

A Human Rights- Based Response to TB

A Legal Workshop : Report

Northwestern

PRITZKER SCHOOL OF LAW
Bluhm Legal Clinic



Stop TB Partnership hosted by **UNOPS**

31 OCTOBER 19

**Hyderabad, India
Trident Hotel**



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Introduction

The “Rhetoric of Rights” has entered the mainstream of the TB response, as seen in last year’s UN High-Level Meeting on TB and workshops like the Mombasa, Kenya “Nairobi Strategy: Measuring Progress and Planning for the Future” meeting. Now is the time to move our efforts to the next level, to build on recent advances to push for a more concrete understanding and activation of a human-rights based response to TB.

To that end, on 31 October, Northwestern Pritzker School of Law, Global Coalition of TB Activists, and Stop TB Partnership held a legal workshop titled A Human Rights-Based Response to TB, geared towards participants from Asia-Pacific and Africa. The first workshop of its kind, it paired together legal and TB community leaders and activists from more than a dozen countries, including Botswana, Cambodia, Canada, India,

Indonesia, Kenya, Moldova, Nepal, Philippines, Romania, Russia, Switzerland, Tajikistan, and the United States. Among the participants were representatives from international institutions like Stop TB Partnership, Treatment Action Group, KELIN, The Global Fund, TBpeople, and Médecins Sans Frontières. This is the first time that both spheres have together for the purpose of advancing understanding and activating a human rights-based response to TB at regional, national and community levels.

At the core of a human rights-based response to TB is the principle “nothing about us without us.” The workshop was designed to enhance participants’ awareness about the content and utility of a human rights-based response to TB through targeted training sessions. The sessions were designed to strength capacity and build expertise around the law, human rights and public health aspects of the epidemic. In doing so, the Workshop worked to equip lawyers and people affected by TB to contribute to the fight against the disease in their countries and communities, and as leaders on the global stage.

Background

TB is the world’s deadliest infectious disease, and the WHO-defined regions of South-East Asia and Africa carry the highest burdens of TB in the world, with India leading the count. Eight countries in the world account for two thirds of the new TB cases, and five of those countries are located in South-East Asia or Africa: India, Indonesia, Nigeria, Bangladesh, and South Africa. According to the WHO, one-third of the world’s burden of tuberculosis (4.9 million cases) is found in South-East Asia alone. About 82% of TB deaths among HIV-negative people occurred in the WHO African Region and the WHO South-East Asia Region in 2016. The African region accounts for 25% of new TB cases and over 25% of TB deaths worldwide, and India alone exceeds 25% of the world TB burden.

On 26 September 2018 at the UN General Assembly in New York, Member States held the first High-Level Meeting on TB. As a result, Heads of State and Government endorsed the UNHLM Political Declaration on TB, outlining [key commitments](#) that must be met for the world to end the TB epidemic by 2030, as called for in the UN Sustainable Development Goals. This Declaration includes specific human rights commitments, aiming to “transform the TB response to be equitable, rights-based and people-centered.” In order to make these global targets relevant at country level and “with a view to drive country level political commitment, facilitate monitoring and accountability,” Stop TB Partnership has produced [country breakdowns for these targets](#).

Most countries' TB policy guidelines are not explicitly human rights-based ones. Much like the HIV/AIDS response has been built on respect for individuals' human rights, the TB response must be so too. Studies have shown that a human rights-based approach to case-finding, diagnosis, and treatment leads to increased success. In order to fulfill the goals of the WHO End TB Strategy and the UNHLM Political Declaration on TB targets by 2030, a human rights-based approach to TB must be implemented. Stop TB Partnership's Global Plan to End TB 2016-2020, a 5-year roadmap to accelerating the impact on the TB epidemic and reaching the targets of the WHO End TB Strategy, lists "a human rights and gender-based approach to TB" as one of the eight areas in which a paradigm shift in the approach to TB is required.

