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Stop TB Partnership hosted by UNOPS

The Global Fund

BACKGROUND PAPER

Tuberculosis and Human Rights

Prepared for a side event on human rights and TB preceding the UN General Assembly high-level meeting on ending TB

Organized by the Open Society Foundations, the Global Fund to Fight AIDS, Tuberculosis and Malaria, and Stop TB Partnership, in collaboration with UNAIDS & the O'Neill Institute for National and Global Health Law

24 September, 2018

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Introduction

Tuberculosis (TB) throughout its long history has disproportionately affected people marginalized by poverty and social exclusion and those living in sub-standard conditions in prison and in the community. These same factors of marginalization, many of which are related to unrealized human rights, can impede people's access to TB prevention, diagnosis and treatment. As noted by the World Health Organization and the Stop TB Partnership, multisectoral action to address the social, economic and human rights-related roots of TB is a precondition to success in ending TB. Ending TB depends on realizing not only the health objectives of the Sustainable Development Goals (SDG) but also the SDGs on reducing inequality, including gender inequality, and ensuring access to justice and human rights for all. It also requires a concerted and coordinated effort among governments, donors and technical partners to scale up programs that have proven effective in addressing the human rights and gender -related barriers that constrain efforts to meet our goals.

Global strategies and key actors in the global TB response have explicitly acknowledged that reducing human rights-related barriers to TB services is essential to realizing TB goals. The global End TB Strategy includes as one of its central principles the "protection and promotion of human rights, ethics and equity."[1] The largest funder of TB services in low- and middle-income countries, the Global Fund to Fight AIDS, TB and Malaria, committed in its 2017-2022 strategy to the objective "promoting and protecting human rights and gender equality" with respect to all three of the diseases in its mandate.[2] Sub-objectives include reducing health inequality, including gender-related inequality, and scaling up programs to reduce human rights-related barriers to health services for the three diseases.

The Stop TB Partnership Global Plan to End TB for 2016-2020 promotes a paradigm shift in the response to TB and espouses a human rights-based approach grounded in equity and gender equality. Stop TB supports a TB and Human Rights Consortium that, among other things, produced the 2016 Nairobi Strategy for a rights-centered approach to ending TB.[3] The Nairobi Strategy urges working with legislators, judiciary personnel and lawyers as well as health workers to improve their capacity to contribute to rights-centered approaches to TB and support to networks of key populations affected by TB. It also calls for efforts to clarify and disseminate the "conceptual, legal and normative content of a human rights-based approach to TB".

Beyond high-level commitments to rights-based approaches, there are a number of practical programmatic guidelines for developing and sustaining programs to reduce human rights-related barriers to TB services and actions to ensure rights-centered TB services. The key population briefs of the Stop TB Partnership, for example, highlight concrete policies and programs to reach marginalized persons affected by and at risk of TB.[4] The Global Fund's technical brief on TB, gender and human rights catalogs types of barriers to TB services and

[1] World Health Organization. *The End TB Strategy*. Geneva, 2015.

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

[3] Stop TB Partnership, KELIN, University of Chicago School of Law. Nairobi Strategy: A human rights-based approach to tuberculosis. Geneva, 2016.

[4] See briefs noted among publications at http://www.stoptb.org/resources/publications/ and particular briefs cited below.

programs to reduce them with illustrations from real programs in many countries.[5] Global Fund-supported evaluations of human rights-related barriers to TB services in 13 countries have documented particular barriers and proposed scaled-up interventions to reduce them. WHO has produced ethics and human rights guidance for the End TB Strategy, including guidance on isolation and involuntary isolation for persons with TB.[6] Stop TB is supporting the roll-out of the CRG-assessments (legal environment, gender and key populations assessments) in 14 countries with the highest number of missing people with TB. All of these materials inform this paper.

The link between HIV and TB also underscores the importance of human rights and gender equity in the TB programs and policies. Though there have been significant gains in successful TB treatment for people living with TB and HIV, TB remains the primary cause of death among people living with HIV, who are 26-31 times more likely to develop active TB than HIV-negative persons.[7] HIV-related stigma and discrimination, gender inequality and gender-based violence, and criminalization of sexual orientation and gender identity, drug use and sex work are all well-studied barriers to health services for people living with HIV. People living with both HIV and TB thus face human rights-related barriers associated with both diseases, a particular challenge for programs and policies.

