaced persons and other migrants. These persons may lack the documentation they need for health services. Some pertinent actions may be advocacy for cross-border referral systems or other ways to relax documentation requirements, assessments of barriers faced by mobile persons, and sensitization of health

[1] Stop TB Partnership: Communities, rights and gender webpage.
[2] www.fixthepatentlaws.org

worker on the needs of these populations for TB care. As noted in the BDB midterm assessment, the NGO TB People in **Kyrgyzstan** successfully advocated for a Ministry of Health order to provide TB treatment without residency documents, a major step forward for internal and external migrants.

Prison conditions: In prison and other detention settings, advocacy efforts may target direct TB risks such as overcrowding and poor ventilation. Strategies may include documenting these conditions to inform advocacy or working on structural causes of overcrowding such as criminalization of minor drug infractions and over-reliance on pretrial detention for non-violent offenses (see also section I below).

TB-related disability: TB may result in hearing impairment, persistent neurological problems, respiratory impairment and other disabilities. Global Fund applicants may request support for advocacy to ensure that national TB programmes address these issues equitably and effectively.

General TB legislative framework: With USAID and Global Fund support through the Stop TB Partnership Challenge Facility for Civil Society, the **Philippines**-based NGO ACHIEVE received support to build capacity of groups of TB-affected people to engage with lawmakers and lobby for rights-centered TB laws and policies. ACHIEVE has helped to develop provisions of what it regards as an improved TB amendment to existing law on which it is training and mobilizing TB-focused community groups to be effective advocates.[liv]

Litigation can be an important tool for challenging TB-related laws and practices. It is, however, often expensive and requires both plaintiffs and lawyers who can see a case through to the end. In a well-documented case in **Kenya**, the NGO KELIN successfully pursued a judgment that TB patients should not be held in jail for non-completion of treatment.[lv] A series of cases in **India** laid the groundwork for further use of litigation as a tool to improve access to TB care for marginalized people.[lvi] A collection of TB-related case law by the TB, Human Rights and Law Consortium highlights cases 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.[lvii]

f) Ensuring people-centered and rights-based TB services at health facilities

Ensuring rights-based health services is part of the TB **program essentials** on eliminating stigma and discrimination and community-led monitoring. The Modular Framework Handbook gives this illustrative list of types of activities in this area:

- Trainings on TB-related confidentiality and privacy issues, mentorship and performance evaluation modifications to sensitize community health workers.
- Integration of the human rights and medical ethics trainings in the pre- and in-service training.
- Periodic and ongoing community-led and community-based monitoring, including “mystery shoppers”, suggestion boxes and exit surveys.
- Establish, strengthen and support health committees led by members of the community and health facility leadership.
- Institute regular meetings between community health committee leaders and health facility directors with participation of TB survivors.

- Collaborative learning among health care workers, including community health care workers, to promote ongoing peer support and discussion among peers.

Achieving rights-based TB services in health facilities means respecting and protecting the rights of people seeking and using services, as well as those providing services. Health workers themselves face high TB risk in many circumstances and need to be supported to protect themselves and to provide respectful services for the often-marginalized persons affected by TB. The protection of privacy and confidentiality of medical records and histories is crucial in TB care for both patients and providers, particularly given the stigma and discrimination that may be associated with the disease.

Many training activities have been developed on rights-centered approaches to HIV in health facilities. Some of these have incorporated TB-related rights. The most effective training programs are those that rely on more than one-time in-service training. Pre-service training for all new recruits is important.

Examples of other kinds of activities that may complement or enhance training are as follows:

- In **Kyrgyzstan**, after many years of advocacy by civil society organizations, the Ministry of Health issued an order that links health workers' compensation to successful treatment of TB. NGOs hope that this order will improve the quality of TB care, especially if it is linked to measures to avoid stock-outs of medicines and to ensure a supportive environment for health workers.
- The NGOs TB-HIV Care and TB Proof in **South Africa** advocate for support and protection for community health workers (CHWs). CHWs are central to TB services, especially for key populations. These NGOs assert the need of CHWs for psychosocial support and personal protective equipment.
- In **Mozambique**, the NGO Namati mobilizes health advocates to monitor health services and empower village health committees. But these advocates strive to engage health workers constructively rather than being antagonistic. An evaluation of Namati's work concluded that this approach was a key to the successful resolution of reported problems in health services.[lviii]
- With Global Fund support, in response to TB patients' reports of disrespectful services, Project Hope in **Tajikistan** complemented health worker training with the mobilization of hundreds of volunteers to raise TB knowledge and awareness in the community. Communities' demand for accountability was deemed as an important factor in improved services.[lix] More recently the NGO has instituted distance learning for health workers with a focus on vulnerable populations.[lx]

