

Tuberculosis and the Law in Latin America and the Caribbean:

Guidelines for legislators and
civil society

Summary

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Introduction



This Background Paper was prepared for the Tuberculosis (TB) and the Law Workshop for the Latin American and the Caribbean region at the 49th Union World Conference on Lung Health held on October 25, 2018. The Workshop's objectives are to:

1. Promote constructive dialogue around the development, enactment and implementation of TB-specific legislation in the region, among lawmakers, national TB program managers, international and regional experts, civil society and people affected by TB;

2. Sensitize stakeholders to the content, aims and utility of implementing a human rights-based, person-centered response to TB through legislation.

The purpose of this Background Paper is to briefly highlight aspects of the current global landscape regarding legislation addressing TB and to discuss some of the key issues and concerns around the development, enactment and implementation of TB-specific legislation, i.e., legislation specifically addressing TB.

Background

Public health legislation can both promote and hinder effective disease responses. The content, scope and objectives of legislation determines the quality and extent of its impact, along with the allocation of sufficient resources and the strength of political will. The necessity and value of disease-specific legislation, in particular, is an unsettled question. The varying impacts of legislation in a wide range of public health areas, including tobacco control, HIV and injury prevention, have demonstrated this. By example, in some countries, HIV-specific legislation has effectively delegated institutional authority and established the rights of people with, while at the same time criminalizing HIV transmission.

In order to strike the correct balance, TB-specific legislation must (1) safeguard public health, (2) define and grant institutional authority and responsibility, and, importantly, (3) establish and protect the individual rights of people affected by TB.

Latin America and the Caribbean are on the forefront of a global trend in the adoption TB-specific legislation. These laws and draft bills present a unique opportunity to accelerate and enhance the TB response at the national and regional levels. Supportive legislative frameworks can be critically important to sustaining the tuberculosis response as countries transition from receiving support from The Global Fund, if they are accompanied by comprehensive legal empowerment programs to increase access to justice. There is therefore a vital need to promote dialogue among the key stakeholders involved in the development, enactment and implementation of these laws, including legislators, national TB program managers, lawyers, people affected by TB, civil society, and legal and human rights experts.



International Standards for TB-Specific Legislation

This section examines the international standards for TB-specific legislation, to the extent that they have been promulgated by the World Health Organization (WHO) and other experts. And it presents specific recommendations for the promotion of human rights-based, person-centered legislation for TB.

WHO Guidelines on TB-Specific Legislation

The WHO End TB Strategy calls for the “protection and promotion of human rights, ethics and equity.”¹ This commitment to ethics and the human rights of people affected by TB is preceded by WHO guidelines that set out principles and best practices for TB-specific legislation and supported by the 2017 WHO Ethics Guidance for Implementation of the End TB Strategy.²

¹ WHO, *Global Tuberculosis Report 2018*, WHO/CDS/TB/2018.20 (2018), see also: *Stop TB Partnership Global Plan to End TB 2016-2020*.

² WHO, *Good Practice in Legislation and Regulations for TB Control: An Indicator of Political Will*, WHO/CDS/TB/2001.290.



A summary of the principles drawn from the legislation guidelines and Ethics Guidance is provided here:

➔ **Purpose:** TB-specific legislation should serve three main purposes—protecting TB patients’ individual rights, safeguarding public health interest, and defining public health institutes’ respective responsibilities. Most importantly, it should balance public interest and individual rights.³

➔ **Treatment on Voluntary Basis:** The completion of treatment should be conducted on a voluntary basis; forced treatment is never ethical.⁴ For people willing to undergo treatment, isolation and detention are neither necessary nor appropriate.⁵ Legislation should facilitate rather than coerce people to undergo treatment.⁶

➔ **Involuntary Isolation:** In accordance with Chapter 15 of the WHO Ethics Guidance, except in narrowly defined circumstances, involuntary isolation is unethical and infringes an individual’s rights to liberty, freedom of movement, freedom of association, and to be free from arbitrary detention. Involuntary isolation should therefore be limited to exceptional circumstances when an individual:⁷

- ◆ Is known to be contagious, refuses effective treatment, and all reasonable measures to ensure adherence have been attempted and proven unsuccessful; OR
- ◆ Is known to be contagious, has agreed to ambulatory treatment, but lacks the capacity to institute infection control in the home, and refuses inpatient care; OR
- ◆ Is highly likely to be contagious (based on laboratory

³ Good Practice, *id.*

⁴ Ethics Guidance, *supra* note 2.

⁵ *Id.*

⁶ Good Practice, *supra* note 2.

⁷ Ethics Guidance, *supra* nota 2, en pág. 37.

evidence) but refuses to undergo assessment of his/her infectious status, while every effort is made to work with the patient to establish a treatment plan that meets his needs.

