



The Nairobi Strategy on Tuberculosis and Human Rights.

A Human Rights-Based Response to Tuberculosis

2016 - 2018 PROGRESS REPORT BY VIVEK DIVAN

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INTRODUCTION

Tuberculosis (TB) remains a critical global health challenge. It ranks as the leading cause of death from infectious disease, killing more people each year than HIV/AIDS. In 2016, an estimated 1.8 million people died and 10.4 million people fell ill with TB. The global burden of TB is unwavering. Nearly 80% of all TB cases are found in 22 countries, nine of which are countries in Sub-Saharan; India alone accounts for 27% of the global burden.

A human rights-based response to TB upholds the rights of people affected by TB, including the rights to life, health, non-discrimination, privacy, informed consent, housing, food and water. The approach:

- focuses on the social and economic determinants of the disease, while addressing stigma, discrimination and undesirable environmental conditions;
- articulates the national and international legal obligations of governments and non-state actors to ensure that good quality prevention, testing, treatment and care services for TB are available, accessible and acceptable, without discrimination; and
- creates an enabling legal environment for research and development of new, more effective TB drugs and diagnostics, and lowers the prices of existing drugs and diagnostics, including new medicines and advanced diagnostics for multidrug-resistant Tuberculosis (MDR-TB).

Stop TB Partnership (“Stop TB”) has called for a people-centred, human rights- and gender-based approach to TB as part of the paradigm shift in addressing TB through the Global Plan to End TB: The Paradigm Shift 2016-2020. Indeed, Stop TB’s Global Plan acknowledges that TB programming will not be successful unless global and national programmes are grounded in human rights. The World Health Organization also recognizes the vital role of human rights; its End TB Strategy establishes “protection and promotion of human rights, ethics and equity” as one of four essential principles to ending TB globally.

Pursuant to this international guidance, the **Nairobi Strategy on Tuberculosis and Human Rights: A Human Rights-Based Response to Tuberculosis** (“Nairobi Strategy”) was developed at a Judicial Workshop on TB in Nairobi, Kenya in June 2016.

The goal of the Nairobi Strategy is “to promote the development and implementation of human rights-based approaches to TB at the global, regional, national and local levels.”



The **Nairobi Strategy** has two objectives, with several key components:

Objective 1.

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

KEY COMPONENTS

- 1. Empower and support networks of affected communities** with TB, TB survivors and broader civil society at global, regional and national levels;
- 2. Enhance judiciary and legal communities' awareness** on implementation of a human rights-based approach to TB;
- 3. Expand legislators' and policymakers' capacity** to incorporate human rights-based approaches to TB into respective laws and policies;
- 4. Engage and advise international organizations and experts** on the incorporation of the human rights-based approach to TB into global policies and programs; and
- 5. Sensitize health care workers** in public and private sectors on the need to incorporate a human rights-based approach to TB in their work.



Objective 2.

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

KEY COMPONENTS

- 1. Formulate and clarify the conceptual, legal and normative content** of a human rights-based approach to TB;
- 2. Conduct qualitative and quantitative research** to generate an evidence base for the effectiveness of a human rights-based approach to TB; and
- 3. Facilitate inclusive, community-led discussions to develop and promote use of ethical standards** to gather and use TB data. **Conduct qualitative and quantitative research** to generate evidence base for the effectiveness of a human rights-based approach to TB; and
- 4. Facilitate inclusive, community-led discussions to develop and promote use of ethical standards** to gather and use TB data.

This **Progress Report** provides an overview of the activities that have been undertaken pursuant to the Nairobi Strategy from June 2016 to August 2018 to advance local, national and global efforts to end TB through the deployment of a human rights-based response.

METHODOLOGY

This report was prepared based on interviews, written inputs and responses to a survey (annexed) from Jaime Argueta, Kathy Brito, Miryan Caballero, Brian Citro, Alberto Colorado, Sandra Patricia Escandon, Kenechukwu Esom, Dr. Georgio Franyuti, Dr. Jennifer Furin, Ernesto Jaramillo, Blessi Kumar, Erica Lessem, Priyam Lizmary, Lynette Mabote, Tendai Mafuma, Prabha Mahesh, Allan Maleche, Wariara Mugo, Justice Mumbi Ngugi, Dr. Hector Javier Perez, Annabel Raw, Luis Sanchez, Chuob Sokchamleon, John Stephens, Paul Thorn, Zulma Unzain, and Movement Against TB.

There are some limitations to this report. First, some experts did not provide feedback and thus, could not be incorporated into this report. Second, some respondents did not articulate how much of their work is solely TB-focused, especially when they also work on HIV-related projects. Finally, some of the aforementioned activities were already ongoing prior to the formulation of the Nairobi Strategy. Care has been taken to not falsely attribute all outlined activities to the Nairobi Strategy, but all activities are described within this report given that they are directly related to the Nairobi Strategy.



I. Empowering & Supporting People Affected by TB

The key **activities** enumerated in the Nairobi Strategy as part of this component are:

- a. Designing and conducting legal training for affected communities and civil society.
- b. Empowering people with TB, TB survivors and civil society to make use of judicial and quasi-judicial mechanisms to safeguard their rights.
- c. Developing, publishing and disseminating materials for community and civil society action.

