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LETTER TO THE EDITOR

Human Rights, TB, Legislation, and Jurisprudence

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People with tuberculosis (TB) experience infringements of their human rights on a daily basis. In far too many cases, they lack access to effective testing and treatment, face discrimination in employment and health care settings, and are unnecessarily detained and isolated against their will. Yet, even as TB has surpassed HIV as the top infectious disease killer in the world and the global threat from multidrug-resistant TB continues to grow, the ethical and legal issues around TB remain largely neglected in national TB programs and research agendas. New approaches are needed to address the social, economic, and structural factors driving the epidemic and drug resistance.

Commendably, this journal featured a special section on *TB and the right to health in June 2016*. As outlined in the editorial and a series of articles in the section, a human rights-based approach to TB establishes and protects the rights of people living with and vulnerable to TB, including the rights to life, health, non-discrimination, privacy, participation, information, liberty of movement, housing, food, water, and to enjoy the benefits of scientific progress. This includes access to the most recent treatments and diagnostic tools. In addition, human rights law at the international and regional levels and national constitutions create corresponding legal obligations for governments and responsibilities for private actors, promoting accountability and access to remedies for rights violations.

In line with this rights-based framework, the Stop TB Partnership's Global Plan to End TB 2016–2020 calls for a human rights- and gender-based approach to TB grounded in international, regional, and domestic law. The Global Plan acknowledges that TB programming will not be successful unless global and national programs ground their work in human rights and gender equity.

As part of the Global Plan's implementation, the TB and Human Rights Consortium—whose members include the Stop TB Partnership, University of Chicago Law School International Human Rights Clinic, and KELIN (Kenya)—has launched an inclusive, consultative process to promote adoption of the Nairobi Strategy on TB and Human Rights. Led by people with TB, TB survivors, and other allies, the strategy aims to implement several streams of work to foster diverse, focused, and sustained advocacy efforts. The objectives of the *Nairobi Strategy* are as follows:

- Support networks of affected communities of people with TB, TB survivors, and civil society at the global, regional, national, and local levels.

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- Enhance the judiciary's and legal communities' awareness of implementation of human rights-based approaches to TB.
- Expand legislators' and policy makers' capacity to incorporate human rights-based approaches into TB into laws and policies.
- Engage and advise international organizations and experts on the implementation of a human rights-based approach to TB in global policies and programs.
- Sensitize health care workers in the public and private sectors on the need to incorporate a human rights-based approach to TB in their work.
- Formulate and clarify the conceptual, legal, and normative content of a human rights-based approach to TB.
- Conduct qualitative and quantitative research to generate the evidence base for the effectiveness of a human rights-based approach to TB.

I was recently invited to give a keynote address at a consultation on the Nairobi Strategy organized by the TB and Human Rights Consortium with support from USAID on March 9–10, 2017, in Geneva, Switzerland. People affected by TB, communities, civil society, judges, lawyers, academics, clinicians, donors, and multilateral representatives engaged in a robust dialogue on the content and implementation of the strategy. The meeting was a follow-up to the TB, Human Rights and the Law Judicial Workshop held in Nairobi, Kenya, in June 2016, where the strategy was first developed. My address is presented here below. It is my hope that the Nairobi Strategy is adopted widely in order to recognize, protect, and fulfill the human rights of people with TB. Without this, current efforts to combat the disease will continue to fall short.

Tuberculosis and human rights: A judge's reflections on human rights-based legislation and jurisprudence

In a constitutional democracy, the primary lawgiver is Parliament—an assembly of elected representatives of the people. But Parliament is not the only lawmaker; judges too make laws, in the process of interpreting the law. It was once said that judges do not make laws; but that is a fairy tale. It is emphatically the province of the judiciary to interpret the law, and in countries where the constitution is the supreme law, the courts have the power to strike down legislation that is not in conformity with the constitution. This is one organ of the state which—because of its independence, knowledge, and integrity of the justices—can be the guardian of the constitution and ensure that the promise of the constitution is effected and that no one is excluded when it comes to the realization of human rights and freedoms.

In our last meeting in Nairobi, sometime last year, we heard heart-wrenching testimonies by many TB patients about widespread discrimination and stigma against TB patients and those affected by TB, as well as about other unacceptable violations of the right to liberty and freedom of movement that result in forced incarceration in circumstances where such incarceration is not strictly necessary to protect public health.