Some lessons from this work:

- One-off training of health workers cannot be expected alone to inspire rights-based change. Pre-service and refresher in-service training is helpful, but other kinds of engagement, as illustrated above, may be necessary.
- Support for facility-based and community-based health workers should recognize and seek to minimize the TB risks they face.
- Survivors of TB and TB key populations should participate in training and other engagement with health workers.
- Buy-in from high-level health officials will help to sustain activities.

g) Ensuring people-centered and rights-based law enforcement practices

Activities related to facilitating engagement with police to improve law enforcement practices can be part of the program essential on access to justice, particularly if policing is a barrier to that access. Various kinds of engagement with law enforcement officers can be designed to prevent harmful policing practices against TB key populations, including people who inject drugs, homeless people, and mobile/migrant populations. Examples of types of programs noted in the Modular Framework Handbook are:

- Development of TB and human rights training materials for law enforcement officers and support integration in the pre-/in-service training, including efforts to ensure participation of TB survivors and family members in training.
- Integration of law enforcement practices in human rights monitoring efforts.
- Working committees/groups with TB Champions and local police focal person to review the CLM data to improve policing.

As with health workers, HIV-related training and other engagement with the police has in some countries included a focus on TB. Though mostly focused on HIV, a few countries have gone beyond traditional training in their engagement with police:

- In **Ghana**, there is a standing technical working group of police officials that meets with civil society representatives to discuss complaints about police conduct. This group consists of the directors of the police unit dealing with domestic violence, the police hospital and the police training centers
- People who use drugs were able to find a safe space with the **Uganda** National Police to explain drugs in circulation and the way they are consumed. They found common ground with some police officers in an acceptance that imprisoning people with drug use disorders was unlikely to help them or their communities.[lxi]

Similar lessons to those with health workers have been learned from these experiences, including:

- Police may have fears about occupational exposure to TB that affects the way they regard and treat people with TB, and these fears should be addressed in training and dialogue with police.
- **It should not be expected that one-time in-service training will have a lasting impact on knowledge, attitudes or practices of police. Pre-service training in police academies is a good practice.**
- Getting buy-in from high-ranking police officials for any kind of engagement can help ensure sustainability and sometimes financial support, as well as provide leadership by example.

Training and other engagement should include basic TB information essential to good policing. Police, judges, prosecutors and judicial personnel should be aware of the TB risks faced by people with HIV and HIV/TB key populations, including people who use drugs. They should know that many prisons and other detention facilities are high-risk environments for TB and should never be used for compulsory isolation for the purpose of treatment. Police should also be aware of the TB treatment and prevention needs of people in police lock-up or pretrial detention. They should know that it is a misuse of criminal law to impose criminal penalties for non-adherence to

treatment, failure to report TB cases or non-intentional TB exposure. National TB programmes should ideally have structures that enable reaching out to and working with law enforcement officials where there are policing-related barriers to TB health services.

h) Community mobilization and advocacy, including community-led monitoring

As specified in the Global Fund's TB **program essentials**, TB funding requests should include "support for community mobilization and advocacy and community-led monitoring for social accountability." Community mobilization is recognized in global TB strategies as an essential element to a rights-based alternative to exclusively top-down TB control measures. Meaningful participation of communities and people affected by TB is integral to respectful and accessible TB care.