The most critical challenge in achieving a human rights-based response to TB at the global, regional, national and local levels is empowering communities affected by TB to advocate for their rights. Though often still in their early stages, people affected by TB and partners have begun developing networks at global, regional and national levels. This section highlights some of this work from around the world.

At the United Nation's High-Level Meeting (UN HLM) on TB, civil society was presented with an international platform to influence the contents of the UN HLM Political Declaration (Political Declaration) on TB. In an open letter to the meeting's leadership entitled "Human rights are imperative to the success of the tuberculosis response", over 230 signatory individuals and organizations from civil society highlighted the necessity to protect and fulfil 12 key human rights commitments in order for the TB response to be successful.

This letter, which was presented to a number of politicians and global leaders in

the field, influenced the drafting of the Political Declaration. The community advocated for the inclusion of explicit language on human rights related to TB and countries' legal rights to utilize Trade-Related Aspects of Intellectual Property Rights (TRIPS) flexibilities to ensure access to TB drugs. While these efforts were only partially successful, they contributed to a Political Declaration that, while still imperfect, better acknowledges the rights of people affected by TB than had the community not had the opportunity, nor platform, to advocate for their rights.

At the international level, there have been other important collective initiatives to empower affected communities and advance rights-based approaches. For instance, the Drug-Resistant TB Scale-Up Treatment Action Team (DR-TB STAT) is a task force of several global TB organizations and civil society representatives demanding rapid scale-up and development of new TB drugs.

DR-TB STAT issues periodic reports on the uptake of new drugs. The team has also worked with the Treatment Action Group (TAG) to develop two guides: (i) Know Your Rights: Tuberculosis Prevention, Diagnosis, and Treatment; and (ii) an activist guide titled, Treatment of Drug-Resistant TB with New and Repurposed Medications: A Field Guide for Optimal Use.

More recently, international community coalitions have formed, including the Global Coalition of TB Activists (GCTA) and TBPeople, both of which are comprised of and empower people affected by TB to articulate rights-based demands through community mobilization at international, regional and national levels. Although the formation of these organizations was not precipitated by the Nairobi Strategy, their creation and development coincides with and contributes directly to advancement of the strategy.

The Stop TB Partnership, hosted by the United Nations Office for Project Services (UNOPS), was established in 2000 to eliminate TB as a public health problem and to promote TB on the world political agenda. Stop TB has supported the development of technology to empower communities through its Oneimpact smart phone app. Oneimpact is designed to help communities report and monitor TB-related issues, including the negative effects of social stigma, poor treatment by medical providers, side effects of TB, the impact of drug stock-outs, and the various challenges associated with national TB programs that communities face.

This platform has the potential to improve accountability and foster an evidence base on rights violations. Affected communities have piloted the app in Tajikistan and Khmer HIV/AIDS NGO Alliance (KHANA) is implementing the technology in Cambodia.

International agencies have also focused on empowering communities to promote rights-based responses to TB. The United Nations Development Program (UNDP) has supported the empowerment of communities and people with TB by facilitating participation in global, national and regional policy programs, such as partners of African Men for Sexual Health and Rights (AMSHeR) and Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN). UNDP, via funding from Global Fund TB grants, supports TB-related legal literacy programs, advocating to address stigma and discrimination, and enhance communication and social mobilization programs. These grants have enabled communities to: participate in rights-based advocacy through campaigns and published materials; build organizational capacity on law and rights; and gain access to the justice system to protect their rights through the courts.

In some regional contexts, like Southern Africa, regional community networks of people affected by TB do not exist. However, within the region, community groups operate at national levels and have impacts across the region. For example, in South Africa, the Treatment Action Campaign (TAC) promotes human rights issues around TB, including access to medication, treatment literacy, countering punitive approaches and discrimination, and seeking accountability from the health sector. TAC has also partnered with a number of other organizations, including SECTION27, the Rural Health Advocacy Project, Médecins Sans Frontières (MSF), and the Southern African HIV Clinicians Society, to create The Stop Stockouts Project (SSP). SSP monitors and reports the supply (and lack thereof) of HIV and TB medicines; it has published an annual report detailing its findings since 2013. Although, it precedes the Nairobi Strategy, the SSP is aligned with the goal and planned activities of the strategy: to empower communities to seek accountability from the health system. The mobilization of the Nairobi Strategy's financial and human resources will enable a closer examination of how the SSP can be adopted as a model for other contexts.

TAC, SECTION27, MSF and partners, also work to empower communities

1 Afghanistan, Belize, Bolivia, Kyrgyzstan, Panama, Sudan, Zambia

affected by TB to demand their right to health services. For example, after these and other groups demanded access to bedaquiline, a new drug for treatment of MDR-TB, the Government of South Africa announced a full rollout of the drug for people with MDR-TB in the country.

The AIDS Rights Alliance for Southern Africa's (ARASA) is an organization that focuses on training and education. Its capacity strengthening program works with TB survivors and those with TB through its annual Training and Leadership Program to engage and educate civil society on issues of HIV, TB prevention and treatment literacy, as well as proposal writing and project management. This initiative has trained over 286 civil society cadres in 18 countries in Southern and Eastern Africa since 2008. Within ARASA's 2013-2017 Strategic Plan, the program supported 37% of its partners' grantees with catalytic small grants, supporting projects that focused on TB national advocacy, World TB Day campaigns, capacity strengthening efforts, and information dissemination on TB and Human Rights at a national level in Kenya, Uganda, Mauritius, Malawi, Swaziland, Botswana, DRC and Zimbabwe. ARASA has also undertaken regional advocacy at the Southern African Development Community (SADC) level, focusing on legal and policy change for ex-miners in Southern Africa since 2008. This work has included providing in-country capacity strengthening and organizational development of ex-miner worker associations, and regional advocacy resulting in a 2012 SADC Declaration on TB in the Mining Industry.

