

HEALTH AND HUMAN RIGHTS RESOURCE GUIDE



FXBCENTER
FOR HEALTH & HUMAN RIGHTS

HARVARD SCHOOL OF PUBLIC HEALTH | HARVARD UNIVERSITY

HEALTH AND HUMAN RIGHTS RESOURCE GUIDE

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Health and Human Rights Resource Guide

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Fifth Edition, November 2013

Cover photograph courtesy of Sven Torfinn - Panos for the Open Society Foundations, "A paralegal nurse named Mercy and a lawyer named Johnson, both with Nyeri Hospice in Nyeri, Kenya talk with Elizabeth (center) about her health and property. She has cancer and is cared for by her granddaughter Caroline (to her left). She wants to ensure her granddaughters can inherit her property even though other relatives are trying to claim it."

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CHAPTER 3



TUBERCULOSIS AND HUMAN RIGHTS

“Tuberculosis is a disease of poverty and inequality. ... Many of the factors that increase vulnerability to contracting [TB] or reduce access to diagnostic, prevention and treatment services are associated with people’s ability to realize their human rights.”

— *The Global Fund to Fight AIDS, TB and Malaria*

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Cover photograph courtesy of Angela Duger, “Mekong Delta, Vietnam”

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INTRODUCTION

This chapter will introduce you to key issues and resources in tuberculosis (TB) and human rights. Some of the issues in this chapter are also addressed in Chapter 2 on HIV, AIDS and human rights.

This chapter is organized into six sections that answer the following questions:

1. How is TB a human rights issue?
2. Which are the most relevant international and regional human rights standards related to TB?
3. What is a human rights-based approach to advocacy, litigation and programming?
4. What are some examples of effective human rights-based work in the area of TB?
5. How can I find additional resources about TB and human rights?
6. What are the key terms to TB and human rights?

I. HOW IS TUBERCULOSIS (TB) A HUMAN RIGHTS ISSUE?

What is TB?

What does TB stand for?

TB stands for tuberculosis, an airborne infectious disease caused by the bacterium *Mycobacterium tuberculosis*. TB typically attacks the lungs (*pulmonary TB*), although it can affect other parts of the body as well (*extra-pulmonary TB*). TB is usually transmitted through the cough, sneeze, or spit of a person with active TB. When a person breathes in these air droplets, TB bacteria enter the lungs. From the lungs, the bacteria can move through the blood to other parts of the body, such as the kidney, spine and brain.¹

Many healthy people exposed to TB are able to successfully fight off infection. Their immune systems destroy the bacteria, eliminating any trace of exposure.² However, other people may lack the resistance to prevent infection or disease.³ Infected individuals can progress to active TB disease and experience symptoms such as cough, chest pains, weakness, weight loss, fever and night sweats.⁴

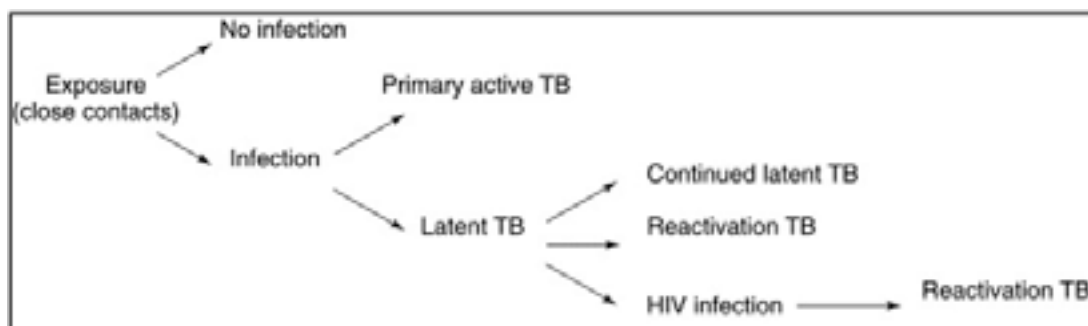
If left untreated, TB kills more than half of those who develop active cases.⁵ People with HIV and other immuno-compromised states are at higher risk of developing TB infection and disease. Additionally, people with HIV and children are at higher risk for developing extra-pulmonary TB.⁶ Accurate diagnosis combined with treatment with anti-TB medicines can greatly reduce mortality rates.⁷ Yet while TB is preventable and curable, barriers to accessing care and maintaining health hinder TB control efforts and contribute to a global rise in drug-resistant strains of TB.

What are latent TB and active TB?

TB develops in two stages. The first stage, known as *latent TB* or *TB infection*, occurs when a person exposed to TB bacteria becomes infected.⁸ When the body's immune system is unable to eliminate the bacteria, it may wall them off with tiny pieces of scar tissue known as granulomas. The bacteria stay in the body but remain dormant or inactive. The individual is infected, but does not have any symptoms and is unable to spread TB.⁹

- 1 Center for Disease Control and Prevention (CDC), *Questions and Answers about Tuberculosis* (2012). www.cdc.gov/tb/publications/faqs/pdfs/qa.pdf.
- 2 See High Court of South Africa, *Dudley Lee v. the Minister of Correctional Services*, Case No. 1041. www.saflii.org/za/cases/ZAWCHC/2011/13.pdf.
- 3 See UCLA School of Public Health, "Susceptibility Definition." www.ph.ucla.edu/epi/bioter/anthapha_def_a.html.
- 4 Center for Disease Control and Prevention, *Questions and Answers about Tuberculosis* (2012). www.cdc.gov/tb/publications/faqs/pdfs/qa.pdf.
- 5 Tiemersma EW et al., "Natural History of Tuberculosis: Duration and Fatality of Untreated Pulmonary Tuberculosis in HIV Negative Patients: A Systematic Review," *PLoS Medicine* 6, no. 4 (2011). www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0017601.
- 6 Zaki SA, "Extrapulmonary tuberculosis and HIV," *Lung India*, 28, no. 1, Letters to the Editor (Jan-Mar. 2011). www.ncbi.nlm.nih.gov/pmc/articles/PMC3099522; Walls T and Shingadia D, "Global epidemiology of paediatric tuberculosis," *Journal of Infection* 48, no. 1 (2004). www.sciencedirect.com/science/article/pii/S016344530300121X.
- 7 World Health Organization (WHO), *Global Tuberculosis Control* 2011 (2011). http://www.who.int/tb/publications/global_report/2010/en/.
- 8 Global Health Education, "TB Tests". www.tbfacts.org/tb-tests.html. Emphasis added.
- 9 Center for Disease Control and Prevention, *Tuberculosis: General Information, Fact Sheet* (2011). www.cdc.gov/tb/publications/factsheets/general/tb.pdf.

The second stage, known as active TB or TB disease, occurs when the bacteria multiply in the body, usually causing the person to become sick.¹⁰ This can happen at any time, even many years after infection.¹¹ People with active TB experience symptoms which can vary depending on whether they have pulmonary or extra-pulmonary TB.¹² Additionally, people with TB of the lungs or throat can spread infection to others.¹³ The following diagram, adapted from Parrish et al., helps illustrate the interaction between latent and active TB:¹⁴



How is TB spread?

According to the World Health Organization (WHO), the probability of developing TB infection and disease increase “with malnutrition, crowding, poor air circulation, and poor sanitation—all factors associated with poverty”.¹⁵ These risks are greater in crowded institutional settings such as prisons and detention centers. While TB bacteria are vulnerable to sunlight and fresh air, they can survive and circulate in closed, poorly ventilated environments. Individuals with active TB “can infect up to 10 to 15 other people through close contact over the course of a year”.¹⁶ Poverty and limited access to health care fuel the spread of TB by impeding diagnosis, treatment and care. Moreover, inappropriate treatment fuels drug resistance, resulting in higher rates of TB and greater disease severity, particularly in resource-constrained settings.

How is TB diagnosed?

There are several types of tests to determine if a person has been infected with TB. Sputum smear microscopy is one of the most widely used, particularly in high burden countries. It involves examining the sputum (lung fluid) of infected persons under a microscope to identify TB bacteria. While the test is fast and inexpensive, it tends to under-identify the number of infected persons (false negatives) and cannot test for drug resistance.

¹⁰ Global Health Education, “TB Tests”. www.tbfacts.org/tb-tests.html.

¹¹ High Court of South Africa, *Dudley Lee v. the Minister of Correctional Services*, Case No. 1041.

¹² Center for Disease Control and Prevention, *Questions and Answers about Tuberculosis* (2012). www.cdc.gov/tb/publications/faqs/pdfs/qa.pdf.

¹³ Center for Disease Control and Prevention, *Tuberculosis: General Information, Fact Sheet* (Oct 2011). www.cdc.gov/tb/publications/factsheets/general/tb.pdf

¹⁴ Diagram adapted from Parrish NM, Dick JD and Bishai WR, “Mechanisms of latency in *Mycobacterium tuberculosis*”, *Trends in Microbiology* 6, no. 3 (1998): 107-112. [http://dx.doi.org/10.1016/S0966-842X\(98\)01216-5](http://dx.doi.org/10.1016/S0966-842X(98)01216-5)

¹⁵ World Health Organization (WHO), *Guidelines for social mobilization. A human rights approach to TB* (2001). www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf

¹⁶ WHO, *Tuberculosis*, Fact sheet no. 104 (2013). www.who.int/mediacentre/factsheets/fs104.

Drug susceptibility testing (DST) is another type of testing to determine if the bacteria are susceptible to treatment or resistant to drugs. For example, culturing involves growing TB bacteria in a laboratory to confirm infection and to test for drug susceptibility.¹⁷ It is currently the only method available to monitor patients' response to treatment for drug-resistant TB. However, it can take weeks and is not always available.¹⁸ In 2011, 19 of the 36 countries with the high burden of TB did not have the recommended laboratory capacity to perform culture and DST.¹⁹

More sensitive diagnostic technologies have been developed in recent years. Gene Xpert MTB/RIF is a new rapid molecular test endorsed by the WHO. It can diagnose TB and drug-resistant TB within hours, and can be used at lower levels of the laboratory network than culture methods. Efforts to expand access and to decrease price are currently underway.²⁰ Nevertheless, advances in TB diagnostic capacity must also be matched by advances in capacity to provide treatment.

What are MDR-TB and XDR-TB?

MDR-TB and XDR-TB refer to multidrug-resistant TB and extensively drug-resistant TB, respectively. Both can arise as the result of inadequate, incomplete or inconsistent treatment practices. People can also contract MDR or XDR-TB in settings where drug-resistant strains are prevalent. Treating TB requires strict adherence to a lengthy regimen of multiple drugs. Most cases of active, drug-susceptible TB can be cured with a standard six- to nine-month course of “four antimicrobial drugs that are provided with information, supervision and support to the patient by a health worker or trained volunteers.”²¹ This approach is known as DOTS, or directly-observed therapy, short-course.

MDR-TB does not respond to standard, first-line anti-TB drugs and is difficult and costly to treat. It accounts for about 3.7% of new TB cases each year and afflicts about 500,000 people. While 60% of these cases occur in Brazil, China, India, Russia and South Africa, MDR-TB has been documented in all countries surveyed to date.²² Yet in 2009, MDR-TB cases accounted for just 10% of all reported TB cases in high MDR-TB countries, and just a fraction of them were enrolled in treatment.²³ XDR-TB is a form of MDR-TB “that responds to even fewer available medicines, including the most effective second-line anti-TB drugs.”²⁴ XDR-TB has been identified in 84 countries, is virtually untreatable, and accounts for around 9% of all MDR-TB cases.²⁵

Lack of diagnostic capacity has hindered effective responses to HIV-associated TB and drug-resistant TB. Few national TB programs can perform drug-susceptibility testing for first-line drugs, and even fewer have the capacity to test for second-line drug resistance. As a result, less than 5% of all MDR-TB cases are currently detected²⁶ and an even smaller percentage of XDR-TB cases are detected.²⁷ Many TB programs

17 Global Health Education, “TB Tests”. www.tbfacts.org/tb-tests.html.

18 WHO, *Global Tuberculosis Report* (2012). http://apps.who.int/iris/bitstream/10665/75938/1/9789241564502_eng.pdf.

19 UN General Assembly, *Report of the Special Rapporteur in the field of cultural rights: the right to enjoy the benefits of scientific progress and its applications*, A/HRC/20/26 (May 14, 2012). www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session20/A-HRC-20-26_en.pdf.