Community-led monitoring (CLM) for a rights-based TB response

Community-led monitoring of TB services and barriers to services can be an effective way to mobilize and empower affected communities to be part of shaping rights-based responses. In addition to the larger studies of human rights barriers such as the Stop TB-CRG assessment, Stop TB Partnership has also developed a mobile phone-based system for CLM called OneImpact. It enables people affected by TB to monitor, report and generate actionable information on their experiences with TB, including barriers to health services.[lxii] OneImpact was piloted in Cambodia, the Democratic Republic of the Congo (DRC), Indonesia, Mozambique, Tajikistan, Tanzania and Ukraine. The app allows for the easy recording and reporting of human rights violations, TB stigma, barriers to TB health services and barriers to TB support services. Depending on how demographic information about users is recorded, data on these barriers can be disaggregated by gender, age and key population status. The system can be linked to advocacy and programs to enable quick response to problems reported.

In the early experience with OneImpact in **Cambodia** for example, it was judged by community-based groups and policy-makers alike to have the potential to shape a comprehensive response to human rights and gender-related barriers to TB services in addition to reporting on health systems concerns.[lxiii] In **DRC**, as noted in the BDB midterm review, information generated through OneImpact enabled the NGO Club des Amis Damien to advocate for the inclusion of a TB stigma study in the Global Fund funding request. The results of the OneImpact reporting also informed priorities for community health advocates and the development of indicators for the HIV and TB human rights observatory that was under development.

Global Fund applicants should be aware of the statement on CLM of 134 leaders of TB-related civil society from across the world, convened by the Stop TB Partnership in Bangkok in 2022.[lxiv] The Bangkok statement is a call to national TB programmes, technical and civil society partners, donors, to "champion, integrate, scale up and mainstream CLM" because empowering TB-affected communities and strengthening community responses is essential to TB. CLM was seen by the Bangkok gathering as especially crucial in facilitating the identification of key populations and undiagnosed people with TB.

Actions to mobilize and empower affected communities

Support for community-led mobilization and advocacy is a Global Fund **program essential** for TB funding requests. The participation of TB-affected community groups is essential to making

the national TB response as effective as possible, including for key populations. But for affected communities to be equal partners in the response, they require resources, technical assistance, tools and organizational and technical capacity-building. As suggested by the World Health Organization, activities that might figure in Global Fund funding requests include:

- Helping people affected by TB to be leaders in community-level awareness-raising to counter misinformation on TB and combat TB stigma.
- Support CBOs and TB affected communities to advocate and mobilize resources to provide financial, nutritional, psychological and mental health support for people with TB and their families, particularly through government social protection schemes and corporate social responsibility programs where possible.
- Helping CBOs advocate for meeting the TB service needs of key and vulnerable populations; and
- Ensuring that people with and affected by TB have access to peer educators, especially TB survivors and their families who can share experiences and advice.[lxv]

Some examples of community mobilization and empowerment for rights-based TB responses are:

- In **Kenya**, 180 community health champions were mobilized in informal settlements in greater Nairobi, equipped by KELIN to respond to TB concerns raised by community members and to monitor TB services.
- TB Proof in **South Africa** mobilizes TB survivors to organize support groups with TB patients. Among other things, patients are helped to navigate the process of applying for government grants for people who have to leave their jobs during TB treatment.
- The ALLIES Project of REACH **India** focuses on community mobilization to achieve the "last mile" of service deliver to vulnerable populations. TB champions, persons known and trusted in their communities, help to empower communities to assert their right to good-quality services, identify problems and demand action and accountability.[lxvi]

Some lessons for work in this area are:

- TB key populations and TB survivors should participate meaningfully in community-based monitoring of human rights-related barriers to TB services.
- CLM in this area should be linked to actions for direct follow-up on violations identified.
- Measures should be taken to ensure the safety of everyone participating in CLM and in actions to empower TB survivors and key populations.

i) Addressing the needs of people 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. As noted in the Global Fund's Prisons and Other Closed Settings: Priorities for Investment and Increased Impact technical brief, TB rates are sharply higher in prisons and other closed settings, making TB screening, preventive therapy and treatment for those with active infection essential for national TB responses. It is a central objective of the WHO End TB Strategy that TB services be widely available in prison and other detention settings.