Organizations, such as the Southern Africa Litigation Centre (SALC), are attempting to strengthen the communities of people affected by TB through legal literacy and support for litigation and advocacy around TB and HIV. SALC's key objective is to respond to the needs articulated by affected communities, and to empower as many communities as possible. SALC's current work on TB is focused on the prison sector in Malawi, helping prisoners with TB navigate the criminal justice system and protect their rights, collecting data on prison conditions, connecting prisoners with TB experts, and facilitating training to help prisoners better understand the legal system and their rights.

In the Americas, work at a regional level takes place through the Americas TB Coalition (ATBC). ATBC is comprised of civil society organizations, human rights activists, researchers and TB survivors who work at domestic and region-

al levels to mobilize funding for work in the region. The funding is used for TB programs that promote the right to health and enable comprehensive and integrated TB and HIV/AIDS prevention, diagnosis, care, social support, operative research, development, and innovation. However, funding to undertake training and capacity building within communities living in remote areas of Latin America is limited, and thus the ability to strengthen networks and coordinate community groups in those regions is challenging.

At national and local levels, in the United States, the Nairobi Strategy has been implemented through a collaboration between the Chicago Department of Public Health and Professor Brian Citro at the Northwestern Pritzker School of Law. With input from people affected by TB and city health care workers, they developed and published a Know Your Rights (KYR) Tuberculosis brochure explaining the rights of people with TB under federal, state and local law in Chicago, Illinois in the areas of employment, housing and disability benefits. The brochure is available in English and Spanish and includes a list of resources, including forums, where people with TB can file discrimination claims.

In India, personal experiences of stigma have often been the drivers of new community-based initiatives, including the founding in 2017 of Touched By TB, a new national network of people affected by TB. Since its creation, Touched By TB has established patient support groups, created a helpline for people affected by TB to report and discuss TB services delivery gaps, and educated and empowered communities to demand their rights to health goods and services in the health system, particularly around access to medicines and people-centred treatment. As a result, a wider network of DOTS (Directly Observed Treatment, Short Course) centres were established in Mumbai in order to improve access to TB treatment. Services offered at counselling facilities were also enhanced, and doctors have made concerted efforts to share accurate health information with patients. Another key outcome was greater publicization of TB-related issues through, promoting accountability among health care workers.

In Mexico, organizations such as ECOSUR along with community activists have long been involved in the empowerment of TB survivors and people with TB through rights-based advocacy. These organizations and communities demand improvements in the quality of health services, predominantly by educating com-

munity members on the law and relevant health standards. In other countries such as Paraguay and the Dominican Republic, civil society organizations such as ALVIDA and ASODENAT (and at a regional level, Medical IMPACT for Latin America and parts of Africa) have robust programs for community empowerment, but they are less focused on the individual rights of TB survivors and people with TB, and are more focused on simply providing information on health and connecting those with TB to with local health services.



2. *Enhancing Awareness of the Judiciary and Legal Communities*

The key **activities** enumerated in the Nairobi Strategy as part of this component are:

- a. Developing, publishing and disseminating a judicial bench guide on TB, human rights and the law.
- b. Developing and supporting a network of lawyers.
- c. Encouraging judicial officers to invite amicus curiae briefs on TB and human rights.
- d. Developing and supporting a network of legal, medical and public health experts.
- e. Creating and supporting a closed online community of legal, medical and public health experts.

Enhancing the awareness of the judiciary and legal communities on a human rights-based response to TB is critical to ensuring the courts can be used, when necessary, to protect and fulfil the rights of people affected by TB. This section highlights concrete efforts that have led to the achievement of some aspects of this component of the Nairobi Strategy.

In the African context, much of this work has been undertaken under the Africa Regional Grant on HIV: Removing Legal Barriers of the Global Fund, of which the Principal Recipient is UNDP. The sub-recipients of this grant include Enda Santé (Senegal), SALC, KELIN and ARASA. SALC has conducted training for lawyers in 10 countries, KELIN has conducted training for law enforcement officers, and national human rights institutions such as ARASA have initiated pro-

grams pertaining to TB and human rights at national and regional levels.

SALC's work under the aforementioned grant has included three regional trainings for lawyers where hundreds of lawyers from across the continent were trained. The themes of the trainings were related to Health Rights (2016), Prisoners' Health and Rights (2017) and HIV and TB criminalization (2018), all of which have incorporated components on TB-related rights, law and policy. The Nairobi Strategy, TB Case Law Compendium and other relevant resources were shared during these trainings.

Complementing this effort is the on-going development of the Judicial Handbook on TB, Human Rights and the Law through an inclusive process by the TB, Human Rights and the Law Task Force of the Global Drug-resistant TB Initiative, led by Professor Brian Citro at Northwestern Pritzker School of Law.