The cost of diagnostic tools and medicines to treat TB, especially drug-resistant forms of TB, is an important barrier to TB care, particularly in view of the economic marginalization of many affected populations. Médecins Sans Frontières (MSF) estimated that only 5% of people who needed treatment for multidrug-resistant (MDR) and extensively drug-resistant (XDR) TB had access to newer and more efficient drugs (delamanid and bedaquiline), partly because of the high price of these medicines, and partly because these medicines are not yet registered for therapeutic use in some countries.[8] Furthermore, the lack of funding for TB research negatively impacts the development of point-of-care affordable diagnostics and more effective and shorter treatment regimes, which in turn contributes to the high cost of drugs.[9] Safeguards to ensure that medicines are affordable to all who need them should be included in the draft of the Declaration for the TB High-Level Meeting (HLM), as they were in the outcomes documents following the UN HLM on HIV in 2011, the UN HLM on non-communicable diseases in 2011, and the Sustainable Developments Goals.

Key and vulnerable populations and human rights-related barriers to TB services

Prisoners and others in custody of the state:[10] People in prison and pretrial detention face high TB risk because of overcrowding and poor ventilation in their living quarters. In many

[5] Global Fund to Fight AIDS, TB and Malaria. Technical brief: Tuberculosis, gender and human rights. Geneva, 2017. At: https://www.theglobalfund.org/media/6349/core_tbhumanrightsgenderequality_technicalbrief_en.pdf?u=636709998030000000

[6] World Health Organization. *Ethics guidance for the implementation of the End TB Strategy*. Geneva, 2017.

[7] World Health Organization. *10 facts on tuberculosis*, revised Oct. 2017, at: http://www.who.int/features/factfiles/tuberculosis/en/.

[8] Lancet (editorial), *Where are the innovations in tuberculosis drug discovery?*, Vol.5 Issue 11, P835 (1 Nov 2017)

[9] WHO Policy Paper, Global Investment on Tuberculosis Research and Development: Past, Present and Future (2017).

[10] Stop TB Partnership. *Key populations brief: Prisoners*. Geneva, 2016.

cases detainees also lack access to the same health services that are available outside prison, which is their right. It was demonstrated empirically in Central Asia (and is likely the case elsewhere) that failure to control TB in prisons undermines TB control in the larger society,[11] which indicates that TB services in prison should be a pillar of all national TB control efforts. Overcrowding in detention facilities is often rooted in over-reliance on pretrial detention – that is, detention of people who have not been convicted of any crime but await formal charges or a trial. Penal Reform International estimates that 30% of people in state custody globally have not been convicted of any crime, and the figure is over 50% in many countries.[12] International standards mandate that people be held in pretrial detention only if they pose a flight risk or a danger to themselves or the community, but in many places people are detained simply because they are unable to pay a cash bail.

People who use drugs: People who use drugs face high TB risk independent of their HIV status, though HIV increases their risk.[13] In many places, people who use drugs share equipment and engage in other practices with direct TB risk, they are likely to be in prison or pretrial detention at some time because of harsh drug laws, they may fear health services because of stigma or the possibility that health workers will turn them in to the police, and they are likely to live in poor housing conditions.[14] Criminalization of minor drug offenses remains part of drug laws in most countries and impedes access to health services and information for those who use drugs. Furthermore, in countries where there is mandatory medical detention during the period of diagnosis or treatment but OST is not provided in health facilities, people who use drugs face additional challenges in accessing and retained in TB services.

Health care providers:[15] Health care workers face high TB risk, especially where resource-constrained health systems do not provide adequate protections and training in the health workplace. Health workers may fear stigmatization if they seek TB services for themselves. Their TB fears may also make them reluctant to treat people with TB or those at risk, resulting in stigma and discrimination in health services.

People living with HIV:[16] As already noted, the risk of contracting TB is high among people living with HIV, and in some countries a significant percentage of people with TB are HIV-positive. TB-related stigma and other barriers to TB services may be magnified by HIV-related stigma and other HIV-related human rights challenges. Stigma and discrimination are further deepened for people living with HIV who are members of key populations such as LGBT persons, sex workers and people who use drugs. In some settings, women and girls living with HIV are especially stigmatized and may be reluctant to seek care, including for TB.