20 WHO, *Global Tuberculosis Report* (2012). http://apps.who.int/iris/bitstream/10665/75938/1/9789241564502_eng.pdf.

21 WHO, *Tuberculosis*, Fact sheet no. 104 (2013). www.who.int/mediacentre/factsheets/fs104/; WHO, “10 Facts about Tuberculosis.” www.who.int/features/factfiles/tb_facts/en/index.html.

22 WHO, *Multidrug-resistant tuberculosis (MDR-TB) 2013 Update* (2013). www.who.int/tb/challenges/mdr/MDR_TB_FactSheet.pdf

23 WHO, *Towards universal access to diagnosis and treatment of multidrug-resistant and extensively drug-resistant tuberculosis by 2015*, Progress Report (2011). http://whqlibdoc.who.int/publications/2011/9789241501330_eng.pdf

24 WHO, *Tuberculosis*, Fact sheet no. 104 (2013). www.who.int/mediacentre/factsheets/fs104/.

25 WHO, *Global Tuberculosis Control 2011* (2011). http://www.who.int/tb/publications/global_report/2010/en/.

26 WHO, *Towards universal access to diagnosis and treatment of multidrug-resistant and extensively drug-resistant tuberculosis by 2015*, Progress Report (2011). http://whqlibdoc.who.int/publications/2011/9789241501330_eng.pdf

27 WHO “TB diagnostics and laboratory strengthening.” www.who.int/tb/laboratory/

wait until the patient fails the standard drug treatment regimen before considering the possibility of drug resistance.²⁸ It is estimated under 1% of persons with MDR-TB receive the quality of care that is considered standard in high-income settings. Effective management of MDR-TB and XDR-TB requires a commitment to equity: evidence-based diagnostics, therapies and adequate health care delivery, particularly in resource-constrained settings.²⁹

What is the connection between TB and HIV?³⁰

TB and HIV are overlapping epidemics which worsen health outcomes for those who are co-infected.³¹ An estimated 14 million individuals have TB-HIV, the majority of whom live in sub-Saharan Africa. At least one third of all people with HIV are co-infected with TB, and nearly one third of all TB deaths are among people co-infected with HIV.³² TB is the leading cause of death among people living with HIV worldwide—it accounts for 26% of HIV-related deaths, 99% of which occur in developing countries³³

TB and HIV health challenges

TB and HIV co-infection causes specific diagnostic and therapeutic challenges. TB and HIV exacerbate one another, accelerating the deterioration of immunological functions and resulting in premature death if untreated. Some evidence suggests that TB may exacerbate HIV infection and accelerate the progression from HIV to AIDS, although the mechanism remains unclear.³⁴ At the same time, people living with HIV are 21 to 34 times more likely to develop active TB than those without HIV, making HIV the most powerful known risk factor for progression from latent to active TB. HIV co-infection also increases the risk of TB-related death.³⁵

There has also been research into the interaction of HIV and drug-resistant TB. At the patient level, HIV infection has not been confirmed to be an independent risk factor for the development of MDR-TB. At the population level, however, HIV has increased the absolute burden of drug-resistant TB. Regardless of whether HIV infection is an independent risk factor for drug resistance, HIV has increased the pool of immuno-compromised patients who serve as hosts and vectors for all forms of TB, including MDR-TB.³⁶

28 WHO Expert Group Meeting, *Policy guidance on TB drug susceptibility testing (DST) and second-line drugs (SLD)* (Geneva, July 23, 2007). http://www.who.int/tb/features_archive/xdr_mdr_policy_guidance/en/.

29 Dalton T et al., "Prevalence of and risk factors for resistance to second-line drugs in people with multidrug-resistant tuberculosis in eight countries: a prospective cohort study," *Lancet* 380 (2012). <http://press.thelancet.com/TB.pdf>

30 HIV stands for human immunodeficiency virus. AIDS stands for acquired immunodeficiency syndrome, which is an advanced stage of HIV defined by the demonstration of certain symptoms, infections and cancers. WHO, *HIV/AIDS: Fact Sheet No. 360*, Fact Sheet (Nov. 2012). www.who.int/mediacentre/factsheets/fs360/en/index.html.

31 TB Alert, "TB & HIV." <http://www.tbalert.org/index.php/about-tuberculosis/global-tb-challenges/tb-hiv>.

32 WHO, *Global Tuberculosis Control 2011* (2011): 1, 83; WHO, *TB-HIV Facts 2011-2012*. www.who.int/tb/publications/TBHIV_Facts_for_2011.pdf.

33 Pawlowski A et al., "Tuberculosis and HIV Co-Infection," *PLoS Pathogens* 8, no. 2 (2012). www.plospathogens.org/article/info%3Adoi%2F10.1371%2Fjournal.ppat.1002464#s1.

34 Ibid.

35 Lonnroth et al., "Tuberculosis: the role of risk factors and social determinants," in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241. http://whqlibdoc.who.int/publications/2010/9789241563970_eng.pdf.

36 Andrews JR, "Multidrug-Resistant and Extensively Drug-Resistant Tuberculosis: Implications for the HIV Epidemic and Antiretroviral Therapy Rollout in South Africa," *The Journal of Infectious Diseases* 196, suppl. 3 (2007). http://jid.oxfordjournals.org/content/196/Supplement_3/S482.long,

TB and HIV programming challenges

The HIV epidemic has overwhelmed and disrupted established TB-control programs, leading to high treatment failure rates and increasing the opportunity for drug-resistant TB to emerge and spread.³⁷ Treatment for drug-resistant TB takes longer and is more complex, expensive, and toxic than treatment for drug-susceptible TB. It therefore results in lower treatment success rates and higher mortality rates, especially for those co-infected with HIV.³⁸

Furthermore, while TB is confined to the lungs in most adult patients, it can be a systemic disease involving multiple organs in TB-HIV patients. All forms of extra-pulmonary TB, including disseminated TB, have been described in patients with HIV.³⁹ Extra-pulmonary cannot be diagnosed through microscopy, which is the most available method of diagnosis worldwide. Therefore TB is also more difficult to diagnose in persons living with HIV.⁴⁰ Diagnosis may also be delayed or incorrect due to logistical difficulties, such as the separation of sites for TB diagnosis and treatment from HIV diagnosis and treatment sites.

Collaborative TB-HIV activities

TB can be cured. While there is currently no cure for HIV, people can live healthy and productive lives with antiretroviral therapy (ART).⁴¹ Studies show that anti-TB drugs can prolong the lives of people with HIV by at least two years, even without ART, which can provide indefinite good health.⁴² Early TB screening and diagnosis, preventative therapy, treatment and adherence support to people living with HIV greatly increases the manageability of both diseases. Delivering integrated services, at the same time and location, is especially critical.⁴³

³⁷ Ibid.

³⁸ Ibid.

³⁹ Pawlowski A et al., "Tuberculosis and HIV Co-Infection," *PLoS Pathogens* 8, no. 2 (2012). www.plospathogens.org/article/info%3Adoi%2F10.1371%2Fjournal.ppat.1002464#s1.

⁴⁰ TB Alert, "TB & HIV." <http://www.tbalert.org/index.php/about-tuberculosis/global-tb-challenges/tb-hiv>.

⁴¹ WHO, *HIV/AIDS: Fact Sheet No. 360*, Fact Sheet (Nov. 2012). www.who.int/mediacentre/factsheets/fs360/en/index.html.

⁴² WHO, *Fight AIDS, fight TB, fight now: TB/HIV information pack* (2004). www.stoptb.org/assets/documents/resources/publications/acsm/InfoPackEnglish.pdf

⁴³ Andrews JR et al., "Multidrug-Resistant and Extensively Drug-Resistant Tuberculosis: Implications for the HIV Epidemic and Antiretroviral Therapy Roll-out in South Africa," *Journal of Infectious Diseases* 196, Suppl. 3 (2007). http://jid.oxfordjournals.org/content/196/Supplement_3/S482.long,

The WHO recommends three types of collaborative TB-HIV activities: (1) establishing and strengthening mechanisms for integrated delivery of TB and HIV services; (2) reducing the burden of TB among people living with HIV and initiating early ART; and (3) reducing the burden of HIV among people with presumptive TB and diagnosed TB.⁴⁴ In large part to the scale-up of such activities, TB deaths in people living with HIV declined by 25% between 2004 and 2011.⁴⁵ Yet further progress is needed. In 2011, just 40% of TB patients were screened for HIV and just 7% of people living with HIV were screened for TB.⁴⁶ The combination of HIV, TB and MDR-TB in prisons has created an urgent human rights crisis in many parts of the world—in African countries such as South Africa, Uganda, and Zambia;⁴⁷ in Central and Eastern European countries such as Russia, Azerbaijan and Georgia;⁴⁸ and in Southeast Asian countries such as Cambodia, Indonesia and Thailand.⁴⁹ For more information on HIV, AIDS, and human rights, please see Chapter 2.

How is TB a global epidemic?

TB is second only to HIV as the leading cause of death from an infectious disease worldwide.⁵⁰ Approximately 2.3 billion people—one third of the world's population—have been infected with TB, the majority of whom have latent TB and therefore do not have active symptoms and cannot transmit the disease to others.⁵¹ However, around one in ten infected persons goes on to develop active TB disease. There are currently an estimated 12 million active cases of TB worldwide and nearly 9 million new cases each year.

According to the WHO, Asia and Africa carry the greatest burden of TB, with India and China accounting for nearly 40% of all cases. Africa accounts for 24% of the world's cases “and the highest rates of cases and deaths per capita”.⁵² In 2011, 1.4 million people died from TB and over 95% of these deaths occurred in low- and middle-income countries.⁵³ While the TB death rate has dropped 40% between 1990 and 2011, the disease has never been eradicated in any country.⁵⁴ Experts caution that progress remains uneven across economic and social lines. These inequalities, combined with growing resistance to anti-TB drugs, require urgent attention.

44 WHO, *WHO policy on collaborative TB/HIV activities: Guidelines for national programmes and other stakeholders* (2012). http://whqlibdoc.who.int/publications/2012/9789241503006_eng.pdf

45 Henry J. Kaiser Family Foundation, *US Global Health Policy Fact Sheet: The Global HIV/AIDS Epidemic*, Fact Sheet (Dec. 2012). www.kff.org/hiv/aids/upload/3030-17.pdf.

46 WHO, *Tuberculosis Global Facts 2011-2012*. www.who.int/tb/publications/2011/factsheet_tb_2011.pdf.

47 Amon J, “The HIV and TB Prison Crisis in Southern Africa,” *Huffington Post*, July 23, 2010. www.hrw.org/news/2010/07/23/hiv-and-tb-prison-crisis-south-ern-africa; Todrys K, “HIV and TB Spread Unchecked in Uganda's Prisons,” *Think Africa Press*, July 25, 2011, www.hrw.org/news/2011/07/25/hiv-and-tb-spread-unchecked-ugandas-prisons; Human Rights Watch, *Unjust and Unhealthy: HIV, TB, and Abuse in Zambian Prisons* (April 27, 2010). www.hrw.org/reports/2010/04/27/unjust-and-unhealthy-o; Amon J, “Zambia's TB-ridden prisons,” *The Guardian*, April 27, 2010. www.hrw.org/news/2010/04/27/zambias-tb-ridden-prisons; and Todrys K et al., “Imprisoned and imperiled: access to HIV and TB prevention and treatment, and denial of human rights, in Zambian prisons,” *Journal of the International AIDS Society* 14, no. 8 (2011). www.biomedcentral.com/1758-2652/content/14/1/8/

48 Dalton T et al., “Prevalence of and risk factors for resistance to second-line drugs in people with multidrug-resistant tuberculosis in eight countries: a prospective cohort study,” *Lancet* 380 (2012); International Committee of the Red Cross (ICRC), “Azerbaijan: combating multi-drug resistant TB in detention,” film, www.icrc.org/eng/resources/documents/film/2013/av003a-azerbaijan-combating-mdr-tb-detention.htm; and WHO, *Literature Review on Tuberculosis in Prisons* (Nov. 18, 2008). www.who.int/tb/challenges/prisons/tb_in_prisons_lit_review_10feb08.pdf

49 IRIN Global, “In Brief: TB, HIV warning for Cambodia's prison” (Oct 1, 2010). www.irinnews.org/Report/90644/In-Brief-TB-HIV-warning-for-Cambodia-s-prisons; IRIN Asia, “Indonesia: Overcrowding fuels TB in prisons,” Jan 25, 2010. www.irinnews.org/Report/87852/INDONESIA-Overcrowding-fuels-TB-in-prisons; WHO, *Literature Review on Tuberculosis in Prisons* (Nov. 18, 2008). Dalton T et al., “Prevalence of and risk factors for resistance to second-line drugs in people with multidrug-resistant tuberculosis in eight countries: a prospective cohort study,” *Lancet* 380 (2012); McNeil DG, “Tuberculosis: Stubborn and Expensive to Treat, Drug-Resistant Strains Show Growth,” *The New York Times*, September 3, 2012. www.nytimes.com/2012/09/04/science/drug-resistant-tuberculosis-strains-show-growth-worldwide.html

50 WHO, *Global Tuberculosis Control 2011* (2011). http://www.who.int/tb/publications/global_report/2010/en/.

51 International Federation of Red Cross and Red Crescent Societies, *Promoting the human rights-based approach to address Tuberculosis*, (Dec. 2, 2011). www.ifrc.org/en/news-and-media/news-stories/international/promoting-the-human-rights-based-approach-to-address-tuberculosis/.

