

Tuberculosis and the Law Workshop:
Latin America and the Caribbean

Key considerations for tuberculosis legislation

Brian Citro, *Professor of Law*
Northwestern Pritzker School of Law
(Estados Unidos)

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Establish and protect the rights of people affected by tuberculosis (TB) ¹

✓ Ground the objectives of the legislation on the State's obligations under international and regional human rights law, as well as the rights established in the nation's constitution.

✓ Recognize and establish the rights of people affected by TB, to life and health, meaning to access good-quality prevention, testing, treatment and support services, including new medicines and diagnostic technologies and counseling.

✓ Recognize and establish the right of people affected by TB to equality and nondiscrimination based on current or former TB status or association with a person with TB in all areas of life, including education, employment, health care, housing, social protection, and create a complaints mechanism to hear and adjudicate discrimination claims.

Safeguard public health

✓ 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 on the Implementation of the End TB Strategy.

✓ Acknowledge the special needs of TB vulnerable communities and key affected populations based on national circumstances, such as children, health care workers, indigenous groups, miners, mobile 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.

Grant and define institutional authority and responsibility

✓ 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.

✓ 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 workers 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.

¹ "TB" refers to both drug-susceptible and drug-resistant TB throughout the document.

Establish and protect the rights of people affected by tuberculosis (TB) ¹

✓ Recognize and establish the right to participation of people affected by TB in the design, implementation, monitoring and evaluation of TB-related laws, policies, regulations and guidelines.

✓ Recognize and establish the rights of people affected by TB to liberty, freedom of movement and to be free from arbitrary detention, with proportional limitations permissible only based on law and with due process rights.

✓ Recognize and establish the rights of people affected TB to privacy and confidentiality, including in their TB status and personal health data, with proportional intrusions only permissible based on law when a person poses an immediate, real and serious threat to public health.

Safeguard public health

✓ Establish clear guidelines for the screening of migrants, both documented and undocumented, with explicit protections for the rights to privacy, confidentiality 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.

✓ Acknowledge the necessity of information about TB, including the mode of TB transmission, that it 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.

Grant and define institutional authority and responsibility

✓ 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.

Establish and protect the rights of people affected by tuberculosis (TB) ¹

✓ Recognize and establish the right of people affected by TB to informed consent for all testing and treatment services, including the right to refuse treatment.

✓ Recognize and establish the right of people affected by TB to information, including about the prevention, testing and treatment of TB, the mode of TB transmission, and the benefits and risks of treatment, including adverse treatment side effects.

✓ Recognize and establish the right of people affected by TB to an effective and timely remedy in court and, if possible, other adjudicatory bodies in the executive branch for violations of the rights established in the legislation.

✓ Recognize and establish the right of people affected by TB to 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.

Safeguard public health

Grant and define institutional authority and responsibility

✓ 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.

✓ 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.