Miners and others facing occupational exposures: [17] In most settings miners are predominately men. In addition to exposure on the job to silica dust and other particulates

[11] 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.

[12] Penal Reform International. *Global prison trends 2018.* London, 2018, p 11.

[13] Stop TB Partnership. *Key populations brief: People who use drugs*. Geneva, 2016.

[14] Ibid.

[15] Stop TB Partnership. *Key populations brief: Health care providers.* Geneva, 2016.

[16] Stop TB Partnership. *Key populations brief: People living with HIV*. Geneva, 2016.

[17] Stop TB Partnership. *Key populations brief: Miners*. Geneva, 2016.

that carry TB risk, miners are also often housed in sub-standard, overcrowded conditions. In cases where they migrate to mines for work and occasionally return home, their families and others in their home communities may as a result also face high TB risk. Construction work may also pose risks from exposure to particulates. As noted by Stop TB Partnership, it is too often the case that mine owners and other employers in risky settings fail to ensure protection of workers from TB transmission, fail to provide adequate TB services, and escape accountability for these failures.[18] Persons who migrate to mining and construction jobs may also not be eligible for care in where their work is located and may face discrimination or linguistic barriers to seeking services.

Mobile populations:[19] In spite of international law that should protect their rights, migrants and other mobile populations may experience conditions associated with TB risk while also facing discrimination, lack of legal documentation and other barriers to health services. The international cooperation required for health authorities to meet their needs may be absent. Migrants may not know their rights or have the means to seek legal services to help protect their rights. They may face harassment from police or in the community that pushes them underground and thus further from health services.

Men and women facing gender-related risk to TB and barriers to services:[20] Globally men carry a greater TB burden than women, partly because of occupational exposures noted above, and in part because in many places they are more likely than women to smoke, use drugs and be incarcerated. In some countries it has been found that men are reluctant to seek health services, seeing health facilities as catering to women and children.[21] But women in general and those who are members of the populations already mentioned above may also face gender-related barriers to TB services. Women may be unable to initiate the seeking of TB diagnosis or treatment for themselves or other family members because of economic subordination in the household. Child care responsibilities may make women unable to attend multiple medical appointments for treatment. In some places, women have been shown to face greater TB-related stigma than men, at times because TB is wrongly perceived to be related to sexual promiscuity.[22] Health services for women in prison or detention are often inferior to those in men's facilities.

People living in poverty in urban and rural settings:[23] TB-related mortality declined 40% globally from 1990 to 2015, but over 95% of TB-related deaths are in low- and middle-income countries.[24] All people have a right to adequate housing, including adequate ventilation and sanitation. While TB has been documented to be more prevalent in urban areas in most countries, rural dwellers may also confront poor housing conditions as well as stigma and lack

[18] Ibid.

[19] Stop TB Partnership. *Key populations brief: Mobile populations*. Geneva, 2016.

[20] United Nations Development Programme. *Discussion paper: Gender and tuberculosis.* New York, 2015.

[21] Horton KC, MacPherson P, Houben RMGJ, et al. Sex differences in tuberculosis burden and notifications in low- and middle-income countries: A systematic review and meta-analysis. *PLoS Medicine*. 2016;13(9):e1002119. doi:10.1371/journal.pmed.1002119.

[22] 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. doi:10.1371/journal.pone.0119861.

[23] Stop TB Partnership. *Key populations brief: Urban populations*. Geneva, 2016. See also Stop TB Partnership. *Key populations brief: Rural populations*. Geneva, 2016.

[24] World Health Organization. Tuberculosis (fact sheet no. 104). March 2016, at: http://www.who.int/mediacentre/factsheets/fs104/en/.

of ready information on TB and TB services, and health services may be less accessible in rural areas. For all people living in poverty, the cost of health care, especially the cost of medicine where treatment is not subsidized, may cause households to spend a high percentage of their meager incomes on TB services. Even in contexts where TB treatment is free, often the charges related to diagnosis and transportation costs to facilities are paid by patients. Informal and poorly regulated health services in both urban and rural communities may be more accessible but of poorer quality than care in formal facilities.