52 WHO, *Global Tuberculosis Control 2011* (2011). http://www.who.int/tb/publications/global_report/2010/en/.

53 Ibid.

54 WHO, *Tuberculosis*, Fact sheet no. 104 (2013). www.who.int/mediacentre/factsheets/fs104; WHO, “10 Facts about Tuberculosis.” <http://www.who.int/features/factfiles/tuberculosis/en/>.

How is TB a Human Rights Issue?

Who Is Affected By TB?

Human rights are inextricably linked with who gets TB. According to the Global Fund to Fight AIDS, TB and Malaria (Global Fund):

Tuberculosis is a disease of poverty and inequality.... Many of the factors that increase vulnerability to contracting [TB] or reduce access to diagnostic, prevention and treatment services are associated with people's ability to realize their human rights.⁵⁵

A lack of respect for human rights fuels the spread of TB⁵⁶ by creating conducive economic, social and environmental conditions. Key vulnerable groups include people living in poverty, ethnic minorities, women, children, people living with HIV, prisoners, homeless persons, migrants, refugees and internally displaced persons. They are more likely to be exposed to conditions that are conducive to TB development and less likely to have the information, power and resources necessary to ensure their health. Additional groups at risk include people who work in institutional settings, and people who use alcohol, tobacco and drugs.⁵⁷

TB also undermines the realization of human rights by increasing vulnerability to the disease. People affected by TB suffer a double burden: the impact of the disease as well as the “consequential loss of other rights.”⁵⁸ TB contributes to poverty, for example, by preventing people from working and by imposing high costs related to treatment and care. People can also be subjected to arbitrary and harmful measures such as involuntary treatment, detention, isolation and incarceration. Finally, TB-associated stigma and discrimination—and overlapping discrimination based on gender, poverty, or HIV status—can affect people’s employment, housing and access to social services.

⁵⁵ Global Fund to Fight AIDS, Tuberculosis and Malaria [Global Fund], *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

⁵⁶ Inter-Parliamentary Union (IPU), UNAIDS, UN Development Programme (UNDP), *Taking Action Against HIV: A Handbook for Parliamentarians* (2007). www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf. Although the cited passage was written about HIV, the analysis of human rights violations apply equally to TB.

⁵⁷ Global Fund, *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

⁵⁸ Inter-Parliamentary Union, UNAIDS, UNDP, *Taking Action Against HIV: A Handbook for Parliamentarians* (2007). www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2007/20071128_ipu_handbook_en.pdf.

These intersecting violations shape the contours of the global TB epidemic. According to the WHO, the number of people falling ill with TB each year is declining and the death rate has dropped by 40% between 1990 and 2010.⁵⁹ Yet this progress is offset by glaring inequalities: over 95% of all TB cases and deaths occur in developing countries and 79% of all TB-HIV cases are concentrated in Africa.⁶⁰ To mount an effective response to TB, public health approaches must be informed by and harmonized with the protection of civil, political, economic, social and cultural rights. Human rights are relevant to achieving universal access to quality TB prevention, diagnosis, treatment, care and support in at least three ways:

1. Human rights violations exist “as core features of risk environments, as barriers to care, and as social determinants of poor health and development”.⁶¹
2. Human rights provide a framework for holding governments and third parties responsible for developing and implementing evidence-based and rights-based responses to TB.
3. Human rights provide a framework for empowering people to reduce their vulnerability to TB and to participate in directing the policies, programs and practices that affect them.

This section examines key human rights issues that impinge on the ability of individuals and communities to maintain health, to access relevant information and services, and to avoid discriminatory and harmful measures. It also identifies interventions that can assist stakeholders in developing inclusive, equitable and effective human rights-based approaches to TB.

How Do People Get TB?

TB is most often seen among individuals and communities who share specific biosocial risk factors for the disease, including poverty, malnutrition, crowding and HIV.⁶² These in turn are embedded in larger economic, social and political realities known as the structural determinants of health.⁶³ TB has no natural constituencies. Instead, it clusters wherever weak and inequitable social policies create vulnerability to the disease. TB risk increases with a lack of access to education, poor nutrition, inadequate housing and sanitation, poor health services and facilities, lack of employment and social security, and political exclusion.⁶⁴ According to Hargreaves et al.:

*Key structural determinants of TB epidemiology include global socioeconomic inequalities, high levels of population mobility, and rapid urbanization and population growth. These conditions give rise to unequal distributions of key social determinants of TB, including food insecurity and malnutrition, poor housing and environmental conditions, and financial, geographic, and cultural barriers to health care access. In turn, the population distribution of TB reflects the distribution of these social determinants, which influence the 4 stages of TB pathogenesis: exposure to infection, progression to disease, late or inappropriate diagnosis and treatment, and poor treatment adherence and success.*⁶⁵

59 WHO, *Tuberculosis*, Fact sheet no. 104 (2013). www.who.int/mediacentre/factsheets/fs104.

60 WHO, *Global Tuberculosis Control 2011* (2011). http://www.who.int/tb/publications/global_report/2010/en/.

61 Jurgens R et al., “People who use drugs, HIV, and human rights,” *Lancet* 376 (2010): 475-485.

62 WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf.

63 Lonnroth et al., “Tuberculosis: the role of risk factors and social determinants,” in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241.

64 Stop TB Partnership, Human Rights Task Force *Tuberculosis and Human Rights*, Working Document on TB and Human Rights (2011). www.stoptb.org/assets/documents/global/htrf/Briefing%20note%20on%20TB%20and%20Human%20Rights.pdf

65 Hargreaves et al., “The Social Determinants of Tuberculosis: From Evidence to Action,” *American Journal of Public Health* 101, no. 4 (2011): 654-662. www.ncbi.nlm.nih.gov/pmc/articles/PMC3052350/. (emphasis added)

For example, people in urban slum housing and people in prison may share vulnerabilities in terms of poor physical space, standard of living and access to health care. Similarly, women and migrant workers may share vulnerabilities in terms of decreased economic, social and legal agency. People who use drugs and people living with HIV may share vulnerabilities in terms of stigmatized and often criminalized medical status. And finally, refugees and homeless populations may share vulnerabilities in terms of mobility and exclusion from social services. These factors in turn determine access to timely and appropriate diagnosis, treatment and care, as well as impact TB-related outcomes. According to Lonnroth et al.:

*The risk of adverse health, social and financial consequences is determined by socioeconomic status, gender, social values and traditional beliefs in the community, the availability of social support services within the health care and social welfare systems, labour laws, and sick leave and pension systems.*⁶⁶

The following social and structural determinants play a significant role in fuelling different stages of TB and shaping the global epidemic.

Poor Physical Environment

Poor living and working conditions increase the risk of TB exposure and infection. Specific risk factors include more frequent contact with persons with active TB, as well as crowding and poor ventilation in homes, workplaces, health care settings, public transportation and prisons. Indeed prisons offer one of the most compelling examples of how substandard physical environments increase vulnerability to TB. Todrys and Amon describe the situation in many under-resourced prison cells in Africa:

*Overcrowding—resulting in and exacerbating food shortages, poor sanitation, and inadequate health care—contributes to the spread and development of disease. Minimal ventilation, poor isolation practices, and a significant immuno-compromised population also facilitate the transmission of TB and the development of TB disease.*⁶⁷

This dangerous environment helps explain why TB is the leading cause of death among the world's prisoners, who account for 8.5% of all TB cases.⁶⁸ While an estimated 9 million people are incarcerated on a given day, four to six times this number pass through the prison system each year due to high prisoner turnover. Prisons act as a conduit of TB transmission, spreading the disease among prisoners, prison staff, visitors and the greater community.⁶⁹ As a result, prisons can have TB levels up to 100 times higher than the non-prison population, and can account for up to a third of a country's total TB burden.⁷⁰ The high concentration of active cases in these settings also accelerates the development of drug resistance. In some prisons up to 24% of TB cases are MDR-TB.⁷¹

66 Lonnroth et al., "Tuberculosis: the role of risk factors and social determinants," in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241.

67 Todrys K and Amon J, "Criminal Justice Reform as HIV and TB Prevention in African Prisons," *PLoS Medicine* 9, no. 5 (2012). www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001215.

68 Gegia M et al., "Developing a Human Rights-Based Program for Tuberculosis Control in Georgian Prisons," *Health and Human Rights* 13, no. 2 (2011). www.hhrjournal.org/index.php/hhr/article/view/429/715.

69 Amon J, "The HIV and TB Prison Crisis in Southern Africa," *Huffington Post*, July 23, 2010. www.hrw.org/news/2010/07/23/hiv-and-tb-prison-crisis-south-ern-africa.

70 WHO, "Tuberculosis in Prisons." www.who.int/tb/challenges/prisons/en/index.html; Gegia M et al., "Developing a Human Rights-Based Program for Tuberculosis Control in Georgian Prisons," *Health and Human Rights* 13, no. 2 (2011). <http://www.hhrjournal.org/index.php/hhr/article/view/429/678>.

71 WHO, "Tuberculosis in Prisons." www.who.int/tb/challenges/prisons/en/index.html.

Similar mechanisms are at work in other crowded, poorly ventilated and underserved settings, such as in urban slum housing, barracks that house men who work in mines, and refugee and internally displaced persons (IDP) camps. For example, the Office of the UN High Commissioner for Refugees (UNHCR) reports that 85% of the world's 32 million refugees and displaced persons originate from, and remain in, countries with high burdens of TB. The poor living conditions in many refugee and IDP camps can facilitate TB development, making the disease an increasingly important cause of sickness and death among these populations.⁷²

Poor Health Status

Poor health increases the risk of TB infection, progression to active disease and poor clinical outcomes. Coexistent conditions such as HIV, malnutrition, alcoholism, smoking-related conditions, silicosis, diabetes and cancer further weaken the immune system.⁷³ The impact of poor health status can be seen at the population level. In a recent analysis of 22 countries with 80% of the world's TB burden, experts estimated that total new cases might be reduced by eliminating the following health risks: malnutrition (34% fewer cases); indoor air pollution (26.2%); active smoking (22.7%); HIV infection (17.6%); alcohol use (13.1%) and diabetes (6.6%).⁷⁴

The dynamic between TB and poor health is particularly lethal in institutional settings such as hospital wards and prison cells. For example, prisons often hold a high proportion of susceptible or immuno-compromised people, including drug-dependent individuals targeted by punitive drug laws.⁷⁵ This environment contributes to high risk of TB, HIV, hepatitis C and hepatitis B, endangering prisoners and the larger community. Risk factors include overcrowding, malnutrition, poor access to health care, sexual activity (including sexual violence), inability to access safe injecting equipment, and lack of access to drug treatment and opioid substitution therapy.