Further, the African Regional Judges Forum (ARJF) on HIV/AIDS and TB, supported by UNDP and spearheaded by Kenyan member Justice Mumbi Ngugi, has provided opportunities to integrate TB-related law and human rights issues into judicial capacity building efforts. In January 2018, the ARJF established a Judicial Education Sub-Committee with the mandate to, among other things, foster and co-ordinate capacity building among judges and magistrates to deal with human rights issues in relation to HIV and TB through the integration of HIV/TB human rights into judicial training curricula. The secretariat of the sub-committee based in the Judiciary Training Institute in Kenya is currently in the process of obtaining buy-in from other judicial training institutions on the continent.

India has also been a site for judicial capacity building. In 2015 in New Delhi, a judicial workshop on "Tuberculosis, Human Rights, and The Law" was organized and conducted by the International Human Rights Clinic at the University of Chicago Law School, KELIN, and members of the University of Chicago Department of Medicine. The workshop involved the participation of current and retired judicial officers from India, Myanmar, Bangladesh and Australia.

In Paraguay, the Center for Studies and Training for Eco-development (ALTERVIDA) has supported the National TB Control Program in conducting workshops for judges to provide guidance on TB in prisons.

TB activists have also undertaken more localized efforts. In Mumbai, India Touched by TB has networked with lawyers who are able to provide legal aid in cases of destitution, or denial of treatment by hospitals. Nevertheless, it is still challenging to engage lawyers who work on broader human rights to handle TB-related cases.

Litigation related to TB has become more frequent with some notable outcomes in line with a human rights-based response. In Kenya, KELIN filed a court case challenging the isolation of prisoners with TB, and interruption of their treatment. In *Daniel Ng'etich and Others v. Attorney General*, Justice Mumbi Ngugi held that prison incarceration of persons who defaulted in their TB treatment was unconstitutional, and that if involuntary confinement is required, it should take place in appropriate health facilities, not penal confines. The government was directed to formulate appropriate policies on involuntary confinement of TB patients, which has since been issued and adopted. This rights-establishing judgment by Justice Ngugi has positively influenced policymakers on the importance of establishing and protecting the rights of people with TB.

In *Sonke Gender Justice v. the Government of the Republic of South Africa and Others*, Sonke Gender Justice, represented by Lawyers for Human Rights, won a judgment requiring the reduction of overcrowding in South Africa's infamous Pollsmoor Prison. The right of access to healthcare services and the risk of TB transmission created by the prison's conditions were critical to the court's reasoning. As is often the case, implementation of the court order has been an ongoing challenge and efforts to enforce implementation persist.

In South Africa, TAC and Sonke Gender Justice, represented by SECTION27, intervened as amici curiae in the case *Nkala and Others v. Harmony Gold Mining Company Limited and Others*, a class action lawsuit against South Africa's gold mining industry after thousands of mineworkers contracted silicosis and TB in the mines. In 2016, the court certified two classes of mineworkers: those who contracted TB in the mines and those who contracted silicosis in the mines. In early 2018, a collection of the largest gold mining companies in South Africa offered to settle the claims against them for ZAR five billion. The settlement agreement will be finalized upon approval of the high court.

Organizations such as ASODENAT in the Dominican Republic have also been involved in litigation, fighting for the rights of people with TB, specifically fighting for rights related to health or helping people with TB who have been suspended from their employment.

Lawyers in India have litigated for access to new MDR-TB drugs on grounds that their inaccessibility violates fundamental rights guaranteed in the Indian Constitution. In *Kaushal Kishore Tripathi v. Lal Ram Sarup TB Hospital and Others*, Anand Grover of the Lawyers Collective in New Delhi, India represented the father of a young girl with Extensively Drug-Resistant TB (XDR-TB) to petition the Delhi High Court for urgent access to bedaquiline available in a pilot program. The young girl had been denied the medicine since she could not show domicile where the hospital was located (New Delhi). After many urgent hearings, the case was decided based on a consent order between the parties, whereby the hospital undertook treatment of the girl and assured that no other patient would be denied the drug on grounds of domicile.

The affidavit of international TB expert Dr. Jennifer Furin of Harvard Medical School provided critical information around bedaquiline and XDR-TB to the Delhi High Court. Dr. Furin connected with Mr. Grover and the Lawyers Collective through participation in the Judicial Workshop during which the Nairobi Strategy was developed, as part of an Experts Roster of TB physicians and researchers willing to serve pro bono as *amicus curiae* in cases related to TB around the world.

The Alpha-Tocopherol, Beta-Carotene Cancer Prevention (ATBC) Study in the Americas recognized the importance of engaging lawyers to help advocate for rights for those affected by TB, but obtaining funding to train and retain the lawyers is a challenge.

In conclusion, it is rare for funding agencies to support strategic litigation by lawyers at non-profit organizations. And while funding for legal capacity building is more easily available, it has only occasionally been used in support of training around TB, human rights and the law. The Nairobi Strategy provides an opportunity to mobilize resources that will engage both the judiciary and lawyers in the fight against TB.

3. Expanding the Capacity of Legislators and Policymakers

The key **activities** enumerated in the Nairobi Strategy as part of this component are:

- a. Organizing and conducting workshops for law and policy makers.
- b. Drafting and promoting principles and guidelines for human rights-based legislation for TB.
- c. Developing, publishing and disseminating a handbook on TB and human rights for legislators and policymakers.
- d. Engaging and advising international organizations and experts on the implementation of a human rights-based approach to TB into global policies and programs.

Expanding the capacity of legislators and policymakers around TB and human rights is key to creating enabling legal and policy environments for a human rights-based response to TB. This section highlights important work done to this end, in furtherance of the Nairobi Strategy.