If isolation is warranted, it must be conducted in line with the Siracusa Principles and must be:⁸

- ◆ In accordance with national law in force at the time of the deprivation;
- ◆ Based on, and proportionate to, a legitimate objective in response to a serious threat to the health of the population or individual members;
- ◆ Strictly required by the exigencies of the situation as a last resort;
- ◆ The least restrictive means available to achieve the objective; AND
- ◆ Not arbitrary, abusive or discriminatory.

In particular, the following conditions must be met to justify involuntary isolation:⁹

- ◆ Isolation is necessary to prevent the spread of TB; AND
- ◆ Evidence that isolation is likely to be effective in this case; AND
- ◆ The person refuses to remain in isolation despite being adequately informed of the risks, the meaning of being isolated and the reasons for isolation; AND
- ◆ The person's refusal puts others at risk; AND
- ◆ All less restrictive measures have been attempted prior to forcing isolation; AND
- ◆ All other rights and freedoms (such as basic civil liberties) besides that of movement are protected; AND
- ◆ Due process and all relevant appeal mechanisms are in place; AND
- ◆ The person has, at least, basic needs met; AND
- ◆ The isolation time given is the minimum necessary to achieve its goals.

➔ **Individual Rights:** According to the WHO, the most important rights include the following.

◆ **Non-discrimination:** The government should protect people with TB against discrimination on the grounds of health status.¹⁰

◆ **Care and Treatment:** The government should ensure both the quality and accessibility of TB care and treatment for people with TB.¹¹ It should be free of charge, and people with TB are entitled to food and travel allowance during the treatment period.¹²

◆ **Information:** Both the general population and individuals with TB have the right to information. The government should provide health education and disseminate information about TB and its treatment to the general public.¹³ People with TB have the right to know the risks, benefits, and alternatives to TB treatment.¹⁴

◆ **Informed Consent and Autonomy:** People with TB have the right to decide the ways in which they want to receive treatment.¹⁵

◆ **Privacy and Confidentiality:** People with TB have the right to keep information relating to their TB status and treatment private and confidential, with certain exceptions concerning close third parties who are at high risk of infection, in which case non-consensual disclosure may be allowed.¹⁶

➔ **Limitation on Individual Rights:** Any restriction on individual rights on public health grounds should be of a limited nature and subject to review.¹⁷

➔ **Vulnerable Groups and Key Populations:** Legislation should prioritize the needs of vulnerable groups and key populations. Vulnerable groups are individuals who face increased risk of becoming infected and developing active disease and those who face challenges of accessing and fully utilizing services. Such groups include, but are not limited to, people living in extreme poverty, people living with HIV, indigenous populations, refugees, asylum seekers, migrants, mine workers, prisoners, substance users (including alcohol), and homeless people. In addition, the needs of women and children warrant special consideration.¹⁸

⁸ UN Economic and Social Council, *The Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights*, UN Doc E/CN.4/1985/4, Annex (28 Sept. 1984).

⁹ *Ethics Guidance*, supra note 2, at p. 38.

¹⁰ *Good Practice*, supra note 2.

¹¹ *Id.*

¹² *Id.*

¹³ *Id.*

¹⁴ See, e.g., *id.*; *Ethics Guidance*, supra note 2.

¹⁵ *Good Practice*, supra note 2.

¹⁶ See, e.g., *id.*; *Ethics Guidance*, supra note 2.

¹⁷ *Good Practice*, supra note 2.

¹⁸ See, e.g., *id.*; *Ethics Guidance*, supra note 2.

A Human Rights-Based, Person-Centered Response to TB in Legislation



The recommendations in this section are put forth to promote human rights-based, person-centered TB legislation, building on the WHO Guidelines in the previous section, in line with the WHO End TB Strategy, Global Plan to End TB 2016-2020 and the UN HLM Political Declaration on TB (https://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/73/3), and founded on international human rights law as established in the Universal Declaration on Human Rights, the International

Covenant on Civil and Political Rights, and the International Covenant on Economic, Social and Cultural Rights.¹⁹ These rights should be explicitly enumerated in legislation, as legally binding provisions. Ideally, they should establish private rights of action, allowing individuals to bring suit in court if they are violated.

Legislation should recognize and establish the following rights of people affected by TB:

¹⁹ UN GA Resolution A/RES/217(III), of 10 Dec. 1948, on Universal Declaration of Human Rights; International Covenant on Civil and Political Rights (ICCPR), New York (United States of America), 16 Dec. 1966, in force 23 Mar. 1976; International Covenant on Economic, Social and Cultural Rights (ICESCR), New York (United States of America), 16 Dec. 1966, in force 3 Jan. 1976.