Even as overall TB prevalence is declining, it is rising in many parts of sub-Saharan Africa and the former Soviet Union due to the epidemic of HIV, TB and MDR-TB in prisons.⁷⁶ For example, Russia has the second largest prison population in the world after the United States, with 850,000 to one million prisoners.⁷⁷ Many are incarcerated for drug-related offenses. Overcrowding, poor nutrition and medical care, and inadequate infection control practices fuel TB in the country's many prisons and prison colonies. The Andrey Rylkov Foundation explains:

*Medical resources are limited and demands on the services are high. Although antiretroviral drugs are available, there is no HIV prevention and no formal drug treatment. When HIV treatment is available, the supply is inconsistent as is the treatment of TB and there are no second line drugs available to treat [MDR-TB].... Collaboration and integration with community health services is poor, and community hospitals are often unable to save the lives of patients who are released from prisons in poor health, only to die outside.*⁷⁸

72 UN Office of the UN High Commissioner for Refugees and the World Health Organization, *Tuberculosis Care and Control in Refugee and Displaced Populations: An interagency field manual* (2007). www.unhcr.org/4b4c986d9.html.

73 Lonnroth et al., "Tuberculosis: the role of risk factors and social determinants," in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241.

74 Ibid.

75 Basu S, Stuckler D, and McKee M, "Addressing Institutional Amplifiers in the Dynamics and Control of Tuberculosis Epidemics," *American Journal of Tropical Medicine and Hygiene* 84, no. 1 (2011): 30-37. www.ajtmh.org/content/84/1/30.full.pdf+html.

76 Jurgens R et al., "People who use drugs, HIV, and human rights," *Lancet* 376 (2010): 475-485.

77 Walmsley R, *World Prison Population List*, 8th ed, International Centre for Prison Studies. www.prisonstudies.org/info/downloads/wppl-8th_41.pdf.

78 Sarang A, "Russian prisons as a source of tuberculosis", BMJ Group Blogs, April 28, 2011. <http://blogs.bmj.com/bmj/2011/04/28/anya-sarang-russian-prisons-as-a-source-of-tuberculosis>. See also Sarang A and Rhodes T, "'The last way' clinic: why tuberculosis remains an incurable disease in Russia", BMJ Group Blogs, April 12, 2011. <http://blogs.bmj.com/bmj/2012/04/12/anya-sarang-and-tim-rhodes-the-last-way-clinic-why-tuberculosis-remains-an-incurable-disease-in-russia>.

People who work in prisons, hospitals and other health care settings can also face increased risk of TB. According to the WHO, health care workers have an ethical obligation to attend to TB patients, even if it involves some degree of risk. At the same time, they are entitled to adequate protection against contracting TB. Therefore, governments and health care systems have a duty to provide the necessary goods and services to ensure a safe working environment.⁷⁹ The WHO's 2010 *Guidance on ethics of tuberculosis prevention, care and control (TB and Ethics Guidance)* provides further information about health care workers' rights and obligations with respect to TB.⁸⁰

Beyond health care, TB is linked with other occupational exposures such as mining. Prolonged exposure to silica dust in mine shafts increases risk of lung diseases, particularly TB. According to the AIDS and Rights Alliance for Southern Africa, "[h]igh rates of HIV transmission and confined, humid, poorly ventilated working and living conditions further increase the risk of TB among mine workers."⁸¹ As miners cross borders in search of work, they spread and often bring it back to their home countries. A recent study of men with TB in Lesotho found that a quarter had worked in South African mines.⁸²

TB and HIV infection increase vulnerability to human rights violations. People with TB often face abuse, stigma, and discrimination—manifested in “social ostracism, loss of income or livelihoods, denial of medical services or poor care within the health sector, loss of marriage and childbearing options, violence and loss of hope/depression (internalized stigma).”⁸³ Experts note that in areas of high HIV prevalence, “TB is perceived as a marker for HIV positivity; therefore, HIV-associated stigma is transferred to TB-infected individuals.”⁸⁴ This phenomenon is confirmed by one Kenyan man, who noted: “I have been stigmatized by friends who thought I was HIV positive. Every time they saw me take the drugs they thought I was taking [antiretroviral medicines].”⁸⁵

TB thus contributes to ongoing cycles of poverty, vulnerability and poor health. Most costs related to TB arise prior to treatment: medical tests, drugs, consultation fees, transportation, and lost income. Additionally, TB diagnosis and treatment themselves can also be very expensive. Accessing care can cause people to incur debt or sell household assets,⁸⁶ leading to “catastrophic expenditures” which can impoverish entire families.⁸⁷ People with TB may lose income because they are sick or seeking care. They may lose their jobs entirely or be unable to find work due to the stigma associated with the disease. Finally, children whose caregiver loses income due to TB may be deprived of education, adequate nutrition and access to social services. For more information, see the section below on “Vulnerability among children”.⁸⁸

79 WHO, *Ethical Issues in Tuberculosis prevention, care and control* (2011). www.who.int/tb/publications/ethics_in_tb_factsheet_28jan11rev.pdf.

80 WHO, *Guidance on ethics of tuberculosis prevention, care and control* (2010). whqlibdoc.who.int/publications/2010/9789241500531_eng.pdf.

81 AIDS and Rights Alliance for Southern Africa, *The Mining Sector, Tuberculosis and Migrant Labour in Southern Africa: Policy and Programmatic Interventions for the Cross Border Control of Tuberculosis between Lesotho and South Africa, Focusing on Miners, Ex-Miners and Their Families* (July 2008). www.tac.org.za/community/files/Mines_TB_and_Southern_Africa.pdf.

82 Human Rights Watch, *No Healing Here: Violence, Discrimination and Barriers to Health for Migrants in South Africa* (Dec. 7, 2009). www.hrw.org/node/86959.

83 See Chapter 2.

84 Lonnroth et al., “Tuberculosis: the role of risk factors and social determinants,” in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241.

85 Howe E, “Timely Treatment for Drug-Resistant TB in Kenya”, Open Society Foundations, Voices, Mar. 2, 2012. <http://archive.blog.soros.org/2012/03/timely-treatment-for-drug-resistant-tb-in-kenya/>.

86 WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf.

87 Stop TB Partnership, “TB and Human Rights Task Force.” www.stoptb.org/global/hrtf/.

88 WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf.

Poor Access to Health Services and Systems

Poor access to health services creates gaps in TB diagnosis and treatment, contributing to higher levels of active TB cases, worse clinical outcomes and the development of drug resistance.⁸⁹ At an individual level, economic, social and legal factors often delay and impede contact with health care systems. Common barriers include a lack of money, difficulty arranging transportation to health facilities, lack of information about treatment options, fear of being stigmatized for seeking a diagnosis, and lack of social support in the event of sickness.⁹⁰ For many, maintaining employment may take precedence over maintaining health. The WHO states:

*Treatment for TB, particularly M/XDR-TB, is lengthy, complicated and expensive. Providing uninterrupted treatment and care remains a challenge for the health systems in many countries. People without access to a social safety net must often choose between following treatment to get well or working to support their families. Not completing treatment often means that people will fall ill again.*⁹¹

At a systemic level, vulnerable and at risk groups are also less likely to have access to functioning health care systems with appropriate treatment options, adequate patient referral chains, and strong mechanisms for coordinating care.⁹² This is often the case in urban slums and in prisons, particularly in parts of Africa, Asia and the former Soviet republics. For example, one study on Georgian prisons noted a lack of coordinated TB screening, delays in diagnosis and therapy, unmanageable case loads, substandard facilities, and poor follow-up of patients.⁹³ Another Russian study on drug dependent TB-HIV patients documented treatment gaps following release from prison or transfers among TB facilities.⁹⁴

Mobile and migrant populations are especially likely to experience fragmented or interrupted care, including total exclusion from social services. Affected groups include migrant workers, undocumented persons, the urban homeless, refugees and the internally displaced. According to Human Rights Watch:

*Normally, TB is easily and cheaply treated. However the prevalence of difficult to treat drug-resistant strains of TB, high incidence of co-infection with HIV, lack of cross-border mechanisms for referral and follow up care and surveillance, and the difficulty of treatment adherence while in transit, make mobile and migrant populations a serious health challenge.*⁹⁵

89 Lonnroth et al., "Tuberculosis: the role of risk factors and social determinants," in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241.

90 Hargreaves et al., "The Social Determinants of Tuberculosis." *American Journal of Public Health* 101, no. 4 (2011): 654-662. www.ncbi.nlm.nih.gov/pmc/articles/PMC3052350/.

91 WHO Regional Office for Europe, "Tackling tuberculosis means looking beyond the disease: experts meet to address its broader causes" (Jun. 29, 2012). <http://goo.gl/BooDy>.

92 Lonnroth et al., "Tuberculosis: the role of risk factors and social determinants," in Blas and Kurup, eds., *Equity, social determinants and public health programmes* (2011): 219-241. http://whqlibdoc.who.int/publications/2010/9789241563970_eng.pdf.

93 Gegia M et al., "Developing a Human Rights-Based Program for Tuberculosis Control in Georgian Prisons," *Health and Human Rights* 13, no. 2 (2011). www.hhrjournal.org/index.php/hhr/article/view/429/715.

94 Andrey Rylkov Foundation, *Delivery of Effective Tuberculosis Treatment to Drug Dependent HIV-positive Patients* (2010). <http://en.rylkov-fond.org/blog/tbr/effective-tb-treatment/>.

95 Human Rights Watch, *No Healing Here: Violence, Discrimination and Barriers to Health for Migrants in South Africa* (Dec. 7, 2009). www.hrw.org/node/86959.

Even where there is point-of-care diagnostics or treatment (i.e., provided where people live or work), problems may persist “when HIV and TB are not treated together aggressively or, cross-border referral and follow up is too slow or insufficient, drug sensitivity is not properly detected.”⁹⁶ Legal insecurity, language difficulties and cultural barriers can compound these access issues, especially for people who migrate in search of work. According to Naing et al.:

*Transnational migrant workers are commonly surrounded by difficult and exploitative circumstances, which may be a result of their terms of employment and often precarious legal status.... Migration itself also has a major impact on access to and utilization of health services by migrant and host populations. There are many barriers to access health services for migrants, such as the fact that migrants need documents to be able to get healthcare services without fear.*⁹⁷

In South Africa, for example, Human Rights Watch has documented cases in which migrants were denied emergency TB treatment because they lacked identity documents or were foreign. As a result, many were forced to visit multiple facilities or to go without treatment, resulting in “late diagnosis and treatment and poorer overall health in migrant communities”.⁹⁸

Unequal TB Treatment and Care

Effective TB diagnostics and therapies have been available for decades, yet many individuals continue to receive substandard care or none at all. This may be due to poverty or other marginalized status. For example, States have a duty to ensure that prisoners receive adequate health services, and that they are at least the same standard of care as those provided to the general population. The limited provision of TB services in prisons described above violates international human rights law.

Additionally, many people who use drugs face unduly restrictive conditions in accessing TB services. This is particularly problematic in Russia, where inpatient treatment is the norm and harm reduction services are denied. If patients leave TB clinics to obtain drugs, they are punished with discontinuation of TB treatment.⁹⁹ According to the Andrey Rylkov Foundation, the “[i]nability of the health system to offer adequate drug treatment creates an institutionalized ‘trap,’ when drug dependent patients are excluded from stable TB treatment de-facto.”¹⁰⁰

96 Human Rights Watch, *No Healing Here: Violence, Discrimination and Barriers to Health for Migrants in South Africa* (Dec. 7, 2009). www.hrw.org/node/86959.

97 Naing T et al., “Migrant workers’ occupation and healthcare-seeking preferences for TB-suspicious symptoms and other health problems: a survey among immigrant workers in Songkhla province, southern Thailand,” *BMC International Health and Human Rights* 12 (2012): 22. www.biomedcentral.com/1472-698X/12/22.

98 Human Rights Watch, *No Healing Here: Violence, Discrimination and Barriers to Health for Migrants in South Africa* (Dec. 7, 2009). www.hrw.org/node/86959.