The Global TB Caucus was set up in 2016 as an international network of elected members of parliament from more than 130 countries, working to end TB by committing to “engag[e] with civil society and all other stakeholders involved”, and “to confront stigma and social isolation” associated with TB. National efforts to accomplish these goals, driven by parliamentarians such as Honourable David Davemetics in Nigeria, are currently underway. Based on experience gained at the UN HLM on TB, organizations, such as Stop TB, are dedicated to facilitating communication between the Caucus and civil society, and in particular people affected by TB. Further, by leveraging funding for TB, these organizations also

serve as a training platform on TB, human rights and the law.

At a regional level, the Americas TB Caucus consists of community focal points in 17 countries that work with local politicians to increase political power and create national TB caucuses. These caucuses foster collaboration between civil society experts and parliamentarians to increase capacity on TB-related legislative issues. In the Americas, parliamentarians from across the region recently agreed to a declaration that would significantly enhance national and regional commitments to address TB through investment in health, financing, coordinated efforts and improved accountability. Parliamentarians from Chile, Guyana and Honduras agreed to launch national parliamentary caucuses within a year.

Under the Africa Regional Grant on HIV: Removing Legal Barriers of the Global Fund, Enda Santé in Senegal has conducted trainings of parliamentarians on TB and the law. ARASA works through the SADC Secretariat, with the SADC Parliamentary Forum, to train parliamentarians on issues related to health (in particular, on HIV, TB and sexual and reproductive health), human rights and law.

In South Africa, after years of advocating, TAC and SECTION27 finally achieved buy-in for rights-based approaches in the country, as reflected in newly-enacted legislation. The Regulations Relating to Notifiable Medical Conditions were brought into force in December 2017. While imperfect, they are a good example of law regulating the notification of communicable diseases as well as the application of mandatory measures, such as isolation to control, TB in a rights-based manner. These regulations constitute a significant part of the essential legal framework of the TB response. The regulations were long overdue; the High Court of South Africa, Cape of Good Hope Provincial Division, in *Minister of the Western Cape v. Goliath*, called for the regulations as early as 2009. Almost a decade of concerted advocacy and support from TAC and SECTION27 legislation was finalized and brought into effect.

In Paraguay, ALTER VIDA has participated in the Country Coordination Mechanism of the Global Fund, by drafting TB legislation—first in 2016, which was rejected, and again more recently. The more recent bill is still pending in the Congress. Also in Paraguay, the civil society organization, ALVIDA, is prioritizing the development of TB legislation. The current effort is robust, consisting of civil society workshops to assess the drafted law, and similar engagements with other

stakeholders, such as national TB program, co-organized by ALTER VIDA. An activist in El Salvador appeared in hearings before the Health/HIV Commission and lobbied with the Parliament to implement a “Parliamentary Front against Tuberculosis of the Americas”. An activist in Guatemala is a member of the parliamentary front and is working with deputies of the Guatemalan parliament to draft rights-based TB legislation.

As part of its partnership with the Inter-Parliamentary Union, UNDP works with legislators to understand and address the legal barriers people with TB face in accessing healthcare. With partners under its Access and Delivery Partnership, UNDP supports legal and policy reform efforts in Ghana, Indonesia and Tanzania and other countries. It is also engaged with development of an African Union (AU) model law.

The lack of data poses a number of challenges for successful engagement with legislators and policymakers. To precipitate rights-based law and policy change, evidence of rights violations and insufficient legal protection for people affected by TB must be gathered and presented; however, this data is scarce and lack of financial resources makes it difficult to undertake the creation of an evidence base. The same challenge exists in the context of engaging international organizations and healthcare workers on TB, law and right issues.

One manner in which evidence is being gathered is via TB Legal Environment Assessments (LEAs), which is dedicated to the promotion of human rights principles. Stop TB and UNDP have developed an Operational Guide for LEAs, which are ongoing in more than a dozen countries, including Kenya, Nigeria, India, Democratic Republic of Congo, Tanzania, South Africa, Myanmar, Bangladesh, Pakistan, Ukraine, Philippines, Cambodia and Mozambique.

LEAs have been undertaken along with research focused on analysing gender and population trends in relation to TB. This research is used for the Stop TB Community, Rights and Gender (CRG) assessment tools. For example, in Kenya, a recommendation in the LEA conducted by KELIN that emerged from the decision in *Daniel Ng’etich & Others v. Attorney General* (discussed above) has caused an important rights-based advancement: the Government of Kenya, in partnership with KELIN, has written and promulgated a rights-based isolation policy, which

empowers affected people instead of punishing them, thereby serving both public health and human rights concerns.

While planned efforts made possible through financial support have occurred, other engagements with policymakers are often ad hoc, and driven by individual initiative rather than by the community as a whole. In India, TB survivor activists leverage opportunities at policy forums to raise human rights concerns. However, in general, there is lack of a planned and sustainable effort where the TB burden is the highest in the world, and where the government is a significant impetus of TB eradication. In certain contexts where TB is most prominent, government policy directives and programs are often not informed by rights-based and evidence-driven perspectives. These TB-affected areas will benefit greatly from community empowerment and other insights from experts to ensure that a rights-based approach is used in addressing TB.