→ **Right to Free Testing and Treatment for TB:**

Testing and treatment shall be made available free of charge to all people with TB, MDR-TB and XDR-TB, including counseling and psychological services for those who need them;

→ **Right to Freedom from Discrimination:**

Discrimination against people with TB shall be prohibited in both public and private settings, including, but not limited to, health care, employment, education, and access to social services;

→ **Right to Privacy and Confidentiality:** Information related to an individual's TB status and treatment must be kept private and shall not be disclosed to any party, unless approved of by appropriate medical professionals under narrowly and expressly tailored circumstances enumerated in law, including to protect third parties who are at serious and imminent risk of infection and to share essential health information with medical professionals providing care to the patient;

→ **Right to Financial and Nutritional Support:**

Financial support to offset travel expenses, lost income, and any other costs associated with TB testing and treatment and food or nutritional supplements shall be provided to people with TB during the period of treatment;

→ **Right to Access Information:** People with TB shall have access to information about the nature of the disease, effective preventative measures, transmission and contagiousness, and treatment availability and

options, including the duration of treatment, the names and kinds of medicines involved, the nature of side-effects, and the risks of treatment nonadherence;

→ **Right to Informed Consent and Freedom from Nonconsensual Testing and Treatment:**

People shall have the right to informed consent prior to testing and treatment for TB and to be free from nonconsensual, compulsory treatment. Under no circumstances is forced treatment ethical or permissible, as established by the WHO Ethics Guidance;²⁰

→ **Right to Liberty and Freedom from Arbitrary Detention:**

People with TB shall have the right to liberty and to freedom from arbitrary detention, including involuntary detention or isolation of contagious persons, except for exceptional circumstances enumerated in law and proportional to what is strictly necessary, using the least restrictive and intrusive means available, to achieve legitimate public health aims, including when a person is known to be contagious and is likely to transmit the disease, refuses treatment, and all reasonable measures to ensure adherence have been attempted and proven unsuccessful;

→ **Right to Due Process:** People with TB who have had their right to liberty restricted through involuntary detention or isolation shall have the right to due process, including the rights to be heard by an independent authority, to appeal the decision to detain or isolate, and to have counsel during the proceedings;



²⁰ Ethics Guidance, *supra* note 2, at p. 38.

→ **Right to Freedom of Movement:** People with TB shall be free to move within and outside the country and to receive free treatment in the location where they reside, not only in their home jurisdiction;

→ **Right to Freedom from Imprisonment for Treatment Nonadherence:** People with TB shall not be imprisoned or detained under any circumstances in a non-medical setting for failing to adhere to their treatment;

→ **Right to Freedom from Torture and Cruel, Inhuman, or Degrading Treatment:** Prisoners with TB and those at risk of contracting the disease in prison shall be free from torture and cruel, inhuman, and degrading treatment during their detention. This requires providing appropriate TB testing and treatment during detention and ensuring sanitary and hygienic prison conditions to avoid transmission of the disease;

→ **Right to Participation:** People with TB, TB survivors and their representatives have the right to participate in decision-making processes affecting their health, including the design, implementation, monitoring, and evaluation of TB legislation and policies;

→ **Right to Access an Adequate, Effective, and Prompt Remedy:** People with TB shall have access to an adequate, effective, and prompt remedy under law for infringements and violations of the rights enumerated here; and

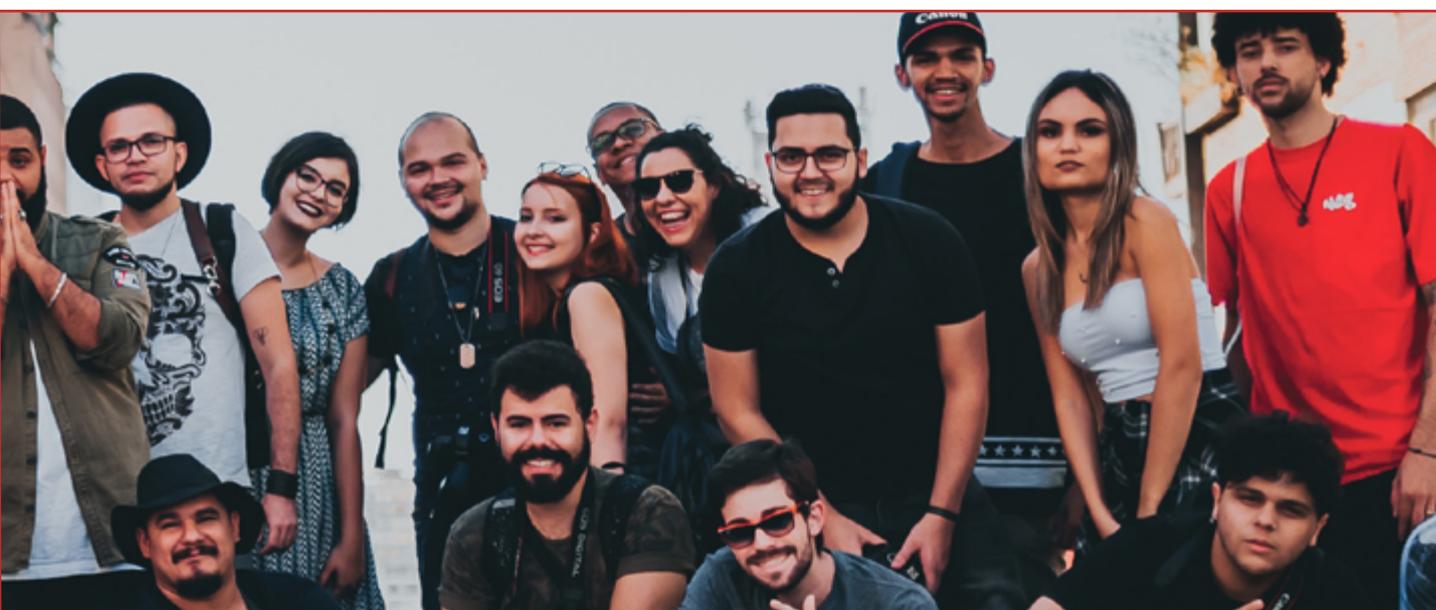
→ **Right to Social Security:** People with TB and TB survivors have the right social security, social protection and social insurance, including in the event of