99 Andrey Rylkov Foundation, Canadian HIV/AIDS Legal Network, and Eurasian Harm Reduction Network, “Atmospheric Pressure”: *Russian Drug Policy as a Driver for Violations of the UN Convention against Torture*, Shadow Report to the UN Committee against Torture in relation to the review of the Fifth Periodic Report of the Russian Federation (2011). <http://en.rylkov-fond.org/wp-content/uploads/2011/12/ARF-CAT-Russia-ENG-2-Nov.pdf>.

100 Sarang A et al., *Delivery of Effective Tuberculosis Treatment to Drug Dependent HIV-positive Patients*, Andrey Rylkov Foundation (2011). <http://en.rylkov-fond.org/wp-content/uploads/2011/07/delivery-of-tb-treatment.pdf>.

Treatment disparities are also linked to global funding and policy inadequacies in resource-constrained settings.¹⁰¹ Existing treatment standards sometimes fail to account for the flexibility required to effectively manage drug resistant TB. Global TB policy has emphasized inexpensive, standardized interventions to treat MDR-TB in low-income settings, despite the success of flexible, tailored protocols in high-income settings. As a result, less than 1% of people with newly diagnosed MDR-TB receive treatment that is considered the standard of care in the United States. Additionally, these divergent approaches to MDR-TB treatment have increased the intensity and scope of the epidemic.¹⁰²

The Green Light Committee Initiative (GLC) was established to address unequal access to MDR-TB treatment and care, including access to affordable second-line drugs and scale-up of MDR-TB services.¹⁰³ The Global Drug Facility, established in 2001, provides TB drugs to countries that could otherwise not afford them either in the form of grants or at the lowest possible price. At the end of 2011, 20 million treatment courses were delivered to 93 countries.¹⁰⁴

Yet due to a lack of market incentive, TB continues to receive little attention from companies that develop improved medicines. To address this neglect, The *Human Rights Guidelines for Pharmaceutical Companies in relation to Access to Medicines* were created to provide guidelines for pharmaceutical companies on issues including transparency, quality, clinical trials, neglected disease, patents, pricings, ethics, marketing and partnerships.¹⁰⁵ Guidelines 23-25 address the steps that pharmaceutical companies should take to address the neglect of poverty-related diseases. The right to the highest attainable standard of health requires that existing medicines are accessible as well as that much-needed new medicines are developed as soon as possible.¹⁰⁶

Vulnerability Among Women

TB afflicts women during their most economically active years and is among the top three causes of death among women aged 15 to 44 worldwide. In 2011, an estimated one third of the 8.7 million new TB cases were among women and 500,000 women died from TB.¹⁰⁷ TB is linked with poor reproductive health outcomes, such as risk of infertility, premature birth, obstetric morbidity, and low birth weight.¹⁰⁸ According to the WHO, vulnerability to TB is related to women's unequal social status and economic dependence:

*Women in many countries have to overcome several barriers before they can access health care. Where they undertake multiple roles in reproduction, production and child care, they may be left with less time to reach diagnostic and curative services than men.... Women may be given less priority for health needs and generally have less decision-making power over the use of household resources. They often have less knowledge of TB, especially of its signs and symptoms, than men, related to the higher rate of illiteracy among women than among men worldwide.*¹⁰⁹

101 Keshavjee S and Beauvais SG, "No One Should Die Of Tuberculosis In The 21st Century," *Huffington Post*, Mar. 24, 2012. www.huffingtonpost.com/sal-maan-keshavjee/world-tuberculosis-day_b_1375891.html.

102 Keshavjee S and Farmer P, "Tuberculosis, Drug Resistance, and the History of Modern Medicine," *New England Journal of Medicine* 367, no. 10 (2012): 931-936. www.nejm.org/doi/full/10.1056/NEJMr1205429.

103 WHO, *Summary of the New Global Framework to support MDR-TB management scale-up*. www.who.int/tb/challenges/mdr/greenlightcommittee/new-global-framework_summary.pdf.

104 Stop TB Partnership, "Global Drug Facility." www.stoptb.org/gdf/.

105 UN General Assembly, *Note by the Secretary-General on The Right to Health*, A/63/263 (Aug 11, 2008). www.who.int/medicines/areas/human_rights/A63_263.pdf.

106 Ibid.

107 WHO, *Global Tuberculosis Control 2011* (2011). http://www.who.int/tb/publications/global_report/2010/en/.

108 WHO, *Tuberculosis*, Fact sheet no. 104 (2013). http://www.who.int/tb/publications/global_report/2010/en/.

109 WHO, *Addressing Poverty in TB Control: Options for National TB Control Programmes* (2005). http://whqlibdoc.who.int/hq/2005/WHO_HTM_TB_2005.352.pdf.

Women often wait longer to seek diagnosis and treatment for TB. This in turn can “increase the severity of their illness, decrease the success of treatment, and raise the risks that they will infect others.”¹¹⁰ Where TB treatment is provided mostly via in-patients modes—the norm in many former Soviet countries—women may face particular difficulty adhering to treatment due to their child care responsibilities or inability to leave home for extended periods. While men and women may both face economic consequences related TB stigma, women can also face lost marriage prospects, divorce, desertion and separation from their children.¹¹¹

Gender-based inequality can also impair women’s ability to exercise and claim their human rights, including the rights to information, participation, freedom of movement, privacy and individual autonomy, and health.¹¹² According to the WHO:

*Gender discrimination, even when not directly related to health care—for example denying girls and women access to education, information, and various forms of economic, social and political participation—can create increased health risk. Even if the best public health services are available, a woman has to be able to decide when and how she is going to access them, and that implies that she has to have the ability to control and make decisions about her life.*¹¹³

Vulnerability Among Children

Children are vulnerable to TB for interrelated biological and social reasons. Each year there are approximately 500,000 new TB cases and up to 70,000 TB deaths among children. TB in children often goes undetected because their symptoms are overlooked, unrecognized as TB, or difficult to diagnose and confirm.¹¹⁴ Key risk factors for TB in children include contact with infected persons, HIV infection, age less than five years, and severe malnutrition.¹¹⁵ According to the WHO:

*Children are exposed to TB primarily through contact with infectious adults—with special risk in high TB-HIV settings—and will continue to be at risk for TB as long as those adults remain untreated. Curing TB and preventing its spread in the wider community is thus one important strategy to reducing children’s vulnerability to TB.*¹¹⁶

TB in children often rapidly and imperceptibly progresses from infection to disease.¹¹⁷ Infants and young children are at particular risk of TB meningitis, a severe and often fatal form of TB, and HIV-infected children have an especially high risk of developing TB meningitis. While the BCG (Bacille-Calmette-Gurin) vaccine can protect infants and children against certain severe forms of TB in children, it is no longer believed to be effective in protecting against pulmonary TB.¹¹⁸ This is particularly problematic for adolescents who are at risk of developing active pulmonary TB.¹¹⁹

¹¹⁰ TB Alert, “TB and Women: TB is the single biggest killer of young women.” www.tbalert.org/worldwide/TBAndwomen.php.

¹¹¹ Courtwright A and Turner AN, “Tuberculosis and Stigmatization: Pathways and Interventions,” *Public Health Reports* 125, Suppl 4 (2010):34-42; Somma D et al., “Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia,” *International Journal of Tuberculosis and Lung Disease* 17, no. 7 (2008): 856-866. www.who.int/tdr/publications/documents/tb-related-stigma.pdf.

¹¹² WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf.

¹¹³ Ibid.

¹¹⁴ WHO, “Childhood Tuberculosis.” www.who.int/tb/challenges/children/en/index.html.

¹¹⁵ WHO, *Guidance for national tuberculosis programmes on the management of tuberculosis in children* (2006). http://whqlibdoc.who.int/hq/2006/WHO_HTM_TB_2006.371_eng.pdf.

¹¹⁶ WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf.

¹¹⁷ Swaminathan S and Rekha B, “Pediatric Tuberculosis: Global Overview and Challenges”, *Clinical Infectious Diseases* 50, no. S3 (2010): 184–S194. http://cid.oxfordjournals.org/content/50/Supplement_3/S184.full.pdf+html.

¹¹⁸ WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf.

¹¹⁹ WHO, “Childhood Tuberculosis.” www.who.int/tb/challenges/children/en/index.html.

According to the WHO, “[c]hildren with TB are often poor and live in vulnerable communities where there may be a lack of access to health care.” Moreover, children who are sick with TB may be taken out of school, depriving them of their right to education. The WHO notes:

*Already marginal households that lose income or incur debt due to TB will experience even greater poverty as budgets are cut and assets sold. If their primary care giver is ill or is preoccupied with caring for other ill family members, the child’s care and education may be neglected. If the principal family provider is ill and cannot work, children risk malnutrition, which increases susceptibility to TB and brings with it lifelong deleterious effects on both health and education.*¹²⁰

These risk factors are heightened for orphaned children, street children and other vulnerable categories of youth, who are more likely to experience housing insecurity, poor nutrition, lack of access to care, and lack of access to education and information.¹²¹ It is estimated that there are over 10 million children orphaned as the result of a parent dying from TB.¹²²

What Happens to People Affected by TB?

Current responses to TB often fail to respect the human rights of people who are vulnerable, at risk or affected by the disease. Under international human rights law, States must respect, protect, and fulfill the human rights of all people, including those with TB. The duty to *respect* means that States must refrain from interfering with the enjoyment of rights. The duty to *protect* means that States must prevent other actors from infringing on these rights. Finally, the duty to *fulfill* means that States must adopt all appropriate legislative, administrative, budgetary, judicial, and other measures toward the full realization of these rights.¹²³

To fulfill the right to health, States must take immediate and targeted steps to ensure that health services, goods and facilities are available, accessible, acceptable and of quality. As the Global Fund notes, “[t]he right to non-discrimination, including on the grounds of social and health status, is an immediately enforceable obligation”.¹²⁴ Additionally, every TB patient is entitled to benefit from advanced and high-quality treatments, medicines, and diagnosis methods on an equitable and affordable basis, consistent with the right to benefit from scientific progress and its applications.¹²⁵ States therefore have a core obligation to ensure access to high quality TB treatment, care and support, and to reduce vulnerability by guaranteeing the underlying determinants of health.

¹²⁰ WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf.

¹²¹ Stop TB Partnership, “TB and Human Rights Task Force.” www.stoptb.org/global/hrtf/.

¹²² WHO, *Global Tuberculosis Control 2011* (2011). http://www.who.int/tb/publications/global_report/2010/en/.

¹²³ WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf.

¹²⁴ Stop TB Partnership, “TB and Human Rights Task Force.” www.stoptb.org/global/hrtf/.

¹²⁵ UN General Assembly, *Report of the Special Rapporteur in the field of cultural rights: the right to enjoy the benefits of scientific progress and its applications*, A/HRC/20/26 (2012).

Nevertheless, widespread concern over TB, MDR-TB, and XDR-TB has many led governments to “routinely cite TB as an example of when it may be justified to limit patients’ rights to protect the health and safety of the public.”¹²⁶ International law provides qualified support. Derogation clauses in the two key international human rights treaties—the International Covenant on Civil and Political Rights (ICCPR)¹²⁷ and the International Covenant on Economic, Social and Cultural Rights (ICESCR)¹²⁸—permit restrictions on individual rights in limited circumstances, provided that they are in accordance with the law, strictly necessary to achieve a legitimate objective, and consistent with other human rights provided for.

Accordingly, many governments have enacted rights-limiting measures in the name of TB control, such as detention of infected persons in prisons, forcible admissions into hospitals, home arrests, and travel restrictions. Yet the extent to which public health concerns may constrain individual human rights is closely circumscribed by the Siracusa Principles, a non-binding document adopted by the UN Economic and Social Council in 1984.¹²⁹ These principles state that restrictions on human rights must be:

- provided for and carried out in accordance with the law;
- directed toward a legitimate objective of general interest;
- strictly necessary in a democratic society to achieve the objective;
- the least intrusive and restrictive available to reach the objective;
- based on scientific evidence and neither arbitrary nor discriminatory in application; and
- of limited duration, respectful of human dignity, and subject to review.¹³⁰

In practice, the Siracusa Principles do not provide governments with adequate guidance for developing measures that protect public health while respecting human rights.¹³¹ Public health authorities are able to exploit ambiguous provisions in the law to oversee and compel treatment, frequently in correctional facilities. This can result in rights restrictions beyond those explicitly called for.¹³² According to Amon et al.:

[It is argued] that involuntary detention may legitimately be used in a limited number of cases when patients infected with drug-resistant strains of TB refuse treatment.... In practice, however, some countries have invoked sweeping rights-limiting policies that affect TB patients who have not been offered the global standard of care.... Reliance on compulsory detention, when less intrusive and less restrictive measures have proven feasible and effective, is not consistent with human rights principles.¹³³

The authoritative interpretations of the Human Rights Committee, which oversees state implementation of the ICCPR, provides further guidance on when human rights can be restricted in the name of public health. According to Todrys et al., the 1999 General Comment on freedom of movement “stresses the

¹²⁶ Howe E, “Is TB a Human Rights Issue?”, Open Society Foundations, Voices, Oct. 4, 2010. www.soros.org/voices/tb-human-rights-issue.