Participants

Presenters

Brian Citro, Northwestern Pritzker
School of Law
Blessina Kumar, Global Coalition of TB
Activists (GCTA)
Lucica Ditiu, Stop TB Partnership
Justice Mumbi Ngugi, Court of Appeal
of Kenya
Mike Frick, Treatment Action Group
Amy Pestenariu, Northwestern Pritzker
School of Law
Allan Maleche, KELIN
James Malar, Stop TB Partnership

Legal Participants

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Adam Houston, Canada
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George Gilbert, Kenya
LM Dingake, Botswana
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Ngina Muyanga, Kenya
Priyam Cherian, India
Roshan, India
Runjun, India
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Community Participants

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Agenda

Introductions, Workshop Objectives, and Expected Outcomes



The day started with group introductions and then opening remarks from Blessina Kumar, CEO of Global Coalition of TB Activists; Dr. Lucica Ditiu, Executive Director of the Stop TB Partnership; and Brian Citro, Assistant Clinical Professor of Law in the Bluhm Legal Clinic at Northwestern University. The speakers

highlighted the recent increase in global discussion about TB and human rights, and the uniqueness of this Workshop bringing together lawyers and community leaders and activists. Advocates doing human rights TB work were encouraged to be persistent, not shy away, and necessarily be equipped with a technical understanding of what a human rights-based approach to TB is.

Keynote Speaker

Justice Mumbi Ngugi of the Kenyan Court of Appeals and author of one of the most ground-breaking, progressive opinions looking at the TB through the lens of constitutional rights, spoke on the critical role of courts and lawyers in the TB response. She spoke about how she was struck by the challenges that people with TB face, including stigma, and the intricate nexus between the lack of respect of the human rights of those affected by TB and the spread of TB.

States' responses have more often taken a public health rather than human rights approach, often involuntarily isolating people, and in Kenya, those who stopped treatment were imprisoned. TB is often treated as a crime.

Daniel Ng'etich v. Attorney General exposed her to the fact that there is a section of society that can be imprisoned and have their rights violated, including discrimination based on health status.



Poverty, stigma, social exclusion, and discrimination result from unrealized human rights, and reduce the likelihood of success of treatment. Lack of socioeconomic rights is a major factor in the spread of TB in developing countries. A rights-based approach to TB is likely to promote adherence and thus decrease the spread of TB.

Lawyers and judges know the law, but if not properly applied, it can be damaging and be a blight on citizens. Lawyers and judges have a duty to adjudicate and protect rights; take up side of those oppressed; and to know, at least at a basic level , the science of TB and the social issues.

The community has to be vigilant and file relevant cases before the courts. It is time that activists lobbied for clear rights for TB. TB should not be such a challenge in this time of science.

Justice Ngugi issued challenges to lawyers, judges, and community members: learn about TB, the science behind it, the circumstances and conditions in which it is spread; learn about the circumstances and challenges to fully enjoying their rights of people affected by TB; get engaged in litigation around the rights of people with TB to ensure states take a human rights-based approach; get engaged in advocacy for legislation and policy; get engaged in advocacy in realization of socioeconomic rights; and question the ethics behind development and access to medicines for TB.

“Even as we dismiss TB as a disease of the poor, we must remember that we breathe the same air, and even though it predominantly affects the poor, no man is an island.” We must make a change in our response to TB.

Session I: Defining a Human Rights-Based Response to TB

The first session laid groundwork for the rest of the Workshop, with Professor Brian Citro of Northwestern Pritzker School of Law defining the framework of a human rights-based (HRB) response to TB.

The WHO End TB Strategy is the current global strategy against TB, the second key principle of which is building a strong coalition. In September 2018, the first-ever United Nations (UN) High-Level Meeting (HLM) on Ending Tuberculosis (TB) produced a historic Political Declaration, with specific, measurable milestones to achieve by 2022. This is the first time that heads of state have committed to doing something about TB, and it mentions human rights throughout. The Nairobi Strategy on TB and Human Rights

is a global strategy supported by STP and other organizations, and it seeks to more concretely define what a human rights-based response to TB is.

The core principles of a HRB response to TB are founded on the dignity and autonomy of the individuals. Cross-cutting principles (from HIV) include non-discrimination and substantive equality, focus on vulnerable and marginalized groups (key populations), participation in decision-making, and remedies and accountability.

There is a three-part rights-based framework: individual entitlements, which are positive obligations for governments to things like life, health, information, science, and social security/protection; individual freedoms and protections, which require the government to stop doing something, like freedom from torture; and rights related to prevention of TB, like the rights to an adequate standard of living, environment, housing, food, water, and sanitation.

One does not need to be a lawyer or human rights expert to do human rights work. There is a spectrum of work for a human rights-based TB response, ranging from litigation, to representation in administrative processes, to advocacy. Learning how to use the language of policy and regulation to advocate for change, research and knowledge generation, and capacity building and sensitization of key stakeholders are all just as much human rights work as litigating is.

Session II: Issue-Based Modules

Each hour-long, issue-based module was conducted in a 20-20-20 format: the first 20 minutes were a PowerPoint-based training given by the designated expert on the subject; the next 20 minutes were spent in break-out sessions, during which lawyers and community members separated into two groups to work through guided discussions, designed to implement the material that was just presented; and the last 20 minutes were a plenary session during which a representative from each group presented to the other the key take-aways from their group's discussion.