unemployment, disability, old age or other circumstances of loss of means of subsistence, without discrimination, even if they are not receiving health care for TB or if they are not adhering to their treatment for TB.

Limitations on the rights of people with TB, including in circumstances involving involuntary isolation, should be specifically enumerated in law and proportional to what is strictly necessary to achieve legitimate public health aims, in line with the Siracusa Principles explained above.

In order for these rights to be effective in supporting national TB responses, people affected by TB and their advocates, through civil society organizations and community groups, must have access to funding and other kinds of technical support. Legislation addressing TB should account for this in providing access to government funding and technical support. Just as importantly, laws or policies restricting civil society or community-based organizations' access to domestic or foreign funding, other than on legitimate grounds of financial misconduct, should be repealed.

Finally, legislation is an inappropriate instrument by which to enumerate duties or obligations for people with TB. Enumerated duties may conflict with the rights listed above or have unintended consequences, such as allowing for involuntary treatment or establishing mandatory reporting by people with TB of presumptive TB cases in their family or community. If duties or obligations are thought to be supportive of the TB response in particular national contexts, they can be listed in ministry guidelines or other non-legally binding instruments.



Safeguarding Public Health and Granting and Defining Institutional Authority and Responsibility



In addition to establishing and protecting the individual rights of people affected by TB, legislation addressing TB must safeguard public health, and grant and define institutional authority and responsibility in order to effectively support the national TB response. This section briefly presents some of the key issues and provisions legislation must include in order to meet these objectives.

Safeguarding Public Health

In order to effectively safeguard public health, among other things, legislation addressing TB should:

- Establish clear guidelines for the operation of surveillance and notification systems, and screening procedures, with explicit protections for the rights to privacy, confidentiality and informed consent;
- Establish clear guidelines for when isolation and involuntary isolation is permissible, and under what conditions, based on the rights to liberty, equality, nondiscrimination, freedom of movement and due process, in line with the 2017 WHO Ethics Guidance;²¹
- Acknowledge the special needs of TB vulnerable communities and key affected populations based on national circumstances, such as children, health care workers, indigenous peoples, miners, mobile and migrant populations, people living with HIV, people who use drugs, prisoners and rural and urban poor, and commit adequate, equitable and sustainable financial resources to protecting their health;
- Establish clear guidelines for the screening of migrants, both documented and undocumented, with explicit protections for the rights to privacy, confidentiality

²¹ Ethics Guidance, *supra* note 2.

and informed consent, that ensure provision of TB treatment and support services for migrants with TB, including preventive therapy, and that do not create restrictions on movement based on TB; and

→ **Acknowledge the necessity of information about TB**, including the mode of TB transmission, that TB is curable, and about the prevention, testing and treatment of TB, to protecting public health and establish and fund programs to develop and disseminate such information throughout the country.