These brief descriptions of the TB vulnerabilities of certain populations suggest a number of important **human rights-related barriers** to TB services that must be addressed for global and national end-TB goals to be met. The Global Fund notes in general that human rights-related barriers include all stigmatising, discriminatory and punitive attitudes, practices, policies and laws that impede people's access to health services or impede the realization of the right to health and other human rights such as the right to be free from cruel, inhuman or degrading treatment, and the right to redress if rights are violated. In the case of TB, among the most important such barriers are:

- Stigma and discrimination related to TB in the community, the workplace, health facilities and so on. These may be exacerbated by stigma and discrimination related to HIV where coinfection occurs.
- Poverty and inadequate housing, which are directly associated with TB risk;
- Poverty and other impediments to access to TB diagnosis and medicines when they are not free or affordable;
- Criminalization and disproportionate incarceration of key affected populations and inadequate services for people in the custody of the state.
- Lack of realization of the right of miners and other worker in risky occupations to workplace protections from TB and to the highest attainable standard of TB services.
- Stigma, discrimination and other marginalization related to status as a migrant or indigenous person.
- Gender-related subordination of women in household decision-making.

In addition to these factors, **involuntary isolation** of TB patients in some countries merits attention as an important barrier to rights-based services. Laws and public health regulations in some jurisdictions allow for compulsory detention in many circumstances, in spite of international guidance suggesting that involuntary isolation should be a measure of last resort.[25] As WHO notes, engaging respectfully with patients to encourage their compliance with treatment should be the default practice and will be effective in the vast majority of cases. WHO notes that in the rare case where, after all "reasonable efforts" have been made but a patient refuses care, a "carefully limited" involuntary isolation, using the least restrictive means possible, may be justified as a last resort.[26] Isolation must not be administered as a form of punishment, and any person subjected to it must be informed in advance of the possibility of it and have the right to appeal it.

[25] World Health Organization. *Guidance on ethics of tuberculosis prevention, care and control*. Geneva, 2010.
[26] Ibid.

Programs to remove human rights-related barriers to TB services

It was understood early in the HIV pandemic that removing human rights-related barriers was crucial to an effective response to the disease. As more interventions were implemented to address stigma and discrimination and increase access to justice for people living with and at risk of HIV, UNAIDS was able to identify seven categories of programs that had a track record of success in reducing these barriers and produced guidance to encourage their implementation.[27] The Nairobi Strategy, the Global Fund's technical guidance on rights-based approaches to TB, and Stop TB Partnership's key populations briefs all suggest that these same categories of programs can be applied to removing human rights-related barriers to TB services. In addition, there are some program areas, such as measures to prevent misuse of involuntary isolation, that are relevant to TB but not necessarily HIV services. All of these are described in this section with some examples of effective programs and practices in these areas.

Reduce stigma and discrimination related to TB: TB-related stigma and discrimination may be rooted in lack of access to information about TB and may be amplified when being part of a key population or coinfection with HIV are in the picture. A number of program approaches have been put forward to reduce stigma and discrimination related to TB, such as the following:

- Reducing stigma and fears among health workers with respect to their own TB risk and their attitudes toward patients with or at risk of TB can be important both to the quality of TB services available and to attitudes in the larger community. Experience has shown the value of working respectfully with health workers to ensure that effective TB infection control measures protect them in their workplace, that they have non-judgmental access to treatment for themselves, and that they receive patients non-judgmentally as well.[28] An intervention in South Africa showed that including as trainers those health workers who survived treatment for TB and drug-resistant TB can be especially effective.[29] In Nicaragua, health workers were supported to take the time to visit their patients at home and to interact with patient support groups in the community.[30] This controlled intervention concluded that stigma was reduced both in the community and in health services.
- Whereas HIV-related stigma has been measured repeatedly in many countries with somewhat standardized instruments, data on TB-related stigma are somewhat rare. Assessing both the extent and the causes of TB-related stigma can inform stigma

[27] UNAIDS (Joint UN Programme on HIV/AIDS). *Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses (Guidance note)*. Geneva, 2012. The seven categories of programs are: (1) stigma and discrimination reduction; (2) training for health care providers on human rights and medical ethics; (3) sensitization of law-makers and law enforcement agents; (4) reducing discrimination against women in the context of HIV; (5) legal literacy ("know your rights"); (6) legal services; and (7) monitoring and reforming laws, regulations and policies relating to HIV

[28] von Delft A, Dramowski A, Khosa C, et al. Why healthcare workers are sick of TB. *International Journal of Infectious Diseases* 2015;32:147-151.