It is now widely accepted that many of the factors that increase a person's vulnerability to TB or reduce their access to services to prevent, diagnose, and treat TB are strongly linked to human rights. It goes without saying, therefore, that a human rights-based approach is the condition *sine qua non* to an effective TB response and that without placing human rights at the heart of the response, no meaningful progress can be achieved. It is also now widely understood that TB is rooted in poverty, as well as legal, structural, and social barriers that together collide and collude to deny patients access to TB services of the highest quality.

Yet despite the above understanding, the policy frameworks and national TB programs of most countries are not generally geared toward addressing human rights violations. In fact, most of the time, the focus tends to be biomedical and pays lip service to human rights, if at all. This is so despite the increasing realization that the promotion and enforcement of human rights is essential to overcome many barriers that stand in the way of

TB patients' access to critical services.

A number of policies in our countries discriminate against marginalized people, such as prisoners, preventing them from accessing care and treatment. In addition, there is a lack of an integrated approach to TB and HIV.

Most policy frameworks appear oblivious to a number of documented challenges or barriers that hinder access to TB services, such as economic, geographical, socio-cultural, and health system barriers.

Economic and financial barriers relate to the direct or indirect costs of TB care, including costs related to travel, diagnosis, and treatment, as well as the opportunity costs of lost employment. Physical barriers relate to distance to the nearest health facilities and concomitant transportation challenges. And issues of stigma relate to community and individual prejudice that militates against access to services.

In my 14 years' experience as a judge, I have discovered that there is a plethora of policies governing issues of TB in many of our countries but that such policies are devoid of significant human rights content. This, accompanied with underdeveloped legal frameworks, makes the job of a judge extremely difficult.

To give but one example, I presided over an HIV-related case many years ago. At the time, I was serving as a judge of the Industrial Court, and there was no specific legislation governing the case at hand. At the end of the day, and having found no local legislative guidance—but only policy, which is not law—I had to invoke the aid of international law in a country where international law is not automatically part of the law, opening the court to charges of judicial activism and back-door legislating.

The question has often been debated as to whether we need TB-specific legislation. This is an issue in which there is no consensus—some experts support broader health legislation, while others think there is merit in enacting specific TB legislation.

Whatever the case may be, the absence of legislation that comprehensively entrenches human rights with respect to TB is a matter of grave concern because it may lead to situations where the courts may simply say there is no law governing the situation at hand and therefore their hands are tied. This has happened in my jurisdiction in the context of HIV/AIDS.

There is an urgent need to sensitize countries on the importance of legislating on TB, whether specifically or as part of the broader health law. This legislation must be inspired by international human rights law and best practices on TB and human rights. Bringing human rights to the center of the TB response is the imperative of our time.

In order to bring human rights to the center of the TB response, we firstly need additional evidence to underscore the link between TB and human rights and to highlight how human rights violations or disregard for human rights-based approaches prevents people with TB (and often HIV and TB co-infection) from accessing services they need. For too long, TB has been a stigmatizing disease—this state of affairs is unsatisfactory and is clearly not helpful if we are to diagnose, treat, and cure those with TB.

Currently, in most countries, the country-level platform for TB control and management is through national TB control programs. These tend to be located within ministries of health and therefore tend to look at the national response to TB through a public health approach devoid of human rights.

TB patients are bearers of rights. These rights are universal, interdependent, inalienable, and non-negotiable. Our governments must understand that as duty bearers they have a duty—not an option—to protect, respect, and fulfill rights and must be willing to account for failing to do so. In order to give effect to this obligation, they must legislate comprehensively on TB so that there is little room for guesswork when it comes to human rights.

The right to health is one of the many rights implicated in the TB response. It comprises the right to access health facilities and protection against epidemic diseases. The right to health requires the realization of a number of underlying determinants, such as safe drinking water, food, adequate nutrition, housing, healthy occupational and environmental conditions, education, and so on.

The law, in its various forms, must underwrite and guarantee human rights. This is so because the

ultimate objective of law is the welfare of society.

The legal enforcement of laws on TB is invariably a balancing act. On the one side are patients' rights. These include the rights to not to be discriminated against, to human dignity, to liberty, to freedom of movement, to privacy and autonomy, to access medical records, and to refuse medical treatment, to mention but a few. On the other hand, there are public health considerations, which include the obligation to prevent disease transmission and protect the public.