¹²⁷ International Covenant on Civil and Political Rights, arts. 4, 12.

¹²⁸ International Covenant on Economic, Social and Cultural Rights, art. 5.

¹²⁹ Todrys KE, Howe E, Amon JJ, “Failing Siracusa: governments’ obligations to find the least restrictive options for tuberculosis control”, *Public Health Action* 3, no. 1 (2013): 7-10 [“Failing Siracusa”]. <http://dx.doi.org/10.5588/pha.12.0094>.

¹³⁰ UN Economic and Social Council, *Siracusa principles on the limitation and derogation provisions in the International Covenant on Civil and Political Rights*, E/CN.4/1985/4 (1985). www.umn.edu/humanrts/instree/siracusaprinciples.html. See also WHO, *WHO Guidance on human rights and involuntary detention for xdr-tb control* (2007). www.who.int/tb/features_archive/involuntary_treatment/en/index.html.

¹³¹ Howe E, “Is TB a Human Rights Issue?”, Open Society Foundations, Voices, Oct. 4, 2010. www.soros.org/voices/tb-human-rights-issue.

¹³² Todrys KE et al., “Failing Siracusa: governments’ obligations to find the least restrictive options for tuberculosis control”, *Public Health Action* 3, no. 1 (2013): 7-10 [“Failing Siracusa”]. <http://dx.doi.org/10.5588/pha.12.0094>.

¹³³ Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.”, *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. www.hhrjournal.org/blog/perspectives/limitations-tb/.

need for restrictions to be provided for by law, demonstrably necessary, consistent with other rights in the ICCPR, and non-discriminatory. In particular, the Committee dwells on the requirement of necessity for a proposed restriction”.¹³⁴

Incarceration and other coercive TB measures unjustifiably interfere with patients’ human rights and dignity.¹³⁵ They also neglect more effective, rights-respecting alternatives—such as the provision of community-based DOTS, adherence support (e.g., counseling or nutritional supplements to reduce the side effects of medicine), and in-patient or out-patient treatment options.¹³⁶ These ambulatory and community-based models of care¹³⁷ have been shown to be highly successful, especially in resource-constrained settings.¹³⁸ Moreover, there is strong evidence that rights-limiting measures increase vulnerability to TB by subjecting individuals to conditions that favor TB infection, transmission, illness and death.¹³⁹ They are generally considered by human rights experts to be “unnecessary from a scientific standpoint and dangerous from a programmatic perspective”.¹⁴⁰

As an important caveat, the implementation and enforcement of rights-restricting measures related to TB varies widely at the local level. However, as Todrys et al. note, “government authorities and local laws sometimes do not fully meet, or entirely disregard, the requirements in the Siracusa Principles that restrictions on right in the name of public health be strictly necessary and the least intrusive available to reach their objective”.¹⁴¹ The following sections describe different laws, policies and practices which undermine the health and other human rights of people affected by TB.

Criminalization of TB Status

Criminalization of TB patients who do not complete treatment is not an effective strategy for TB control and treatment and violates basic human rights.¹⁴² Failure to complete treatment can lead to imprisonment in certain countries. Criminalization however discourages individuals with TB symptoms from seeking diagnosis and treatment for fear of imprisonment and can thereby delay diagnosis and increase the risk of transmission.¹⁴³

*People are more likely to use HIV and TB services if they are confident that they will not face discrimination, their confidentiality will be respected, they will have access to appropriate information and counseling, and they will not be coerced into accepting services.*¹⁴⁴

¹³⁴ Howe E, “Is TB a Human Rights Issue?”, Open Society Foundations, Voices, Oct. 4, 2010. www.soros.org/voices/tb-human-rights-issue.

¹³⁵ See Todrys KE et al., “Failing Siracusa: governments’ obligations to find the least restrictive options for tuberculosis control”, *Public Health Action* 3, no. 1 (2013): 7-10 [“Failing Siracusa”]. <http://dx.doi.org/10.5588/pha.12.0094>.

¹³⁶ Ibid.

¹³⁷ Ambulatory care is care delivered in clinical settings on an outpatient basis. Community-based care is care delivered primarily at patients’ homes by trained community health workers. For more information, please see the Glossary at the end of this chapter.

¹³⁸ Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.,” *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. www.hhrjournal.org/blog/perspectives/limitations-tb/.

¹³⁹ Ibid.

¹⁴⁰ Ibid.

¹⁴¹ See “Failing Siracusa: governments’ obligations to find the least restrictive options for tuberculosis control”, *Public Health Action* 3, no. 1 (2013): 7-10 [“Failing Siracusa”]. <http://dx.doi.org/10.5588/pha.12.0094>.

¹⁴² Howe E, “Is TB a Human Rights Issue?”, Open Society Foundations, Voices, Oct. 4, 2010. www.soros.org/voices/tb-human-rights-issue.

¹⁴³ Francis LP and Francis JG, “Criminalizing Health-Related Behaviors Dangerous to Others? Disease Transmission, Transmission-Facilitation, and the Importance of Trust,” *Criminal Law and Philosophy* 6 (2012): 47–63.

¹⁴⁴ Open Society Foundations, Ford Foundation and UNDP, *Factsheet on Human Rights, HIV, TB and Malaria* (2011). www.undp.org/content/undp/en/home/librarypage/hiv-aids/factsheet_human_rightshivtbbandmalaria.html.

Criminalization and imprisonment of TB patients increases discrimination and stigmatization and intensifies the wrong done to people who are already ill. Many individuals with TB do not complete treatment due to a lack of understanding of or education about treatment methods, lack of access to drugs, and negative side effects from treatment.¹⁴⁵

TB legislation is often focused on punishing patients who “default” from treatment rather than access to quality and affordable medicines. In some countries, patients can be imprisoned for months without proper information, legal representation, or an opportunity to defend their actions. For example, in Kenya, a patient that was placed in jail stopped taking his medicine because he had severe negative side effects that were exacerbated by hunger caused by drought. Another patient was never told how long to stay on treatment, stopped taking his medication once he felt better, and was placed in jail as a result. Kenya’s criminalization and imprisonment mechanisms are contrary to the internationally recommended standards.¹⁴⁶ TB patients are placed in prisons with criminal offenders, often in cramped living environments and without proper nutrition. While in jail, they can easily infect other prisoners or be re-infected. There are little to no mechanisms in place to ensure that other prisoners do not contract TB from the infected individuals, re-infect individuals once they are well, or spread the disease back to their homes and communities when they are released.¹⁴⁷

Involuntary Treatment

The issue of involuntary treatment centers on the question: when, if ever, is it justified to compel treatment of TB patients over their objection? As a preliminary matter, the Siracusa Principles state that with respect to rights-restricting measures invoked on the grounds of public health, “[d]ue regard shall be had to the international health regulations of the World Health Organization.”¹⁴⁸ The WHO affirms that it is unethical to force TB patients to undergo treatment if they have objected to it; moreover, it is also unlikely to achieve its intended public health purpose. The WHO’s TB and Ethics Guidance states in relevant part:

*In general, TB treatment should be provided on a voluntary basis, with the patient’s informed consent and cooperation... [E]ngaging the patient in decisions about treatment shows respect, promotes autonomy, and improves the likelihood of adherence. Indeed, non-adherence is often the direct result of failure to engage the patient fully in the treatment process.*¹⁴⁹

Contagious TB patients who refuse treatment and/or infection control measures can be isolated to prevent the spread of disease. Within isolation, if patients provide an informed refusal of treatment, their decision should be respected. The WHO states:

*Forcing these patients to undergo treatment over their objection would require a repeated invasion of bodily integrity, and could put health-care providers at risk. Moreover, as a practical matter, it would be impossible to provide effective treatment without the patient’s cooperation.*¹⁵⁰

¹⁴⁵ KELIN Kenya, “Press Release: Should we treat TB Patients like Criminals?” (Aug. 17, 2011). <http://kelinkenya.org/tag/imprisonment-of-tb-patients/>

¹⁴⁶ Ibid.

¹⁴⁷ Ibid.

¹⁴⁸ UN Economic and Social Council, *Siracusa principles on the limitation and derogation provisions in the International Covenant on Civil and Political Rights*, E/CN.4/1985/4 (1985). www1.umn.edu/humanrts/instree/siracusaprinciples.html.

¹⁴⁹ WHO, *Guidance on ethics of tuberculosis prevention, care and control* (2010). http://www.who.int/tb/features_archive/ethics/en/.

¹⁵⁰ Ibid.

Involuntary Isolation¹⁵¹

The WHO's *TB and Ethics Guidance* states that compelled isolation (and detention) is to be viewed as a last resort measure, and limited to three “exceptional circumstances” when an individual is:

- “known to be contagious, refuses treatment, and all reasonable measures to ensure adherence have been attempted and proven unsuccessful”;
- “known to be contagious, has agreed to ambulatory treatment, but lacks the capacity to institute infection control in the home”; or
- “highly likely to be contagious (based on symptoms and evidence of epidemiological risk factors) but refuses to undergo assessment of his/her infectious status”.¹⁵²
- The given justification is that TB patients who do not voluntarily undergo diagnosis, or who fail to adhere to treatment or infection control measures, pose serious risks to public health. The WHO further states that in rare cases where compulsory isolation is justified, measures must comply with the procedural limitations set forth in the Siracusa Principles.¹⁵³

Nevertheless, compulsory isolation often violates these guidelines. First, it cannot be considered an effective “last resort”, as it comes at the expense of less-restrictive measures. Community-based treatment models have proven effective to ensure patients complete treatment, while also preventing the spread of TB, when compared to more traditional hospital-based care.¹⁵⁴ This has been demonstrated in South Africa,¹⁵⁵ which has the second highest incidence of TB cases in the world, the highest rate of MDR-TB in Africa, and the fourth highest prevalence of HIV/AIDS.¹⁵⁶ Additionally, more attention is needed to support access and adherence to treatment in the first place. For example, the severe side effects of MDR-TB drugs can pose problems: “Many adults default with their treatment, after which the TB germ develops resistance to the routine antibiotics with which we treat the condition. They then infect their children with MDR (TB).”¹⁵⁷

Second, compulsory isolation measures are often ineffective in containing TB. South Africa requires the isolation of MDR-TB and XDR-TB patients in specialist provincial hospitals for a minimum of six months. In some cases patients are held as long as two years; in others they are released after just six months. Many TB patients are isolated in sub-standard conditions that violate their basic constitutional rights as well as South African health legislation.¹⁵⁸ According to Amon et al., because no assessment of infectiousness is ever made, these patients lack access to the drugs they need, “resulting in almost universal mortality.”¹⁵⁹ In addition, given the size of the epidemic, hospital space and cost constraints make a blanket policy of isolation impractical.¹⁶⁰

The Open Society Foundations notes that Kenya is also investing limited anti-TB resources in building expensive isolation facilities. Despite the WHO's guidance that “reasonable social supports” be provided to isolated patients and their families, in practice this may not take place. In Kenya, South Africa and else-

¹⁵¹ Involuntary measures are those undertaken against the individual's will. Compulsory measures are also undertaken against the individual's will and may also be required by law.

¹⁵² WHO, *Guidance on ethics of tuberculosis prevention, care and control* (2010). http://www.who.int/tb/features_archive/ethics/en/.

¹⁵³ Boggio A et al., “Limitations on human rights: Are they justifiable to reduce the burden of TB in the era of MDR- and XDR-TB?” *Health and Human Rights* 10, no. 2 (2008). www.hhrjournal.org/index.php/hhr/article/view/85/169.