[29] Ibid.

[30] 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.

reduction programs. In 2018, the KNCV Tuberculosis Foundation with USAID support issued a detailed TB stigma measurement guide covering stigma in health services, stigma in the workplace, legal discrimination on the grounds of TB status, stigma in rhetoric and many other aspects.[31] Application of tools such as this should expand the evidence base on TB-related stigma.

- Approaches to addressing TB in the community can include mass information campaign emphasizing the importance of diagnosis and of supporting those in treatment, patient support groups, anti-discrimination messaging about key populations, and work with major employers and thought leaders. In Ethiopia, TB clubs comprising current and former patients helped with sustaining treatment, and clubs also met with local religious leaders and congregations to reduce fears about TB.[32] Evaluations of this effort found improvements in treatment completion and case-finding in the community.

Reducing gender related barriers to TB services: The reluctance of men in numerous countries to seek TB services can be addressed by working with men's groups in the community and improving the capacity of health service providers to provide care sensitive to men's situations and accessible with respect to their work hours. For women, providing child care in health facilities may improve accessibility of services. In HIV-endemic areas, integration of TB services with HIV mother-to-child transmission services may increase accessibility of care for women. The Zambart Project, a health NGO in Zambia, having studied TB stigma and concluded that women there have experienced TB-related stigma in the form of abandonment or threats of abandonment by their spouses, developed a stigma reduction tool with gender-responsive material for both men and women to reduce fears of TB and encourage support for those who need treatment.[33] The NGO Survivors Against TB in India, needing to combat the widespread idea that women who have had TB could not conceive a child and to answer many other questions about the disease, launched a user-friendly Hindi web site with scientifically sound information on TB and advocate for more accessible services for both women and men.[34] Both men and women can benefit from active case-finding outreach that is sensitive to their respective situations and concerns, preferably with the participation of people or organizations they trust.[35]

Training and sensitization of health workers on human rights and ethics related to TB: As suggested above, health workers concerns are twofold: that they should provide respectful rights-based TB services, but they also have justifiable fears as persons frequently exposed to TB. TB training for health workers should respect this dual focus. TB training is unlikely to be effective if health workers feel that they are inadequately protected from infection in their daily

[31] KNCV Tuberculosis Foundation, TB Challenge and USAID. *TB stigma measurement guidance.* Amsterdam, 2018.

[32] Getahun H, Maher D. Contribution of TB clubs to tuberculosis control in a rural district in Ethiopia. *International Journal of Tuberculosis and Lung Disease* 2000;4(2):174-8.

[33] Zambart Project, International HIV/AIDS Alliance and EU-STAMPP. *Understanding and challenging TB stigma: Toolkit for action*. Lusaka, 2009. At: http://targets.lshtm.ac.uk/resources/Publications/TB_and_Stigma_Eng2.pdf

[34] Cousins S. "Women survivors of TB speak out against stigma in India," *NewsDeeply*, 23 March 2017, at https://www.newsdeeply.com/womenandgirls/articles/2017/03/23/women-survivors-tb-speak-stigma-india; see also "Survivors Against TB launches India's first website on TB in Hindi," *The Hans India*, 26 September 2017, at http://www.thehansindia.com.

[35] UNDP, *Gender and tuberculosis*, op.cit.

work or if they perceive that their own privacy and confidentiality with respect to TB are not certain. A South African study found, in fact, that helping to mobilize health workers as advocates for workplace TB protections may be central to building their capacity to deliver TB services.[36] Other researchers in South Africa concluded that it may be helpful to assess the extent and causes of TB-related stigma experienced by health workers to inform training for them and provide practical suggestions for that assessment.[37] For the training of community health workers, WHO published the ENGAGE-TB materials, which have a heavy emphasis on stigma reduction.[38] As community health workers may play a key role in case-finding and providing TB information to the general population, developing context-specific rights-centered training programs for them is important.