Adequate coverage and effectiveness of TB services in prisons depends on right-centered approaches. Peer-based approaches can be empowering, enabling as much participation as possible from people in prison themselves, including TB survivors in the prison population. Engagement with prison personnel, not only on the basics of TB care but also on ensuring links to non-discriminatory post-release care in the community, can be effective. TB control is included in the comprehensive package of 15 interventions for HIV prevention, testing, treatment, care and support in prisons and other closed settings, recommended by WHO, UNAIDS and the United Nations Office on Drugs and Crime (UNODC).[lxvii]

The Modular Framework Handbook offers these examples of appropriate types of activities to contribute to reducing human rights-related barriers to TB services in prison and other detention settings:

- Advocacy for non-custodial alternatives for non-violent offenses and pretrial periods to reduce overcrowding**.**
- Engagement of prisoner leadership on peer-led TB activities and stigma and violence reduction efforts, including building capacity of peer educators**.**
- Coordination of prison TB care with post-release care in the community to eliminate interruptions in care upon release**.**
- Continued TB treatment support and linkage to available social protection services by ex-prisoner support groups and civil society organizations (CSOs) working with prisoners and their families**.**
- Training ex-prisoner support groups/networks and CSOs working with prisons and their families on TB, human rights and legal literacy**.**
- Integration of programs to prevent, address, monitor and report violence in prisons and other closed settings, including community-based and community-led monitoring of stigma, discrimination**.**
- Pre-service and in-service training for prison guards/management and other staff (medical and non-medical) on infectious disease control (HIV and TB), stigma, discrimination and violence reduction.

The Global Fund Prisons and Other Closed Settings: Priorities for Investment and Increased Impact technical brief has many other suggestions of types of programs that would contribute to rights-centered TB actions in closed settings.

Efforts in a number of countries have focused both on improving access to respectful TB services in prisons and on tackling TB risks in these settings, for example:

- TB People and community-based paralegals supported by the Global Fund in **Kyrgyzstan** work with the prison system to ensure that upon release people can regain their property and realize other rights, including access to health care.
- The NGO Sonke Gender Justice in **South Africa** successfully sued the government over conditions in a prison near Cape Town, explicitly citing overcrowding and poor ventilation as TB risks and noting the high TB mortality in the country. As a result of the ruling, there was some reduction in overcrowding, and people in prison were allowed more outdoor exercise.[lxviii] The NGO TB-HIV Care in South Africa also trains and supports TB and HIV peer educators in prison.

- The US Centers for Disease Control and Prevention supported the NGO Health Strat in **Kenya** worked with prison staff on their own occupational safety concerns in addition to ways to improve services for those in their custody. The Kenya Prison Service endorsed the work, which also provided information to families of prison staff.[lxix]
- The Southern Africa Litigation Centre assisted the NGO CHREEA in **Malawi** to bring a case to the Malawi High Court that would prevent hospitals from returning MDR-TB patients to prison while they are still being treated.[lxx] The case is pending at this writing. CHREEA is also working with the Malawi Inspectorate of Prisons to monitor prison conditions, planning to present the results to parliament for analysis against national TB program standards.[lxxi]
- With European Union support, Panos Institute for Southern Africa and Development Aid from People to People (DAPP) aim to improve prison health in **Zambia** both by working with authorities to improve conditions and by raising awareness among incarcerated persons about preventive actions they can undertake. The work includes visiting the homes to which released prisoners will return to improve health conditions there.[lxxii]

Some lessons from this work:

- It is crucial to ensure that incarcerated persons who participate as peer educators or in other ways are protected from retaliation and otherwise safe. Empowerment or capacity-building activities should be understood and approved by prison officials before implementation.
- Advocacy to address the root causes of overcrowding can be effective. NGOs should work with lawyers who understand sentencing and pretrial detention practices that contribute to overcrowding.
- The integration of the TB response in prisons into the national TB response and ensuring that the national TB programme has a central role in TB prison services are essential. Addressing the fears and gaps in TB knowledge of prison staff is a crucial step.

5. Key Programmatic Steps According to Stage of Development of TB-related Rights Interventions

The level of implementation of programs to reduce TB-related human rights barriers varies from country to country, CCM to CCM. In developing TB funding requests, CCMs should consider the stage of development of TB-related human rights programming and ensure that program essentials and programmatic building blocks appropriate to that stage are in place. Table 1 provides a rough guide for this reflection. It emphasizes that program essentials are both a place to start and central pillars for building a rights-centered TB response that strives to be comprehensive.