Granting and Defining Institutional Authority and Responsibility

In order to successfully define and grant institutional authority and responsibility in support of national TB responses, among other things, legislation addressing TB should:

→ **Ground institutional authority and responsibility on the State's obligation to respect, protect and fulfill the right to health** of its people, with recognition of global targets, such as the End TB Strategy and the UNhLM TB Political Déclaration;

→ **Commit adequate, equitable and sustainable financial resources** to the various institutions involved in implementing and enforcing the legislation, including for the procurement of preventive, diagnostic and treatment technologies, and for the wages of health care works and other National TB Program implementers;

→ **Establish periodic reporting requirements** for the Ministry of Health to report to the legislature on, among other things, the implementation of the legislation, prospective budgetary needs and use of funds from previous periods, epidemiological data demonstrating the impact of the legislation, and the content of implementing regulations and their alignment with the legislation;

→ **Acknowledge and grant institutional authority and responsibility in a multi-sectoral manner in order to address the social, economic and environmental determinants of TB**, including, among others, the

Ministries of Health, Labor, Social Protection and Justice, but with the primary responsibility to implement the law and its regulations to the National TB Program;

→ **Grant authority and define responsibility for an inclusive, multi-sectoral process for drafting implementing regulations**, led by the Ministry of Health, through the National TB Program, including participation of people affected by TB, and representatives from relevant ministries and the private health sector;

→ **Acknowledge and clearly define the role of public health officials in implementing the law**, with explicit limitations on their authority based on, among others, the rights to liberty, equality and nondiscrimination, privacy, confidentiality and due process;

→ **Recognize and empower the courts and other adjudicatory bodies** in the executive branch to receive and adjudicate claims under the legislation from people affected by TB;

→ **Recognize, support and facilitate civil society and community groups** to work closely with the National TB Program and other stakeholders in the design, implementation, monitoring and evaluation of TB policies, regulations and guidelines;

→ **Recognize and incentivize the role of the private health sector**, in coordination with the National TB Program, to provide good quality prevention, testing, treatment and support services, and to abide by the notification system requirements; and

→ **Grant authority, define responsibility and commit financing to the Ministry of Health, through the National TB Program and existing public research institutions, along with other stakeholders, including relevant Ministries, universities, private research institutions and international organizations**, to conduct TB research and to develop new health technologies for TB based on ethical and human rights principles and including community-based participatory research methods.

A Global Snapshot: Legislation Addressing TB around the World

This section briefly highlights important aspects of the global landscape of legislation addressing TB. It starts with a global overview and then focuses on Latin America and the Caribbean.

The Current Global Landscape: Opportunities and Risks

The current global landscape of legislation addressing TB can be divided into two main categories: public health-based laws and rights-based laws. This section briefly describes both approaches, noting the opportunities and risks associated with legislating public health and TB in particular.

Most countries do not have TB-specific legislation. Only two countries on the WHO's list of 30 High-burden TB countries²² have TB-specific legislation: the Russian Federation²³ and the Philippines.²⁴ In most countries, TB is addressed under the umbrella of general infectious disease and/or public health laws, not TB-specific legislation.

The specific responsibility and authority to address TB often lies with the executive branch and occurs in the form of administrative regulations. While regulations are necessary and important—they establish the operational details of national TB programs—legislation is unique. Legislation is written and enacted by democratically elected bodies, reflecting a democratic consensus. In comparison, administrative regulations reflect prerogatives

of unelected members of the executive branch in most countries. Legislation is more permanent and difficult to amend or repeal. Regulations are often drafted in accordance with relevant legislation, which means they follow the principles and frameworks laid out in legislation. Finally, legislation carries the force of law—it is enforceable in court—and may create private causes of action, allowing people to bring individual claims in court under the law. For these reasons, this Background Paper focus on the content of legislation addressing TB.

Public Health or Rights-Based?

In most countries, legislation that addresses TB predominantly takes a public health approach, emphasizing prevention and control of TB, and defining and granting institutional authority to implement and enforce the law. These laws, generally, do not establish legal rights for people with TB. They take many forms, but prominent among them are legislation on infectious or communicable diseases and public health acts.²⁵

New research from the O'Neill Institute at the Georgetown Law Center supported by Stop TB Partnership shows the risks involved in legislating TB without regard for human rights. In 20 of the 30 countries on the WHO's list of high-burden TB countries, legislation addressing TB provides insufficient and inconsistent protections for basic human rights, such as liberty, privacy, and due process.²⁶ The research shows that the norm in these laws is to grant health authorities essentially unchecked powers, including to enter and search homes and medically examine people, as well to detain and isolate people without basic due process protections required by human rights law and most constitutions. For example, all but one country—South Africa—fail to provide substantive legal protections regulating when involuntary isolation may be used,²⁷ in accordance with the WHO Ethics Guidance.²⁸

²² *Global TB Report*, *supra* note 1.

²³ *About the Prevention of Diffusion of Tuberculosis in the Russian Federation (en vigor el 18 de junio de 2001)*, <http://cis-legislation.com/document.fwx?rgn=1727>.

²⁴ *Comprehensive Tuberculosis Elimination Plan Act (en vigor el 26 de abril de 2016)*, <https://www.officialgazette.gov.ph/2016/04/26/republic-act-no-10767/> (Filipinas).