Improving TB services in prisons and other detention facilities: The support of the Global Fund and other donors has greatly improved access to TB services for prisoners and detainees in many countries in recent years,[39] but there is much more to be done. From a human rights perspective, it is worth emphasizing that reducing prison overcrowding may be as useful for prevention of TB as improved services.[40] As noted above, over-reliance on pretrial detention is a major cause of overcrowding in many countries, and it can be remedied. Health workers in prisons and prison reform advocates in the community can be mobilized as an advocacy voice for reducing pretrial detention if they are made familiar with best practices in this area. With respect to improved services, there are many experiences showing that peer-based approaches in prisons help to ensure the non-judgmental and non-stigmatizing provision of information and services.[41] A PEPFAR-supported peer education program on TB in Tanzanian prisons was evaluated and found that the peer trainees appreciated the approach to "breaking the silence" and reducing TB-related stigma and were eager to get even more communications skills.[42] As with health workers, prison guards and other corrections staff have legitimate concerns about TB transmission risks in their daily work, and addressing these should be part of TB training for them.

Training and sensitization of law enforcement, legislative and judicial personnel: Compared to the analogous HIV programs, there are relatively few evaluated experiences of TB training of police, judges, prosecutors or legislators. The Nairobi Strategy emphasizes the importance of action in this area, calling for workshops with judges and other judicial

[36] Zinatsa F, Engelbrecht M, van Rensburg AJ, Kigozi G. Voices from the frontline: barriers and strategies to improve tuberculosis infection control in primary health care facilities in South Africa. *BMC Health Services Research*. 2018;18:269. doi:10.1186/s12913-018-3083-0.

[37] Wouters E, Masquillier C, Sommerland N, et al. Measuring HIV- and TB-related stigma among health care workers in South Africa: a validation and reliability study. *The International Journal of Tuberculosis and Lung Disease* 2017;21(11):19-25

[38] World Health Organization. ENGAGE-TB – Training of community health workers and community volunteers (facilitators guide). Geneva, 2015.

[39] Dara M, Acosta CD, Melchers NV, et al. Tuberculosis control in prisons: current situation and research gaps. *International Journal of infectious Diseases* 2015;32:111-117.

[40] Ndeffo-Mbah ML, Vigliotti VS, Skrip LA, Dolan K, Galvani AP. Dynamic models of infectious disease transmission in prisons and the general population. *Epidemiol Rev.* 2018;40(1):40-57.

[41] See, e.g., Zishiri V, Charalambous S, Shah MR, et al. Implementing a Large-Scale Systematic Tuberculosis Screening Program in Correctional Facilities in South Africa. *Open Forum Infectious Diseases.* 2015;2(1):ofu121-ofu121; Médecins Sans Frontières and Southern Africa Medical Unit. *Operational Toolkit: Providing Comprehensive Medical Services Through A Three-Phase Model in Malawian Prisons.* Cape Town, 2018;

[42] Mihyo Z, Casto J, Chiyaka I. Training of Trainers: Peer education program for inmates and staff to reduce tuberculosis and HIV risk in Tanzania prisons. Arlington, VA: Strengthening High Impact Interventions for an AIDS-free Generation (AIDSFree) Project, 2016.

personnel on health and human rights aspects of TB and the development of a "judicial bench guide" that would summarize relevant case law.[43] The Strategy also calls for maintaining a roster of legal and health experts who can be called on to testify in court or contribute to amicus briefs in key cases. The training of legislators and development of model legislation related to TB are also espoused in the Nairobi Strategy.

Increasing rights literacy and legal services related to TB: People at risk of TB, especially some of the key populations noted above, may not know the extent and nature of their right to health services, their right to TB protections in the workplace, their right to services while in custody of the state and related rights. And if they know their rights, they may not be able to assert them without legal assistance; right literacy and legal service activities often go hand in hand. Some civil society organizations have begun to make strides in this area. For example, the NGO Namati in Mozambique has trained people as health advocates or *defensores* who as paralegals help people bring to local authorities their formal complaints about grievances related to health services, including TB services.[44] Lawyers are available to back up this paralegal action if needed. Namati concludes that in the best cases, health service providers have seen the *defensore* activity as allied to their own efforts to improve their ability to provide good-quality services. A second example comes from India where the New Delhi-based NGO Human Rights Law Network used extensive judicial precedents to bring litigation to force improvement in the quality and accessibility of TB services in the Delhi area.[45] The case *Sanjai Sharma v. NCT of Delhi* resulted in a court order to improve TB treatment services, though it did not pass judgment explicitly on the rights violations alleged by the plaintiff. The lawyers involved note that litigation in such a case must be only one of many forms of advocacy to address exclusion from services.