Table 1. Key steps in planning, implementing and scaling up programs to remove human rights-related barriers to TB services

Stage of development of TB-related programs to reduce human rights barriers	Steps to be taken
New to programs to reduce human rights-related barriers	• Rapid TB-related human rights assessment undertaken to identify human rights-related barriers to TB health services; results used to ensure that, at a minimum, human rights **program essentials** fully implemented: • Stigma and discrimination activities are undertaken [**program essential**], possibly beginning with assessment of TB-related discrimination and stigma. • Key population outreach and peer education includes TB-related human rights training, information on patients' rights developed and disseminated in health care settings and other accessible locations, access to justice programs initiated [**program essential**]. • A national plan or strategy to remove human rights-related barriers is developed or updated as part of the national TB strategy. • An oversight mechanism is adequately supported to monitor and evaluate progress in reducing TB-related human rights-related barriers – it may be the same mechanism as for HIV in some cases. • From the outset, an effort is made to ensure all programming is gender responsive.
Expanding and improving programs	• Stigma and discrimination activities expanded. • Activities to reduce human rights barriers expanded to include needs of key populations or locations missed earlier.

	• Interventions to reduce human rights barriers expanded to include activities for all staff of prisons and other closed congregate settings. • Legal literacy and access to justice services expanded to include formal and informal mechanisms, including trained lawyers and paralegals on TB-related rights issues. • Reducing human rights barriers includes monitoring led by communities or organizations of TB-affected persons. • Laws, policies and practices that are harmful to the TB response are identified and activities to reform them are funded, including community-led efforts.
Programs brought to comprehensive scale	• Interventions exist at scale in all program areas and for all populations experiencing TB-related human rights-related barriers. • Reducing human rights barriers includes coordination mechanisms to sustain efforts to reach national coverage and impact. • Scale-up plans developed and implemented for human rights programs. • Trainings related to reducing human rights barriers systematically institutionalized into pre- and in-service curricula for health care workers, law enforcement and lawyers. • A growing share of programs is funded domestically, and there are efforts with relevant ministries to develop plans for transition to government funding. • Increased and sustained investment in building strong organizational and human rights capacities at all levels, as well as monitoring and evaluation (M&E) for programmatic improvement.

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[xx] See baseline assessment reports at https://www.theglobalfund.org/en/funding-model/throughout-the-cycle/community-rights-gender/

[xxi] A summary of the baseline assessments is found at crg_breakingdownbarriersbaselineassessmentskeyfindings_summary_en.pdf (theglobalfund.org)

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https://www.stoptb.org/prioritising-people-human-rights-gender/communities-rights-and-gender-crg

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7. Annex: Key Resources for Further Reading

Breaking Down Barriers assessments

The assessment reports from the Breaking Down Barriers initiative provide many examples of programs to overcome human rights and gender-related barriers to TB services. They are found at https://www.theglobalfund.org/en/funding-model/throughout-the-cycle/community-rights-gender/.

Assessment tools and results

Undertaking a Rapid Assessment of Information on Human Rights-Related Barriers to HIV and TB Services: Guidance and Tools. The Global Fund (2022).

TB stigma assessment implementation handbook. Stop TB Partnership, 2019: https://www.stoptb.org/stp-tb-stigma-assessment-implementation-handbook

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Gender assessment tool for national HIV and TB response. Stop TB Partnership and UNAIDS, 2016. Gender Assessment Tool for National HIV and TB Response | HIV/AIDS Data Hub for the Asia-Pacific Region

TB CRG country-level assessment protocol template (working document). Stop TB Partnership, undated, https://stoptb.org/assets/documents/communities/TB%20CRG%20Country-Level%20Assessment%20Protocol%20Template_DRAFT.pdf

Results of Stop TB Partnership-assisted CRG, legal and gender assessments are available here:

https://www.stoptb.org/prioritising-people-human-rights-gender/communities-rights-and-gender-crg

Key populations

The 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 are available here: http://www.stoptb.org/resources/publications/

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Global Fund documents

Gender Equality Technical Brief

Removing Human Rights-related Barriers to HIV Services Technical Brief

Community Systems Strengthening (CSS) Technical Brief

Harm Reduction for People Who Use Drugs Technical Brief

Prisons and Other Closed Settings: Priorities for Investment and Increased Impact Technical Brief