In India, the lack of planned engagements on the part of policymakers, legislators, the judiciary and the health sector is notable and serves as a direct hindrance to empowering communities affected by TB and achieving a rights-based approach to TB. In Cambodia, KHANA's efforts to develop a TB law with the support of experts at the directive of the Manager of the national program has not been fruitful due to a lack of resources.



4. *Engaging and Advising International Organizations and Experts*

The key **activities** enumerated in the Nairobi Strategy as part of this component are:

- a. Engaging and advising international organizations and experts on the need to incorporate a human rights-based approach to TB in their work.
- b. Engaging and advising multilateral aid organizations and philanthropic foundations on the need to incorporate a human rights-based approach to TB in their funding and programming.

Engaging and advising international organizations and experts around a rights-based response to TB is necessary both to promote integration of the approach at the level of global policy, but also to harness the technical and financial resources of international organizations and experts. This section highlights work done in furtherance of this component of the Nairobi Strategy.

Allan Maleche, Professor Brian Citro and others provided input on TB, human rights and the law during the development of the Supplement to the Report of the UNDP-led Global Commission on HIV & the Law. The Commission report, “Risks, Rights & Health,” issued in 2012, was far-reaching in its recommendations on rights and law related to HIV. The 2018 Supplement extends and asserts these rights in the context of TB, particularly in relation to confidentiality of health status in digital and other forms, non-discrimination of affected communities, the inappropriate use of criminal law, and recognition of the right to health. Among other things, the Supplement calls on countries to ensure intellectual property and other trade-related barriers do not impinge the ability of people with TB to access effective and affordable diagnostics and treatment. UNDP has also presented to the UN Interagency Coordination Group on Antimicrobial Re-

sistance (AMR) and supported increased attention to and resources for TB as part of the global AMR response.

The WHO's Ethics Guidance for the Implementation of the End TB Strategy issued in 2017, is "meant to assist those working towards ending TB in the 21st century by proposing practical answers to key ethical questions and enabling patients, families, civil society, health workers and policy makers to move forward and address current challenges." Professor Brian Citro contributed to the document through an expert consultation in Geneva, Switzerland and made direct inputs in the chapters related to isolation, screening and notification, as well as the introduction, which established the document's grounding in human rights principles and law.

The work of civil society with the UN Special Rapporteur (UNSR) on the Right to Health has been significant, particularly in relation to the UN HLM and the draft Political Declaration on TB. The UNSR issued a letter to the UN HLM Chairs, whereby the UNSR argued for a rights-based approach to TB, supported by international human rights law and commitments by member states. The UNSR noted that "the lack of adequate progress in the TB response can largely be attributed to the failure of States to fulfil these obligations," and that UN Member States must be held accountable in this regard.

The UNSR also articulated a legal obligation of wealthier states to assist in the TB response, therefore providing a human rights basis for international funding, not simply a charitable purpose. Further, the UNSR recognized its duty to "progressively realize" rights as "not perpetually deferrable but rather [ones that] require action toward measurable advancement in the TB response."

At a 2017 G20 Heads of State Communiqué that included TB as a health priority, Stop TB, along with civil society partners, played a crucial role in delivering enhanced commitments by G20 and BRICs (Brazil, Russia, India and China) Ministers of Health.

The creation of the TB, Human Rights and the Law Task Force in the Global Drug-resistant TB Initiative (GDI), with the support of Stop TB, has been a direct outcome of the Nairobi Strategy. This GDI Task Force has supported development of the aforementioned Judicial Handbook and TB Case Law Compen-

dium. Further, a course on Drug-Resistant TB (DR-TB), which includes medical, public health, and human rights components, is in development to build capacity of civil society and community advocates.

In spite of these advancements, many challenges remain in ensuring that financial resources are secured to execute the Nairobi Strategy. Identifying effective and appropriate community and law and policy partners to apply for these funds is a challenge. A great deal of support for the Strategy has been received from United States Agency for International Development (USAID), through Stop TB, but buy-in is required from other donors to propel the strategy forward.



5. Sensitizing Healthcare Workers

The key **activities** enumerated in the Nairobi Strategy as part of this component are:

- a. Organizing and conducting workshops with healthcare workers.
- b. Developing, publishing and disseminating a handbook on TB and human rights for healthcare workers.

Sensitizing healthcare workers on a rights-based response to TB in their critical work is necessary to fully implement the approach. This section highlights work done in furtherance of this component of the Nairobi Strategy.

Efforts to sensitize healthcare workers have been well-received in parts of Africa. In particular, the Africa Regional Grant on HIV: Removing Legal Barriers of the Global Fund is particularly supportive of this initiative. Healthcare workers have been trained on TB and human rights at national and regional levels. Healthcare administrators have also been part of such training efforts in Kenya as undertaken by KELIN.

One challenge in sensitizing the healthcare sector is illustrated through efforts in Kenya where health programs are decentralized through 47 counties with differing levels of progress and buy-in, which makes it difficult to ensure consistent implementation and capacity building. In Nigeria, the evaluation of this work is currently underway. As a principal recipient of Global Fund grants for TB, UNDP also supports programs to train medical personnel on TB prevention in prisons and develop ways to reduce gender-based inequities in the context of TB services.