Measures to address involuntary isolation, coerced or compulsory treatment: The measures noted above to improve access to justice in matters related to TB may be especially relevant to ensuring that involuntary isolation for treatment of other forms of compulsory treatment are not misused. Laws, policies and practices on involuntary isolation may not be clear or consistent, even in the minds of health professionals. "Know your rights" efforts for TB patients, their families, and potential patients may be especially important, along with access to legal assistance. Patient groups or other community organizations should be informed of examples of good practice in alternatives to involuntary isolation. An especially egregious practice that should be confronted is the use of prisons or other criminal detention centers for compulsory TB treatment. The Kenyan NGO KELIN had a signal litigation victory in 2016 when it challenged the imprisonment of two men – in grossly inhumane conditions – for TB treatment non-compliance.[46] The court's ruled in this case that the use of prisons was inappropriate for this purpose as the goal was treatment, not punishment. The court did not award damages to the plaintiffs but ordered the government to revisit its policies on treatment non-compliance.

[43] Nairobi Strategy, op.cit.

[44] Feinglass E, Gomes N, Maru V. Transforming Policy into Justice: The Role of Health Advocates in Mozambique. *Health and Human Rights*. 2016;18(2):233-246.

[45] McBroom K. Litigation as TB rights advocacy: A New Delhi case study. *Health and Human Rights* 2016;18(1):69-84.

[46] 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.

Increasing access to TB medicines: As with HIV, continued advocacy is needed to ensure access to medicines, including for drug-resistant forms of TB, and to diagnostic tools for all who need them. Many civil society organizations have long worked to promote the use of the public health safeguards in the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPs) to improve access to TB medicines.[47] Advocates have also urged concessionary pricing on new, non-injected medicines for drug-resistant TB, which are currently unaffordable in many countries, and for registration of these medicines for use in TB treatment in all countries.[48] Investment is also needed in research for affordable diagnostic and prevention tools within the reach of resource-constrained environments.[49] Donor support to sustain advocacy and action in these areas is essential.

Addressing occupational risks: Often with the support of the International Labour Organization (ILO), some countries have created national silicosis elimination programs to address TB in the mining industry.[50] These usually include commitments to institute dust control and ventilation measures, health inspections in the mines, and the use of technologies that reduce silica dust. The Southern African Development Community (SADC) in 2015 produced a code of conduct on TB in mining to which members states are committed.[51] There are ILO guidelines for TB control in the workplace, including for health workers.[52] But in many countries, efforts to hold mining and construction industries accountable are weak; advocacy in this area is needed. Stop TB Partnership recommends efforts on several fronts to hold miners and construction industry employers to account, including support for TB-related advocacy of labor unions, government mechanisms to ensure adequate compensation to people suffering TB-related health consequences because of workplace exposure, requiring companies to provide data on TB illness associated with their workplaces, and constant oversight to ensure that the safest practices and used and sustained.[53] Some efforts at improving access to TB services for miners have been undertaken. The PROMISE study supported by PEPFAR, in process at this writing, is investigating the acceptability of integrated TB and HIV services especially designed for miners and their families in Lesotho, which includes stationing services at locations convenient to miners and their families.[54]

Addressing barriers associated with HIV-TB coinfection: HIV-related stigma and discrimination and other human rights-related barriers can amplify TB-related barriers for persons living with both diseases, particularly for HIV key and vulnerable populations such as sex workers, LGBT persons and people who use drugs. Where coinfection is a significant health

[47] See, e.g., most recently: Knowledge Ecology International, "South Africa breaks the silence procedure: UN Political Declaration on tuberculosis," 27 July 2018, at: https://www.keionline.org/28579

[48] Médecins Sans Frontières, "MSF calls on Johnson & Johnson to make key drug bedaquiline affordable for all people who need it," 17 August 2018;

[49] Médecins Sans Frontières, Briefing on ending tuberculosis for the 71st World Health Assembly in preparation for the General Assembly High-Level meeting on TB, May 2018, Geneva.