²⁵ See, e.g., *Infectious Disease Act, 2020 (effective Feb. 28, 1964)*, http://www.vertic.org/media/National%20Legislation/Nepal/NP_Infectious_Diseases_Act.pdf (Nepal); *The Law of The Republic of Indonesia Number 36 (effective 2009)*, http://www.sabin.org/sites/sabin.org/files/indonesia_health_law_2009.pdf; *The Law on Prevention and Control of Infectious Diseases (effective Nov. 21, 2007)*, <http://www.ifrc.org/docs/idrl/1011EN.pdf> (Vietnam); *Uganda Public Health Act (1935)*, <http://www.ulii.org/ug/>

legislation/consolidated-act/281; Public Health Act (effective Jan. 1, 1925; rev'd 1996), <http://faolex.fao.org/docs/pdf/zim21475.pdf> (Zimbabwe); *The Communicable Disease Act (effective Mar. 28, 2012)*, <http://eng.moph.go.th/index.php/policy-advocacy/90-the-communicable-disease-act> (Thailand); *The Prevention and Control of Communicable Diseases Law (effective Mar. 20, 1995)*, http://www.ilo.org/wcmsp5/groups/public/-ed_protect/-protrav/-ilo_aids/documents/legaldocument/wcms_202087.pdf (Myanmar).

²⁶ O'Neill Institute at Georgetown Law and Stop TB Partnership, *Coercion and Criminalization in TB-related Public Health Laws: Insufficient and Inconsistent Rights Protections in 20 High-burden Countries*, John Stephens (September 2018).

²⁷ *Id.*

²⁸ *Ethics Guidance*, *supra* note 2.

Latin America and the Caribbean

The emerging trend in Latin America and the Caribbean around TB-specific legislation, as with the global level, presents unique opportunities and risks. This section examines the enacted laws and emerging legislative projects, both to provide a clearer picture of what's happening in the region and to highlight the opportunities and risks.

The Law on Prevention and Control of TB in Peru

Enacted in December 2014, the Law on Prevention and Control of Tuberculosis in Peru is unique in the region and across the world for its inclusion of an entire chapter on the rights of people affected by TB.²⁹ The law represents a tremendous opportunity to implement a rights-based, person-centered response to TB in Peru. To this end, the law establishes, among others, the rights to comprehensive health care, to nondiscrimination and to file complaints, to privacy and dignity, to enjoy state programs for social inclusion, to access information, to receive a timely, clear and concise description of one's diagnosis and treatment, including side effects, and to receive nutritional and other kinds of support during treatment.³⁰

Chapter V of the law establishes benefits for workers affected by TB. These include the right to a leave of absence following TB diagnosis, the right to be reassigned to other work duties for a period indicated by a physician to ensure the affected person can work without compromising their health or security, and the establishment that any employment termination or dismissal due to TB is null and void.³¹ Chapter VI establishes TB as an occupational illness linked to the health care sector, and creates a right for health care

workers to prioritized TB testing and treatment. Chapter XI requires institutions of basic and higher education to provide "favorable academic conditions for students affected by tuberculosis," so they can complete their treatment and avoid losing their enrolment or failing to complete their academic year.³²

Chapter XIII commendably calls for the participation of civil society in the design, implementation and assessment of TB policies, but appears to limit this participation to legally constituted organizations. This Chapter would be strengthened if all members of communities affected by TB were permitted to participate in the design, implementation and assessment of TB policies, in accordance with the right to participation.

Chapter III establishes the duties of people affected by TB, but contains a number of risks. The chapter may open the door to involuntary treatment, failure to protect confidentiality and privacy of TB status, and unwarranted duties for people affected by TB to conduct active case finding and to report members of their community who may have TB. The law also could go further in establishing legal protections and providing clear direction around the circumstances in which the isolation and involuntary isolation of people affected by TB is lawful, in line with the WHO Ethics Guidance.³³

Belize, Bolivia, Costa Rica, the Dominican Republic, El Salvador, Guatemala Honduras, Nicaragua, Panama

On March 22, 2018, the Central American Parliament issued a Declaration against TB.³⁴ The Parliament is a regional political institution and parliamentary body integrated by **Belize, Costa Rica, the Dominican Republic, El Salvador, Guatemala, Honduras, Nicaragua and Panama**. The statement represents an initial proposal for a regional framework on TB and therefore presents

²⁹ *Ley de Prevención y Control de la Tuberculosis en el Perú, Capítulo II (en vigor el 14 de diciembre de 2014)*, <http://www.leyes.congreso.gob.pe/Documentos/Leyes/30287.pdf>.