In South Africa, TB Proof is an organization of healthcare workers that aims to

create safer healthcare environments, destigmatize TB, and mobilize resources for TB prevention. ARASA has had extensive interaction with healthcare workers to promote patient-centered care. It conducted research in Botswana and Swaziland in 2012 (unpublished) on the rights of healthcare workers and the relationships between patients and healthcare workers, to promote rights-based responses to TB. Many challenges were revealed through this research including: effects of decentralization of TB services with insufficient human capacity, and weak safety mechanisms for healthcare workers resulting in workplace exposure to and acquisition of TB.

The main recommendations that emerged, which ARASA is working on at the regional level (for domestic implementation), include social protection of nurses during times of strikes due to poor working conditions and fostering patient-centric approaches in providing care to those affected by TB.

In Paraguay, ALVIDA works to motivate local healthcare services in provinces to receive support of civil society organizations to provide coordinated care of people with TB. ALTER VIDA has also developed and undertaken training on TB including training on stigma and discrimination, as a way of sensitizing healthcare personnel. The lack of financial resources often prevents this type of training from being implemented regularly. Similar concerns have been expressed in relation to work in El Salvador.

UNDP, together with partners under its Access and Delivery Partnership, supports health system strengthening efforts in Ghana, Indonesia and Tanzania and other countries. As a principal recipient of funding, UNDP is managing a number of Global Fund TB grants. Under these grants, the work that is supported includes training of medical personnel in prisons on TB prevention, and training of healthcare providers on human rights and ethics related to TB in Afghanistan, Belize and Sudan.

More locally, as a follow-up to activities in the Nairobi Strategy, students at the Northwestern Pritzker School of Law developed a KYR brochure, legal memo and presentation that was used to train public health staff at the TB program of the Chicago Department of Public Health.

Despite this progress in sensitizing healthcare workers, challenges remain, especially given in circumstances where stigma exists among healthcare workers around people with TB. More funding and mobilization of technical and human resources under the Nairobi Strategy is required to build upon the work being done to sensitize healthcare workers on TB and human rights.



6. Further Developing the Conceptual, Legal and Normative Content and Evidence Base

The key **activities** enumerated in the Nairobi Strategy as part of this component are:

- a. Researching, developing and publishing a conceptual, legal and normative framework for a human rights-based approach to TB.
- b. Organizing and conducting interdisciplinary academic workshops and collaborations.
- c. Researching, drafting and publishing scholarly articles on the various aspects and components of a human rights-based approach to TB.
- d. Researching, drafting and publishing a case law compendium on TB, human rights and the law.
- e. Designing, creating and maintaining an online database of case law involving TB.

In order to fully implement a rights-based response to TB, it is necessary to further develop the conceptual, legal and normative content of the approach, and to build the evidence base for its effectiveness. This section highlights work done in furtherance of this component of the Nairobi Strategy.

Stop TB has developed a guidance available online—“Know your epidemic”—focused on key populations that highlights the vulnerabilities, and health and rights needs of communities that face enhanced susceptibility to TB. It proposes to develop guidance on what “people-centric approaches to TB” entails based on the work conducted by and findings published by organizations in high-burden countries (e.g. nomadic communities in North Africa, and indigenous communi-

ties in India) that have received grants. Stop TB is presently supporting TBPeople in updating the Patients' Charter for Tuberculosis Care to create the International Declaration on the Rights of People Affected by TB, to be used as an advocacy document and normative guidance on rights-based, patient-centric approaches to TB.

Many other important tools have been developed. Under the supervision of Professor Brian Citro, the TB, Human Rights and the Law Case Compendium, which outlines summaries of legal cases involving TB from more than 20 countries, researched in six languages, was published and disseminated widely.

In 2016, a dedicated volume of the Health and Human Rights journal (No. 18, Issue 1, June 2016) focused on TB and the right to health. Professor Brian Citro, Dr. Evan Lyon, Dr. Kiran Pandey and Mr. Mihir Mankad led the effort and acted as guest editors for the special edition, which highlighted issues ranging from the right to benefit from scientific progress to the TB epidemic in North Korea. Three human rights-related papers have been published or are forthcoming in the International Journal of TB and Lung Disease (IJTLD):

- An editorial to the Stigma Supplement of the IJTLD, “Measuring TB Stigma”;
- “Health Care Gaps in the Global Burden of Drug Resistant Tuberculosis”; and
- “Ethics and Human Rights Considerations Regarding Involuntary Isolation of Persons with TB”.

ARASA has published a few pieces on TB and Human Rights:

- <http://www.arasa.info/info/newsletters/newsletter-issue-22/close-gap-tb-and-human-rights-activists-guide/>
- Tuberculosis in South Africa's Gold Mines; A United Call to Action: <https://www.results.org.uk/blog/new-report-highlights-public-healththreat-tb-south-africa%E2%80%99s-gold-mines>

A multi-stakeholder workshop entitled “Developing a Rights-based Approach to TB” involving medical professionals, healthcare workers, lawyers, academics, community members, and policy makers, was hosted by the All India Institute of Medical Sciences and the University of Chicago in New Delhi in 2014, as one of the early attempts to illustrate the connection between TB and rights.

Professor Brian Citro and colleagues hosted an Infectious Disease Law and Policy Forum with the National TB Center of the China CDC in Beijing, China in June 2018. Among other presentations, Professor Citro presented on “A Rights-Based Approach to Tuberculosis: Concepts, Case Law, Legislation and Assessment” that led to a robust discussion around the role of law and human rights in the TB response in China. This Forum has led to an ongoing collaboration between the China CDC and Northwestern Pritzker School of Law around TB law and policy in China.