Rights to Privacy and Confidentiality for People Affected by TB

This session, led by Prof. Brian Citro and based on the work of Megan Richardson of Northwestern Pritzker School of Law, described how the rights to privacy and confidentiality are implicated in the context of TB, and how they must be protected both to combat stigma and discrimination and to promote better TB testing and treatment outcomes.

Privacy and confidentiality are bulwarks against stigma based on health status as well as other defining characteristics. Potential privacy violations have both effects on people with TB as well as public health effects. People with TB may experience delayed diagnosis, interrupted or incomplete treatment, increased travel burden to leave the community, increased use of poor-quality private clinics, or failure to disclose TB status to at-risk contacts. If people cannot anticipate that their privacy and confidentiality are protected, they are more likely to be diagnosed later because just the act of being diagnosed or going to a TB clinic is revealing. Consequential public health effects are increased disease transmission, poor health outcomes, and a weakening of the fabric of trust between healthcare providers and users.

Confidentiality is a part of medical ethics, even if we don't talk about human rights. Privacy is broader and establishes the right of people to decide how info is shared or disclosed, and protects against nonconsensual disclosure of private information. The right to privacy and confidentiality also protects against the intrusion of the State into the zone in which sensitive decision-making occurs about a person's health and family. The right to privacy is not absolute, but the focus of exceptions must be on those to whom people with TB pose a real risk of transmission and then only for the duration of the risk.

In the context of TB, issues of privacy and confidentiality arise in such areas as case finding, physical infrastructure, operational procedures like DOTS, data privacy, and public records and processes. Policy recommendations to address potential violations in these areas were also presented.

During the break-out sessions, community members discussed possible methods by which a community-based approach may be structured so as to protect privacy and confidentiality, and the potential roadblocks to treatment that a lack of privacy and confidentiality creates, especially for key populations like migrants and drug users. The legal participants did a case study and discussed the necessity of anonymous litigation, identifying information, and non-consent.

Right to Access Good Quality TB Diagnostics and Treatment

This session, led by Mike Frick of Treatment Action Group, presented the current landscape for TB diagnostics and treatments, including new technologies for drug-resistant TB and explain how a rights-based approach is key to ensuring the availability and accessibility of TB diagnosis and treatment.



Last month, Treatment Action Group (TAG) released their 2019

Drug Pipeline Report and National TB checklist, which TAG uses to tell organizations like the Global Fund where they should be focusing their funding. “Science-based treatment activists” focus not just on new technologies but also existing technologies that are not freely accessible either because of an IP monopoly, like with bedaquiline, or because although they’re off-patent, they are only being supplied by one company, like Sanofee with Rifapentine. Mike Frick presented the current landscape of existing and up-and-coming TB technologies for prevention, diagnosis, and treatment.

In the world of research, Mr. Frick asserted that we now in a place where things are changing far more quickly than before; we can expect new technologies every 2 to 3 years, and thus a possible need for protocol changes every 2 to 3 years. Countries will have to get faster at re-training and re-tooling, as we are no longer in a place where they have 5

years to do a pilot or 6 months to train a health cadre. The right to science has been called the “forgotten human right,” but organizations like TAG are working towards its realization, and knowledge of the current technological landscape is essential for activists to know what they should be demanding.



During the break-out sessions, lawyers discussed a case of a prisoner with TB and his treatment or lack thereof. The court recognized that a lack of adequate treatment provided by the state to a prisoner may constitute a violation of the right to freedom from torture. At the same time, community members, led by Mike Frick, discussed topics like minimum core versus progressive realization for the right to science, and shared experiences from their own countries. For example, in Kenya, while treatment is free, diagnostics is often a barrier, including transportation, and lack of nutritious food is often a barrier to successful treatment. While delamanid and bedaquiline are in the country, not every patient gets them because there are no guidelines. There is a fear that the drugs must be used before the expire, so decision-makers select people they think will benefit, but there is no unified standard of care. In Indonesia, prevention is not something that the government considers a priority and thus, the drug ends up expiring. In Indonesia, it is already difficult to move the preventative drug from one district to another because of the complicated reporting requirements, and so stock-out is often an issue. Diagnosis in Indonesia and Nepal is also an issue because the centers do not have capacity to test all of the sputum samples they get brought.