¹⁵⁴ Howe E, “Is TB a Human Rights Issue?”, Open Society Foundations, Voices, Oct. 4, 2010. www.soros.org/voices/tb-human-rights-issue.

¹⁵⁵ Heller T et al., “Community-based treatment for multidrug-resistant tuberculosis in rural KwaZulu-Natal, South Africa,” *International Journal of Tuberculosis and Lung Disease* 14, no. 4 (2010): 420-26. www.ncbi.nlm.nih.gov/pubmed/20202299.

¹⁵⁶ Center for Disease Control and Prevention, “Tuberculosis: DTBE in South Africa.” www.cdc.gov/tb/topic/globaltb/SouthAfrica.htm.

¹⁵⁷ Taylor D, “Children Bear Brunt of South Africa's Tuberculosis Epidemic”, *VOA News* (Jul. 19, 2012). www.voanews.com/content/children-bear-brunt-of-tuberculosis-epidemic/1213097.html.

¹⁵⁸ AIDS Law Project, *Protecting Public Health and Human Rights in the Response to TB in South Africa: State and Individual Responsibilities* (2009).

¹⁵⁹ Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.,” *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. www.hhrjournal.org/blog/perspectives/limitations-tb/.

¹⁶⁰ AIDS Law Project, *Protecting Public Health and Human Rights in the Response to TB in South Africa: State and Individual Responsibilities* (2009).

where, TB patients who are isolated may be required to leave their jobs and their families, depriving their dependents of support and increasing their vulnerability to TB. In many cases, compulsory isolation simply “fails to protect the rights of individuals, fuels stigma and discrimination, potentially worsens health status, and is deemed unnecessary from a public health standpoint.”¹⁶¹

Involuntary Detention

According to the WHO TB and Ethics Guidance, the three “exceptional circumstances” described above—which determine whether involuntary isolation is ever justified—apply equally to involuntary detention. Similarly, the five Siracusa criteria set forth the applicable safeguards for implementing involuntary detention. The justification often given is that involuntary detention is justified to protect “both the human right to health and health as a public goods,” particularly in the face of high TB, MDR-TB and XDR-TB rates.¹⁶² Involuntary detention, however, has not been proven to be an effective TB treatment and prevention mechanism. It can deter sick individuals from seeking diagnosis. Additionally, it does not prevent the spread of disease: because of the delay between diagnosis and admission to a facility, widespread infection may have already occurred. Poor hygiene and living standards at confinement facilities themselves can further spread infection to healthcare workers and visitors, which in turn can spread the infection to families and communities.¹⁶³ Lastly, drug-resistant TB has shown to be no more infectious than drug-susceptible TB, so more extreme measures are not justified for drug-resistant, including XDR-TB, patients.

The 2007 WHO Guidance on human rights and involuntary detention for xdr-tb control states that governments should make prevention and access to accurate diagnosis and high-quality treatment high priorities. Involuntary treatment or compulsory detention may be used to prevent or treat XDR-TB cases only as a last resort, only when all voluntary measures have failed or have been insufficient, and only when all criteria of the Siracusa Principles have been met.¹⁶⁴ However, involuntary detention often does not comply with applicable human rights principles in practice. According to Sacco et al.:

*... [P]ersons with TB are detained even when they are capable of adhering to infection control regimens and to treatment.... Treatment in the community has been shown to be a more effective and less rights-violating alternative to detention of people with TB, who in any case have an absolute right to freedom from ill-treatment in confinement and to due process to challenge their confinement.*¹⁶⁵

Additionally, while involuntary confinement in theory should only limit one right—a patient’s freedom of movement—it has the potential to and often does limit many other rights, including a patient’s right to dignity if the health facility conditions are substandard, right to work if they lose their job while involuntary confined, right to raise a family if they are forcibly separated from young children and have no alternative caregiver, and right to housing if they lose their homes as a result of confinement.

South Africa demonstrates an evolving approach to detention as a means of addressing TB. Until recently, TB patients who entered the public health system faced the risk of incarceration, whereas those who could afford private sector healthcare could be treated at home. As an outgrowth of HIV advocacy, and due in

¹⁶¹ Open Society Foundations, Ford Foundation and UNDP, *Factsheet on Human Rights, HIV, TB and Malaria* (2011). www.undp.org/content/undp/en/home/librarypage/hiv-aids/factsheet_human_rightshivtbandmalaria.html.

¹⁶² Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.,” *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. www.hhrjournal.org/blog/perspectives/limitations-tb/.

¹⁶³ Ibid.

¹⁶⁴ WHO, *Guidance on human rights and involuntary detention for xdr-tb control* (2007). www.who.int/tb/features_archive/involuntary_treatment/en/index.html.

¹⁶⁵ Sacco S, Maleche A, and Ombati O, “Forcible Isolation of Tuberculosis Patients in Kenyan Jails,” *INTERIGHTS Bulletin* 16, no. 4 (2011): 195-200. www.interights.org/document/198/index.html

part to the high co-infection of HIV and TB in South Africa, South Africa's National Strategic Plan (NSP) now includes TB in its goals and strategic objectives.¹⁶⁶ It recognizes human rights violations against TB patients and outlines strong commitments to protect their rights and to move towards community-based care.¹⁶⁷ Specifically, it calls for the development and implementation of “a national policy that permits the detention of patients with drug-resistant TB only when necessary and under conditions consistent with international good practice.”¹⁶⁸

Given evidence of the effectiveness and scalability of community-based delivery models in resource-constrained settings, involuntary detention could rarely be considered the least restrictive means available—particularly if less restrictive means have not been applied. Moreover, involuntary detention is often applied in an arbitrary and discriminatory manner based on the ability to pay for health care. According to Amon et al., “[t]he ability to pay for health care is not a rational basis for deciding who should be deprived of liberty and who should not.”¹⁶⁹

Failure to Address Stigmatization and Discrimination

People with TB often face profound stigma and discrimination.¹⁷⁰ They can face social rejection by family, friends and community members, expulsion from school, reduced income and loss of employment.¹⁷¹ A recent analysis of TB stigma literature notes:

*TB stigma has a more significant impact on women and poor or less-educated community members, which is especially concerning given that these groups are often at higher risk for health disparities. TB stigma may, therefore, worsen preexisting gender- and class-based health disparities.*¹⁷²

The WHO notes that patients may go to great lengths to escape stigma and isolation, “lengths that may prolong both their own suffering and the length of time they remain infectious.”¹⁷³ Infected individuals may hide their TB status from their families; at the same time, families may conceal TB-related death causes from the larger community.¹⁷⁴ TB stigma has been identified as a barrier to timely TB screening, diagnosis, care-seeking and adherence to and completion of treatment:

*Individuals with TB-like symptoms may first attempt to see private physicians so as to avoid TB stigma. Because private clinics typically have longer waits for appointments, this may translate to diagnostic delay and increased financial costs for patients.*¹⁷⁵

Once treatment has begun, TB patients may fear being identified and drop out of treatment programs. TB related stigma and discrimination make people more afraid to learn their status, disclose their status

¹⁶⁶ UNAIDS, *UNAIDS guidance for partnerships with civil society, including people living with HIV and key population*, UNAIDS Guidance Note (2011): 8. www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/JC2236_guidance_partnership_civilsociety_en.pdf; UNAIDS, *South Africa launches its new National Strategic Plan on HIV, STIs and TB, 2012–2016* (Dec 20, 2011). www.unaids.org/en/resources/presscentre/featurestories/2011/december/20111220sansp/.

¹⁶⁷ South African Department of Health, *National Strategic Plan on HIV, STIs, and TB 2012–2016* (SANAC, 2011): 14. www.doh.gov.za/docs/stratdocs/2012/NSPfull.pdf

¹⁶⁸ Ibid.

¹⁶⁹ Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.,” *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. www.hhrjournal.org/blog/perspectives/limitations-tb/.

¹⁷⁰ TARGETS TB, “Launch of the TB Anti-Stigma Toolkit.” http://targets.lshtm.ac.uk/tb_news.php.

¹⁷¹ WHO, *Guidelines for social mobilization: A human rights approach to TB* (2001). www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf.

¹⁷² Courtwright A and Turner AN, “Tuberculosis and Stigmatization: Pathways and Interventions,” *Public Health Reports* 125, Suppl 4 (2010):34-42

¹⁷³ Stop TB Partnership, “TB and Human Rights Task Force.” www.stoptb.org/global/hrtf/.

¹⁷⁴ Courtwright A and Turner AN, “Tuberculosis and Stigmatization: Pathways and Interventions,” *Public Health Reports* 125, Suppl 4 (2010):34-42

¹⁷⁵ Ibid.

to others, to seek care and to adhere to treatment. This increases their vulnerability, suffering and loss of other human rights. People with TB are also more likely to suffer from discriminatory measures that perpetuate stigma and exclusion. For example, in one district in Ghana, people with TB are prohibited from selling goods in public markets or attending community events. While the right to nondiscrimination is an immediately enforceable obligation under international human rights law, in practice there are few domestic laws prohibiting discrimination on the basis of TB or suspected TB status.

Societal, institutional and legal stigmatization of TB violates the human rights of individuals with TB while also impeding larger efforts at prevention and control.¹⁷⁶ The Committee on Economic, Social and Cultural Rights notes that “[n]on-discrimination and equality are fundamental components of international human rights law” and essential to the exercise of the right to health.¹⁷⁷ State parties to the ICESCR are therefore obligated to take all appropriate measures to eliminate discrimination against people on the basis of TB status. Direct measures include reform of laws and policies that discriminate against people on the basis of TB status. An example might include legislation requiring people showing active TB symptoms to enter hospitals, where they risk exposing others and being exposed to drug resistant forms of the disease.¹⁷⁸ Indirect measures focus on the conditions and attitudes contributing to discrimination, including by private individuals and entities. Education and information play an important role: this approach has been well-documented to reduce the stigma attached to HIV and to mobilize government and community resources in efforts to combat the disease.¹⁷⁹

What are current interventions and practices in the area of TB?

The interventions, practices, programs and policies outlined below all strive to end the HIV epidemic and support people living with TB to live lives with dignity. Some of the interventions and practices focus on the biomedical response to TB including recommended treatments, whereas others and policies focus on vulnerable groups and human rights issue areas.

Universal Access to Treatment as Prevention

Quality Assured Diagnostics

A sputum smear microscopy test is the most widely used method to detect TB. However, this test has low sensitivity, especially in HIV-positive individuals and children, and is unable to determine drug-resistance. TB can also be diagnosed with culture methods or rapid molecular tests in countries with more developed laboratory capacity.¹⁸⁰ A new rapid, fully automated test called the Xpert MTB/RIF test provides a highly accurate diagnosis that identifies the presence of TB and drug-resistant TB. The new test is not as susceptible to human error and allows people to be offered proper treatment immediately.¹⁸¹

Drug Susceptibility Testing

Drug resistant TB diagnosis depends on the slow process of bacterial culture and drug susceptibility testing. Drug resistant TB patients may be inappropriately treated during this slow diagnostic process, and

¹⁷⁶ Ibid.

¹⁷⁷ UN Committee on Economic, Social and Cultural Rights, *General Comment No. 20: Non-Discrimination in Economic, Social and Cultural Rights*, E/C.12/GC/20, Art. 2, para. 2 (July 2, 2009). www2.ohchr.org/english/bodies/cescr/comments.htm.

¹⁷⁸ Amon J, Girard F, and Keshavjee S, “Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.,” *Health and Human Rights* (Oct. 7, 2009) [“A reply to Boggio et al.”]. www.hhrjournal.org/blog/perspectives/limitations-tb/.

¹⁷⁹ Open Society Foundations, Ford Foundation and UNDP, *Factsheet on Human Rights, HIV, TB and Malaria* (2011). www.undp.org/content/undp/en/home/librarypage/hiv-aids/factsheet_human_rightshivtbbandmalaria.html. See also Chapter 2.

¹⁸⁰ WHO, *Tuberculosis*, Fact sheet no. 104 (2013). http://www.who.int/tb/publications/global_report/2010/en/.