As a general rule, TB treatment should be provided on a voluntary basis, with the patient's informed consent and cooperation; and as part of respect for patients' autonomy, health professionals must explain the medication they are dispensing, including any side effects, to patients. This has a bearing on adherence. It is generally accepted that non-adherence is often the direct result of failure to engage the patient fully in the treatment process.

Coercive measures such as detention should never be routinely utilized unless they are strictly necessary in the interest of public health. Involuntary isolation must be used only as a last resort—and since having TB is not a crime, any isolation must be linked to the legitimate purpose of preventing disease transmission and must take place in a health facility and not a penal institution.

Where it is considered necessary to effect involuntary isolation, the manner in which the isolation is done must comply with human rights as set out in international human rights instruments and guidelines, such as the Siracusa Principles, which require that measures must, among other things, be in accordance with the law, be based on a legitimate objective, be strictly necessary, and be the least restrictive possible.

We need to come up with laws that strike the correct balance between individual rights and the public interest. South Africa's National Health Act balances the confidentiality of a patient's health information against an allowance for the disclosure of such information to prevent a "serious threat to public health." In Zambia, the Public Health (Infectious Diseases) Regulation 8 restricts individual hardship to that which is necessary and unavoidable, which helps ensure that the government is limited in its authority to isolate and report people with communicable diseases.

This balancing of public interest and civil liberties is paramount in public health law, given the costs of excluding people from school, isolating them from social contacts, and disclosing their disease status.

In South Africa, a complex assortment of acts, regulations, and other policies governs TB infection control. The highest law governing health in South Africa, which may be cited as a good example, is Section 27 of the Constitution, which states in part that "everyone has the right to have access to: (a) health care services."

In Botswana, the Public Health Act authorizes the isolation of persons certified to have communicable diseases on the order of a registered medical practitioner until such persons are determined to be free from infection or no longer pose a danger to public health.

The Public Health Act also addresses the reporting of TB, listing TB as a notifiable disease and requiring health officers to notify cases to the minister of health. Furthermore, Botswana's TB infection control guidelines call for the routine screening of all health care workers for TB and HIV infection. These guidelines use mandatory language (for example, "must"), raising the possibility of the guidelines being an instrument of coercion.

In conclusion, I reiterate the importance of strengthening the evidence on linkages between human rights, law, and effective national TB responses. While policies are good, legislation is far better. We need to involve people infected with and affected by TB in the planning, implementation, monitoring, and reviewing of TB programs—to ensure that the TB programs are based on human rights and sensitive to people's rights.

We also need to assemble a group of experts to work together with infected and affected people and other critical stakeholders to develop a guidance document on mainstreaming human rights into national TB programs. This can be carried out together with the development of tools, guidance documents, and policy briefs for key stakeholders,

such as judges, parliamentarians, policy makers, and law enforcement officers.

It may also be a good idea to mobilize and support the idea of developing an international TB control framework similar to the Framework Convention on Tobacco Control. This may be a long-term vision, but it needs to be pursued with vigor and determination. This will ensure a strong political commitment to addressing TB. There are four distinct advantages to the development of an international framework. First, having a framework akin to the tobacco framework will institutionalize the strategy at the international level and make it obligatory for countries to sign it. Second, such a convention provides a point of reference for civil society organizations, the bar, and the bench for strategic litigation. Third, ratification of such a convention may make resources available for additional research and studies in the context of TB medication and so forth. Lastly, there is a link between smoking, chest infections, and TB prevalence—so a convention linked to the tobacco framework may be a possible way to further advance global TB control.

It seems to me that the Nairobi Strategy is a timely and welcome intervention that seeks, among other things, to develop rights-based legislation and sensitize all critical stakeholders, including legislators, lawyers, and judges, on the development of a jurisprudence that is based on reasonableness and proportionality and is informed by empirical evidence and scientific advancement. It may therefore be a good idea for the Global Fund to encourage countries to include activities such as the above in their concept notes being developed this year.

I hope I have not exaggerated the value of law and given the impression that law is the panacea of all ills. On the contrary, what I sought to convey is that law in the hands of men and women of integrity and good will can be a force for good; but in the wrong hands, it can occasion serious harm. In the right hands, law can help fight and dislodge stigma and wanton violations of human rights that ultimately endanger public health.

My very last parting word is this: for human rights to take root and endure, we need more than good constitutions, treaties, lawyers, and judges. We also need a vigilant and active civil society. Constitutions and treaties are just promissory notes. It is all of us—judges, lawyers, and civil society—who can ensure that the promise of constitutions and treaties is kept.

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