³⁰ *Id. at Ch. II.*

³¹ *Id. at Ch. V.*

³² *Id. at Art. 35.*

³³ *Ethics Guidance, supra note 2.*

³⁴ *Respaldo al Frente Parlamentario Regional de las Américas contra la Tuberculosis, Declaración AP/1-CCXCVI. Tuberculosis, Declaración AP/1-CCXCVI.*

an exceptional opportunity to establish a human rights-based, person-centered response to TB in Latin America and the Caribbean, in line with international standards and the fundamental rights and freedoms established in the national constitutions of each nation.

Commitments in Bolivia

Bolivia has publicly declared its intention to initiate a project to develop a legislation on TB.³⁵ The declaration commits the legislature to implementing a program that ensures the prevention, diagnosis and treatment of TB, without discrimination, and increases funding for TB research. The declaration further commits to transforming the TB response in Bolivia to be founded on the rights of people affected by TB, although specific human rights are not mentioned.

Progress in Guatemala

The Congress of the Republic of **Guatemala** is engaged in an ongoing legislation project on TB.³⁶ The bill, entitled the Law for the Prevention and Control of TB in Guatemala, represents an opportunity to lay the legal foundation for a rights-based, people centered-response to TB in the country. The bill's introduction explains that Congressional

authority to enact the law is founded on the fundamental right to health, without discrimination, established in the Constitution of Guatemala. The bill establishes the authority and responsibility of the National TB Program, as part of the Ministry of Health, to supervise health service providers' compliance with the law.³⁷ The bill also creates an obligation for the National TB Programs to define and propose practices, policies and educational activities for public and private schools and universities that aim to reduce the incidence of TB in the country.³⁸ And Article 22 obliges the Ministry of Health to allocate part of its budget for the prevention, testing, treatment and control of tuberculosis, in order to comply with the law.

Article 9 of the Guatemalan bill establishes the rights of people with TB to receive ongoing, free and permanent treatment regulated by the Ministry of Health. The article further creates rights to be professionally diagnosed, to receive appropriate treatment, to access comprehensive preventive care and to receive rehabilitative services.

Article 10 establishes the right of people with TB to be free from discrimination, and Article 12 prohibits terminating a worker who has been diagnosed with TB.

Article 11 creates a set of rights for people with TB during



³⁵ Asamblea Legislativa Plurinacional de Bolivia Camara de Senadores, Declaracion Camaral No. 130/2018-2019.

³⁶ Ley para la Prevención y Control de la Tuberculosis en Guatemala, De la Iniciativa de ley Número 5354 (2018).

³⁷ *Id.* at Art. 5.

³⁸ *Id.* at Art. 7.

treatment: to privacy and respect for dignity, and religious and cultural beliefs; to access information about available treatments; to receive a timely and clear description of one's diagnosis, treatment, complications, adverse drug reactions, prognosis and evolution of one's disease; and to be informed of the medical and legal consequences associated with a communicable disease.

Like Peru's law, however, the Guatemalan bill lists duties of people affected by TB that present a number of risks. The duties established in Article 13 could lead to criminalization of people with TB who do not provide certain kinds of information, requiring involuntary treatment, and entrenching in law the Directly Observed Therapy (DOT) treatment strategy that requires people with TB to travel to a health clinic daily simply to receive their medications.