7. Conducting Qualitative and Quantitative Research

The key **activities** enumerated in the Nairobi Strategy as part of this component are:

- a. Designing and conducting interdisciplinary quantitative and qualitative research examining various aspects and components of a human rights-based approach to TB.

In order to build the evidence base for the effectiveness of a rights-based response to TB, researchers in collaboration with people affected by TB must conduct qualitative and quantitative research on specific aspects of the approach. This section highlights work done in furtherance of this component of the Nairobi Strategy.

The development of the Stop TB Community, Rights and Gender assessment Tools, including the LEA and gender and key populations assessments, has significantly contributed to augmenting the evidence base on TB, human rights and the law. Such documentation strengthens the ability of affected communities to demand realization of their health and health-related rights while also enriching the information on intersectionality of TB with other markers of health (such as gender, incarceration, migration etc.).

Many research initiatives are underway. In Paraguay, ALTER VIDA has funded research, involving the Technical Secretariat of Planning, to study the living conditions of people affected by TB. Based on the results, work is being done to connect those who meet the inclusion criteria with social protection programs.

A qualitative study is being undertaken at the University of Cape Town and the University of KwaZulu-Natal that documents the treatment experiences of people with DR-TB, with a focus on how they would define “patient-centered care”. Stop TB is supporting the O’Neill Institute for National and Global Health Law at Georgetown University in researching rights issues of prisoners and migrants.

It is also supporting research on the contents of national health equity strategies and how they inform the TB response. Stop TB plans to support the O'Neill Institute in researching themes pertaining to common concerns and rights violations that emerge from the various TB LEAs. In order to understand TB-related stigma and how to measure it, Stop TB is supporting the development of a stigma measurement tool (currently in draft form).

Challenges in relation to rights-related research on TB include the scarce availability of resources to undertake it. An acute need to have data and evidence that supports the need for a rights-based approach to TB has been expressed, particularly in high burden countries where there is a very limited body of evidence to inform health policy analysis. It has been suggested that a research agenda paper is a powerful tool to motivate scholars to undertake such research. Similarly, a desire to undertake research on TB, stigma associated with TB, and human rights in Latin America by civil society coalitions in partnership with academic institutions was expressed, subject to the availability of funding.

8. *Facilitating Inclusive, Community-Led Discussions to Develop and Promote use of Ethical Standards*

No information was obtained on this aspect of the Nairobi Strategy. However, a need to prioritize the creation of an evidence base and undertake research on the impact of legal frameworks on health outcomes in relation to TB was expressed.



ANNEXURE

Survey Questionnaire

The objective of this survey is to gather information about work done in the area of TB and human rights during the last two years, since 2016. With your experience and engagement in the TB response, please reply to the following questions with as much detail as possible (and specific illustrations where applicable, which could be local, national, regional, and/or international in their focus):

AFFECTED COMMUNITIES

Q1

- a. *Have you been involved in community empowerment of people with TB and TB survivors? This could include supporting the development of networks or the strengthening of existing networks.*
- b. *In what manner has this development or strengthening taken place? For instance in articulating rights-based advocacy (through campaigns, published materials etc.), building capacity on law and rights, accessing the justice system to claim rights and protection of the law.*

Q2

What are the challenges and priorities in relation to empowerment of TB-affected communities?

THE JUDICIAL AND LEGAL SYSTEMS

Q3

- a. *Have you been involved in or are you aware of efforts at working with the judicial system and/ or legal communities to enhance their capacity on TB-related rights, law and policy? If so, please describe how (for example conducting workshops, publishing legal resource material, supporting legal aid etc.)*
- b. *Have you been involved in TB-related litigation? If so, please provide some information about the case(s).*

Q4

What are the challenges and priorities in relation to engaging with the judiciary and legal communities on TB-related law and policy, including for litigation and advocacy?

THE LEGISLATIVE AND POLICY SPHERES

Q5

Have you been involved in legislative or policy advocacy related to TB in your country, or at the regional or global level? If so, please provide some information about kinds of advocacy and results/ impacts.

Q6

- a. *Have you been involved in or are you aware of efforts at working with legislators or bureaucrats to enhance their capacity on TB-related rights, law and policy? If so, please describe how (for example conducting workshops, publishing legal and policy resource material, developing or reviewing legislation).*
- b. *What are the challenges and priorities in relation to engaging with the legislators and bureaucrats on TB-related law and policy?*

INTERNATIONAL ORGANIZATIONS

Q7

- a. *What engagement has occurred at the international level with multilateral, philanthropic and other global organizations to advance rights-based approaches in the TB response? (This could include advocating for and ensuring inclusion of such an approach in policies, programming and assistance.)*
- b. *What are the challenges and priorities in relation to engaging with the international organizations on promoting rights-based approaches to TB?*

THE HEALTH SECTOR

Q8

- a. *What work has been done in sensitizing and building capacity of healthcare workers and administration on rights-based approaches in relation to TB?*
- b. *What are the challenges and priorities in relation to engaging with the health sector on promoting rights-based approaches to TB?*

TB-RELATED RESEARCH & SCHOLARSHIP

Q9

Have you conducted any TB-related research or produced any scholarship that takes human rights into account? If so, please provide some information on the research or scholarship.

Q10

What challenges have you encountered in conducting TB-related research or scholarship taking human rights into account?