A common theme in the community discussion was that diagnosis is oftentimes harder to access than treatment because governments would rather put funds into treatment

than diagnosis. They concluded that treatment literacy is the foundation for community power to access goods and services, it is time for activists to educate communities and the government on how to end TB.

Session III: Spotlight Session

TB in Prisons—The Rights of Prisoners and Other People Deprived of Their Liberty in the Context of TB

This Spotlight session, led by Prof. Brian Citro, introduced the key challenges for prisoners and other people deprived of their liberty in the context of TB and presented a rights-based response to TB in prisons and other detention settings.

The State has a special duty of care for prisoners because while in prison, the state controls their treatment, living conditions, food, water, sanitation, etc. Prisoners often lack access to good quality TB care, but the health system in prison should not be different from the outside, and prisoners retain the rights to (among others) adequate conditions, good quality TB care, informed consent and bodily integrity, and privacy and confidentiality.

Prison environments and conditions around the world promote both spread of TB and conversion from latent to active TB. Should conditions be poor enough, they may constitute a violation of the right to freedom from torture. There is some discussion about alternatives to incarceration for nonviolent offenders with TB to decrease time spent by individuals in detention facilities. Prisons also often have poor quality health services, and prisoners and other detainees are especially vulnerable to coerced or forced testing and treatment for TB because of punitive norms and practices. There are legitimate penological objectives to prevent spread of disease and treat all prisoners with TB, but prisoners, like people outside of prison, have the right to refuse treatment.

Participants discussed whether TB in prisons has pushed people to make demands for open prisons, which are more ventilated and allow more mobility, even to the point where sometimes, prisoners may leave to work a job and come back in the evening. Also discussed was whether the issue of TB may be the entry point to making jails more humane and healthy; if governments do not want TB to be a problem in their jails, they should reform prisons.

Session IV: Issue-Based Modules (continued)

Isolation and Involuntary Isolation for TB

This session, led by Amy Pestenariu of Northwestern Pritzker School of Law, described the global environment for isolation and involuntary isolation in the context of TB, and presented the legal and ethical standards that must be established in order to protect the rights of people with TB and promote public health.



Isolation is the practice of separating a contagious individual from un-affected individuals in order to prevent the spread of the communicable disease. However, diagnosis of active TB does not automatically call for isolation, and quarantine (isolating a person and waiting to see if a person will develop the symptoms of the disease) is never ethically justified for TB.

There is a general lack of TB-specific policy guidance on isolation, and when a person with TB is involuntarily isolated, there are additional risks of human rights violations, including the rights to liberty and freedom of movement. As such, involuntary isolation is only justifiable in a specific set of circumstances and must meet strict standards. Four major issues surrounding involuntary isolation were also discussed: (1) a lack of data about involuntary isolation, (2) the use of isolation as punishment, (3) not isolating in a medically appropriate setting, and (4) forced treatment.

Involuntary isolation of persons with TB disease is appropriate only when they pose a serious threat to others and there is no other less restrictive method. Deprivation "must only occur as a last resort in order to protect the individual or others from serious harm," for the shortest possible period of time, in an appropriate medical setting, and be accompanied by procedural due process and substantive safeguards.



During the break-out session, lawyers discussed a case in which the court found that involuntary isolation was appropriate for an MDR-TB patient, following the principles presented earlier. The legal participants also presented critiques of the case regarding the apparent lack of consideration given to possible alternatives to involuntary isolation and whether such publicization of the case (and its decision) was not actually counter to public health goals, deterring MDR TB patients from seeking treatment for fear of possible involuntary isolation.

Community participants, during their break-out session, worked through a scenario in which they had to decide whether involuntary isolation was justified and what the decision-making process should be. Issues of available treatment and its quality, risk to others, and complicating factors of stigma and immigration status were considered. To supplement the conversation during the final plenary, a community member and MDR TB survivor shared her personal experience with TB, which was in a similar context.

Remedies and Accountability for Human Rights Violations in the Context of TB

This session, led by 2019 Kochon Prize-winner Allan Maleche of KELIN, focused on how to use courts and administrative processes, as well as international and regional human rights mechanisms, to protect the rights of people affected by TB. This session was interactive throughout, asking participants to share thoughts and experiences during the



presentation, with a dedicated Q&A session at the end.

Mr. Maleche led the group through primers on remedies and accountability, using examples that were discussed by the participants. He outlined some preliminary points to consider:

- What legal remedies are available (in my country) to people with TB when their rights are violated?
- What accountability exists under laws (of my country) for government or private actors that violate the rights of people with TB?
- Do national human rights monitoring and enforcement mechanisms (in my country) consider TB-related issues?
- Are cases of TB-related discrimination and other human rights violations recorded, documented, and addressed?
- What kind of remedy do you want? Examples?
- Beyond the court process, what other mechanisms exist?