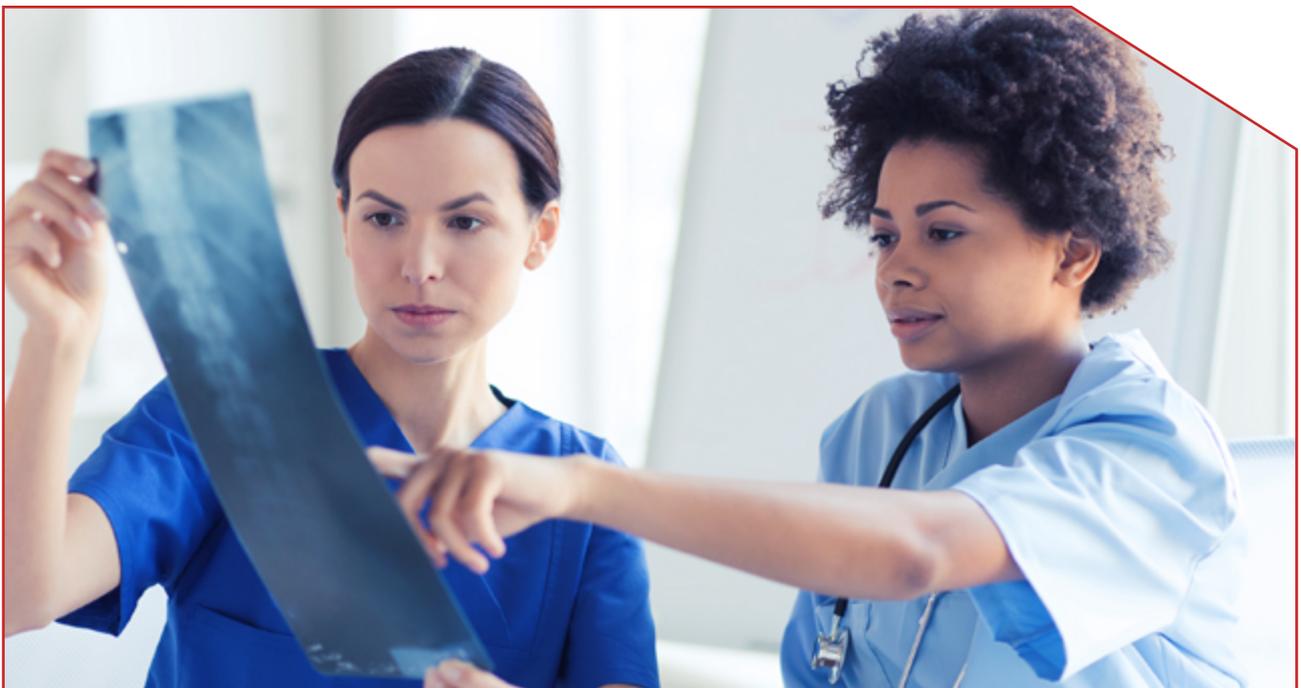
Paraguay and the Fight against TB

The Congress of the Republic of **Paraguay** is also engaged in an ongoing legislation project on TB.³⁹ Like for Guatemala, the bill, entitled the Law on the Prevention and Control of TB, represents an opportunity to lay the legal foundation for a rights-based, people centered-

response to TB in the country. The bill's stated purpose is the prevention, detection, diagnosis, treatment and control of TB, in order to stop the spread of the disease and to decrease TB mortality.⁴⁰ Articles 3 and 4 grant the authority and responsibility to implement the law to the Ministry of Public Health, but require all public and private health institutions to comply with the law. Article 27 establishes the National TB Program as a specialized agency under the Ministry of Public Health to ensure compliance with the law.

The bill establishes a series of rights for people affected by TB. These include the right to free diagnosis, to free access to treatment without discrimination, to counseling, and to confidentiality. Importantly, Article 5 prohibits discrimination against people with TB, and Article 6 provides a broad and inclusive definition of discrimination to include

"... any distinction, exclusion, restriction or preference, in any public or private sphere, that is established or exercised against said person for reasons of his or her health condition, and having the purpose or effect of nullifying or limiting the recognition, enjoyment or exercise, under conditions of equality, of one or more of their human rights or freedoms enshrined in the National Constitution,



³⁹ *De Prevención y Control de la Tuberculosis, Exp. No. D-1432858 (2015).*

⁴⁰ *Id.* at Art. 1.

international instruments of human rights ratified for the Republic of Paraguay, national legislation and other regulations that make up the national legal order.”

Article 8 further establishes the right of a person affected by TB to submit a complaint of discrimination by public or private actors directly to the Ministry of Justice, or through the National TB Program, that must be resolved within 30 days.

However, Article 5 also states that the temporary isolation of people with TB at the start of treatment will not be considered a discriminatory act, as long as it is indicated by a medical professional. This provision could be interpreted to allow for the involuntary isolation of every person with TB and should therefore be revised in accordance with the international standards established in the WHO Ethics Guidance.⁴¹ The bill’s broad delegation of power to the Ministry of Public Health, without further clear guidance in key areas, including involuntary isolation, could present serious risks for the development and implementation of regulations at the Ministry level.

Conclusion

Legislation addressing TB can and should play a role in designing and implementing a human rights-based, people-centered response to TB in Latin America and the Caribbean. Several countries are on their way, and the entire region can learn from these experiences, both about the opportunities and risks associated, particularly, with

TB-specific legislation. The political will demonstrated by these countries—who are leading the way globally to better legislation for TB—is to be commended. If other countries choose this path, they will do well to study the laws in the region and examine and align their legislation with the international standards and human rights law briefly introduced in this Background Paper.

Enacting legislation, however, is just the first step. Legislators and policymakers must follow through to ensure successful implementation of the law. This includes providing adequate funds through legislative budgetary processes and drafting and promulgating of effective and comprehensive implementing regulations that align closely with the spirit and letter of the law. Successful implementation also requires periodic reporting to the legislature by officials and departments tasked with implementing the law, in order to monitor and evaluate the implementation process. Moreover, in order to ensure the law is understood and utilized by people affected by TB, comprehensive legal empowerment programs targeting affected communities and key populations should be implemented. In addition, the judiciary and legal community should also be sensitized and educated on the legislation, including its overall purpose and objectives. Without these programs and targeted efforts, even well-crafted legislation will not achieve its intended objectives to support and accelerate the response to end TB.

⁴¹ *Ethics Guidance, supra note 2.*

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