[50] International Labour Organization, "Occupational health: Silicosis" (online summary of programs), at: http://www.ilo.org/safework/areasofwork/occupational-health/WCMS_108566/lang--en/index.htm

[51] Southern African Development Community. *Code of conduct on tuberculosis (TB) in the mining sector*. Doc. no. SADC/ELSM&SP/1/2016/7. Gaborone, 2015.

[52] International Labour Organization. *Tuberculosis: Guidelines for workplace control activities*. Geneva, 2003; International Labour Organization, World Health Organization and UNAIDS. The joint WHO-ILO-UNAIDS policy guidelines on improving health workers' access to HIV and TB prevention, treatment, care and support services: Guidance note. Geneva, 2010.

[53] Stop TB Partnership. *Key populations brief: Miners*. Geneva, 2016.

[54] U.S. National Library of Medicine, PROvide MIner-friendly SErvices for Integrated TB/HIV Care in Lesotho Study (PROMISE), 2018, described at https://clinicaltrials.gov/ct2/show/NCT03537872.

problem, health worker training should focus on provision of non-stigmatizing services for people affected by both diseases. Integration of HIV and TB services in facilities where privacy and confidentiality practices are well developed would help engender trust for people living with co-infection. Assessment of TB-related stigma should include a focus on HIV so that both can be addressed in stigma reduction programs.

Monitoring and reforming policies, regulations and laws that impede TB services: Support is needed for advocates striving to improve the legal and policy framework for a rights-based response to TB. Many possible areas of advocacy on law, policy and government practice are important, some of which have already been suggested in this paper, such as the following:

- Law or policy to ensure that pretrial detention is used only when absolutely necessary, as specified in international agreements;
- Improvement of prison conditions to reduce TB transmission risk;
- Ensuring that the legal and policy environment allow for use and registration of generic medicines and for use of TRIPs flexibilities to improve access to TB medicines and diagnostic tools;
- Laws and policies to ensure accountability of employers in workplaces that carry TB risk;
- Decriminalization of minor drug infractions to facilitate utilization of health and social services by people who use drugs;
- Legal and policy protections for migrants and other mobile populations to ensure access to services, facilitate cross-border collaboration of health authorities, and reduce discrimination; and
- Easily understandable law or policy on involuntary isolation for TB treatment as a last resort and policy to institutionalize the training of health professionals in this area.

Conclusions

As has been reflected in the End TB Strategy, it is clear that removing stigma and discrimination related to TB and other human rights-related barriers to TB services must be central to any effective TB response. The marginalization and unrealized human rights suffered by many of the populations most affected by and at risk of TB, which constitute impediments to seeking and using TB services, cannot be left unchallenged. Without concerted efforts to dismantle or overcome these impediments, large numbers of people will be left behind, and strategic goals for ending TB will not be achieved.

Governments and donors alike must work together to mobilize sufficient resources to scale up programs that have begun to show concretely that human rights-related barriers to TB services can be removed. Practical guidelines and lessons from existing programs have been and are continuing to be developed. National governments and other health service providers increasingly have an evidence base on which they can build interventions to reduce human rights-related barriers as a central and integrated element of their TB strategies. Governments and donors must embrace the difficult task of ensuring that resource constraints do not undermine these interventions. Programs to reduce human rights-related barriers must be at a scale that enables them to reach all affected persons and must be sustained at adequate scale to make a difference.

As noted in the TB and human rights technical brief of the Global Fund, a rights-based response to TB is more than the sum of the several types of program interventions described here, as important as these are. A human rights-based and gender-responsive approach to ending TB entails integrating in all aspects of program design, implementation and evaluation the principles of non-discrimination, gender equality, transparency, accountability and meaningful participation of affected persons in decision-making. Laws and policies related to TB should incorporate the same principles. There is a long history in many places of delivering TB services in a top-down way. Addressing human rights-related barriers to TB services calls for new ways of engaging and working with affected populations and new commitments to accountability for all actors in the TB response.

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