Next was a walk-through of *Daniel Ng'etich v. Attorney General*, which Mr. Maleche and KELIN successfully litigated, explaining considerations that lawyers and community advocates must have when deciding whether or not to litigate a case, and how the two may work together for success. When deciding to litigate, lawyers need to build evidence for their case, especially if not urgent, in order to prove that they have asked the government to do something and they have not. Civil society is helpful in this aspect because they can advocate (without legal consequences because they are not the ones litigating the case) and support the narrative that the government is aware of the issue

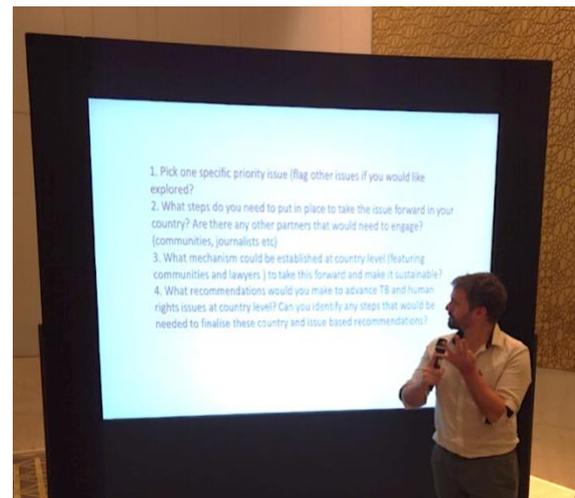
but have not taken action. KELIN extensively consulted, especially with civil society, to develop ideas in this case. The more one works with civil society, the more information one gets, and they can apply pressure to actors on your behalf.

After judgment, to hold the government accountable, KELIN used civil society to keep up the pressure, but had to balance this strategy against the interest of not antagonizing the government to the point where they would not want to comply with future work. Plaintiffs need to develop strategies to keep the conversation going, regardless of the outcome of the case, and those having the conversation (or advocating on your behalf) must be literate on the issue.

During the Q&A, it was observed that a lot of innovation around human rights and what they mean has come from the global south. It is important to emphasize this politically because in global health, there is still a perception that EuroAmerica is the savior and the global south is the recipient.

Session V: Human Rights Joint Action Plans

During the final session of the day, led by Blessina Kumar of GCTA and James Malar of STP, lawyers and community were provided the opportunity to breakout in Country Teams to reflect on the previous sessions and draft Action Plan outlines to implement a human rights-based response to TB in their countries and communities. During the latter portion of the session, a representative from each Country Team presented to the rest of the teams their Action Plan.



Teams were asked to consider the following questions:

1. Pick one specific priority (flag other issues if you would like explored).
2. What steps do you need to put in place to take the issue forward in your country? Are there any other partners that would need to engage (communities, journalists, etc.)?
3. What mechanism could be established at country level (featuring communities and lawyers) to take this forward and make it sustainable?

4. What recommendations would you make to advance TB and human rights issues at country level? Can you identify and steps that would be needed to finalize these country- and issue-based recommendations?



Common themes across countries' action plans included 1) affected people are unaware of what their rights are, what diagnostics and treatments to demand, and what the available avenues there are for remedies and

accountability; 2) there is need for awareness campaigns to increase treatment literacy; 3) diagnostics need immediate attention; 4) need for increased collaboration between lawyers and civil society, especially to increase information and documentation; 5) there need to be solid, human rights-based TB guidelines for governments and decision-makers to follow; 6) lack of funding is a common issue, so advocacy to funding bodies is also needed. Participants came away with greater understanding of issues in TB in their own country and others, and the need and tools for collaboration between lawyers, community members and activists on a human rights-based approach to TB.

Next Steps

GCTA, STP, and Northwestern plan to stay in touch with all participants, and hope that this is the beginning of a relationship amongst the participants, increasing collaborative, regional and worldwide networks. All materials used in the workshop, as well as supplemental content, will be available to participants as well.

Additional opportunities to further human rights-based TB work include 1) having the conversation about investing in TB work with your country-level authorities, and making sure it is in funding requests; 2) the next round of the Stop TB Partnership Challenge Facility for Civil Society will be launched within the month, giving access to funding that specifically targets civil society, human rights and these issues; and 3) if you think that other regions would benefit from this kind of workshop, talk to the global donors to advocate for it.