¹⁸¹ WHO, *Tuberculosis: Diagnostics: Xpert MTB/RIF Test*, Fact Sheet (May 2011). www.who.int/tb/features_archive/factsheet_xpert_may2011update.pdf.

drug-resistant strains and resistance may continue to spread during this time.¹⁸² Lack of diagnostic capacity is a critical barrier to effect TB treatment.¹⁸³

TB Prevention or Prophylaxis

People with latent TB should benefit from interventions to prevent progression to active disease, including isoniazid preventive therapy.¹⁸⁴ This is true even for patients who live in resource-constrained settings.

Adherence Support

Adherence support refers to medical, social and economic initiatives to help patients follow and benefit from TB treatment and care. According to Partners In Health, it “specifically targets TB patients who face barriers to accessing care: the elderly, pregnant women, geographically isolated patients, and patients who suffer from socio-economic problems such as poverty and alcoholism”.¹⁸⁵ Examples include providing travel vouchers or transportation to health care facilities, food packages, peer support, education and follow-up, and engaging community health workers to accompany patients as they access health care.¹⁸⁶ These initiatives help ensure continuity of care and increase patients’ chances for complete recovery.

HIV Screening and Treatment

As part of its policy guidelines on collaborative TB-HIV activities, the WHO recommends offering routine HIV testing to patients with presumptive or diagnosed TB, as well as to their partners and family members.¹⁸⁷ As the Global Fund notes:

*Early diagnosis among people living with HIV is challenging but vital. Prevention, diagnosis and treatment of TB should be integrated or coordinated to meet the needs of patients with HIV, Hepatitis C, diabetes, those on opiate substitution therapy and other common co-morbidities. Integrating and coordinating services facilitates adherence and ensures patients are not forced to choose between needed therapies.*¹⁸⁸

Examples of a collaborative approach include HIV counseling and testing, the use of antiretroviral therapy in TB-HIV patients and isoniazid preventative therapy to reduce TB risk among HIV patients. These measures require strong links with the HIV community.

Harm Reduction Measures

Ensuring access to harm reduction measures is an effective approach to reducing vulnerability to TB, particularly among people who use drugs and prisoners. “Harm reduction” refers to policies, programs, and practices aimed at reducing drug-related risks and harms, rather than on reducing and punishing drug use.¹⁸⁹ Examples include needle and syringe programs, safe injection facilities, opioid substitution therapy, overdose prevention, outreach and education and decriminalization of people who use drugs. Harm reduction strategies form a part of States’ human rights obligations.¹⁹⁰ They are recommended by the

¹⁸² Ibid.

¹⁸³ WHO, “TB diagnostics and laboratory strengthening,” www.who.int/tb/laboratory.

¹⁸⁴ WHO, *Global Tuberculosis Report 2012* (2012): 44. www.who.int/tb/publications/global_report.

¹⁸⁵ Partners In Health, “Pavlodar: Adopting the Accompaniment Model of TB Care” (Dec. 17, 2010). www.pih.org/news/entry/pavlodar-adopting-the-accompaniment-model-of-tb-care/; Partners In Health, “Accompaniment Model Informs Global Response to Shortage of Health Workers” (April 1, 2007). www.pih.org/blog/pih-model-for-accompaniment-informs-global-response-to-shortage-of-health-workers/.

¹⁸⁶ WHO, *Global Tuberculosis Control 2012* (2012): 44. www.who.int/tb/publications/global_report.

¹⁸⁷ WHO, *WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders* (2012). http://www.who.int/tb/publications/2012/tb_hiv_policy_9789241503006/en/.

¹⁸⁸ Global Fund to Fight AIDS, Tuberculosis and Malaria [Global Fund], *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

¹⁸⁹ Open Society Foundations, “Harm Reduction.” www.soros.org/topics/harm-reduction.

¹⁹⁰ UN General Assembly, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53 (Feb. 1, 2013). www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

WHO in its Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users.¹⁹¹ Specific recommendations include treatment adherence programs, continuity and communication across all health care access points, and provision of the same services to drug users as provided to the general civilian population.¹⁹² For more information on harm reduction and human rights, please see Chapter 4.

Palliative Care

Providing home-based palliative care for TB and related comorbidities is a necessary complement to effective, rights-respecting TB treatment and care.¹⁹³ Palliative care is “seeks to improve the quality of life of patients diagnosed with life-threatening illnesses through prevention and relief of suffering” and addresses the psychosocial, legal and spiritual aspects associated with life-threatening illnesses. Palliative care measures in the context of TB include pain control, relief of TB symptoms and drug side effects, nutritional support, ongoing psychosocial support and end-of-life care. Palliative care services can promote the health and improve the lives of people with TB by implementing effective infection-control in the home and in-patient settings, intensifying case finding and referral to treatment, providing effective treatment support, among other benefits.¹⁹⁴ For more information on palliative care and human rights, please see Chapter 5.

Models of Delivery

Point of Care Diagnostics and Treatment

There is an overemphasis on clinical interventions for Vulnerable and at risk groups, including harmful detention and in-patient hospitalization of patients with drug resistant TB. This is despite limited evidence of the effectiveness of this approach, and ample evidence of the effectiveness of ambulatory and community-based models of service delivery. More attention is needed to providing individuals with quality treatment and care where they live and where they work. Point-of-care diagnostics and treatment are needed to reach vulnerable populations where they work, such as mines and garment factories, and where they seek care, such as maternal-child health clinics and general practitioners’ offices.¹⁹⁵

Community-Based Care

The WHO recommends that “community-based care should always be considered before isolation or detention is contemplated. Countries and TB programmes should put in place services and support structures to ensure that community-based care is as widely available as possible.”¹⁹⁶ Community-based care can help reach vulnerable groups by reducing the costs associated economic and social costs associated with seeking continued access to care.¹⁹⁷ Sacco et al. note that community-based care is generally the appropriate method of treatment for all forms of TB.¹⁹⁸ For example, Lesotho has provided free, community-based treatment for TB since 1991. In 2007, PIH launched Lesotho’s first MDR-TB treatment program, using paid, trained community health workers to help deliver medication, support, counseling to families, and accompaniment to hospitals for very ill patients. This program is coupled with the training of “expert patients” to act as role models, the refurbishing the national TB laboratory, and the converting a former leprosy clinic into a new

¹⁹¹ WHO, *WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders* (2012). http://www.who.int/tb/publications/2012/tb_hiv_policy_9789241503006/en/.

¹⁹² WHO, *Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users: An Integrated Approach* (2008). http://whqlibdoc.who.int/publications/2008/9789241596930_eng.pdf

¹⁹³ WHO, *Global Tuberculosis Control 2012* (2012): 44. www.who.int/tb/publications/global_report.

¹⁹⁴ Hospice Palliative Care Association of South Africa, *Guidelines for Providing Palliative Care to Patients with Tuberculosis* (2011). www.hospicepalliativecaresa.co.za/pdf/patientcare/TB_Guidelines_2011.PDF.

¹⁹⁵ Keshavjee S, “Let’s Learn From HIV Activists How to Achieve Zero Tuberculosis Deaths”, *Huffington Post*, Jul. 25, 2012, www.huffingtonpost.com/sal-maan-keshavjee/tb-hiv-patients-awareness_b_1700450.html.

¹⁹⁶ Sacco S, Maleche A, and Ombati O, “Forcible Isolation of Tuberculosis Patients in Kenyan Jails,” *INTERIGHTS Bulletin* 16, no. 4 (2011): 195-200. www.interights.org/document/198/index.html.

¹⁹⁷ Global Fund, *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

¹⁹⁸ Sacco S, Maleche A, and Ombati O, “Forcible Isolation of Tuberculosis Patients in Kenyan Jails,” *INTERIGHTS Bulletin* 16, no. 4 (2011): 195-200. www.interights.org/document/198/index.html.

MDR-TB hospital.¹⁹⁹ The effectiveness of community-based models has also been demonstrated in Latvia, Estonia, Georgia, Peru, the Philippines, Nepal, and the Russian Federation.²⁰⁰

Health Literacy and Reduction of Stigma and Discrimination

Reducing the stigma and discrimination associated with TB are an essential component of reducing vulnerability to the disease. This has been widely documented as effective with respect to similarly stigmatized diseases which implicate people's human rights, including HIV. Examples of relevant efforts include education and outreach to improve health literacy about the disease and prevention and training health care workers and providers about "non-discrimination, informed consent, confidentiality and duty to treat".²⁰¹ Other measures include legal and policy reform to eliminate all forms of discrimination against people living with and affected by TB.

Empowering Patients and Communities

The empowerment of the most vulnerable groups is a priority, including women and children. This requires the participation, engagement and mobilization of the entire community. The Global Fund notes that "Patients and communities play an integral role in TB treatment literacy, social support, advocacy, communication and social mobilization. TB cannot be adequately addressed without meaningfully involving those most affected in the planning and implementation of policies and programs that impact them."²⁰²

Social Protection

Income-Generating Activities

Interventions that reduce poverty and malnutrition among vulnerability and marginalized populations can help to reduce their high TB burden. A number of social protection interventions have been shown to improve health, education and nutrition in different settings in Latin America and South Africa. Examples include direct transfers of food or money to vulnerable households and increased access to microfinancing opportunities. Sometimes these schemes have been conditioned on behavioral requirements related to improving the success of the intervention, or directly related to improving health, such as sending children to school, participating in health literacy trainings, or accessing health care. The benefits of such activities could include improving the socioeconomic circumstances of people affected by TB and reducing financial barriers to diagnosis, treatment and care.²⁰³

Urban Regeneration

Many of the factors which increase vulnerability to TB at both the individual and population level are associated with urbanization—substandard housing, overcrowding, economic and legal insecurity and inadequate health facilities. Urban regeneration and slum upgrading schemes could reduce vulnerability to TB by directly affecting the physical environments in which people experience disease as well as increasing living standards by ensuring access to health services, schools and employment.²⁰⁴

199 Partners In Health, "Pavlodar: Adopting the Accompaniment Model of TB Care" (2010). <http://www.pih.org/blog/pavlodar-adopting-the-accompaniment-model-of-tb-care>; Partners In Health, "Accompaniment Model Informs Global Response to Shortage of Health Workers" (2007). <http://www.pih.org/blog/pih-model-for-accompaniment-informs-global-response-to-shortage-of-health-workers>.

200 Amon J, Girard F, and Keshavjee S, "Limitations on human rights in the context of drug-resistant tuberculosis: A reply to Boggio et al.," *Health and Human Rights* (Oct. 7, 2009) ["A reply to Boggio et al."]. www.hhrjournal.org/blog/perspectives/limitations-tb/.

201 Global Fund, *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

202 Ibid.

203 Hargreaves et al., "The Social Determinants of Tuberculosis: From Evidence to Action," *American Journal of Public Health* 101, no. 4 (2011): 654–662. www.ncbi.nlm.nih.gov/pmc/articles/PMC3052350/.

204 Ibid.

Legal Assistance and Advocacy

Legal Assistance

Legal assistance can assist people affected by TB claim their economic, social, cultural, political and civil rights. Providing patients with representation can help them access care, combat discrimination and challenge measures which unjustifiably restrict their substantive and due process rights to liberty and freedom of movement. For example, recent litigation in South Africa's Constitutional Court has successfully held prison authorities accountable for failure to prevent and treat TB in prisons. This work was supported by Section 27, the former AIDS Law Project, and is a successful example of legal advocacy to promote and enforce the rights of TB patients under constitutional law and human rights principles. For more information, see below: "Example 5: Litigating for prisoners exposed to TB in South African prisons."²⁰⁵

Criminal Justice Reform

Reforming the criminal justice system can be a cost-effective method of reducing TB and HIV transmission, given its role in fueling the spread of TB. Poor resourcing and management of prisons, and poor judicial and correctional processing of individuals, contribute to overcrowding and substandard conditions. According to Todrys and Amon, examples of reform include reducing arbitrary pretrial detention, large-scale prisoner releases, reforming bail guidelines, expanding community service and parole programs, increasing judges, and improving access to legal representation.²⁰⁶ Moreover, the severity of law enforcement does not meaningfully reduce the prevalence of drug use and fuels the HIV and TB epidemics.²⁰⁷ Criminalization deters drug users from seeking prevention and care services and pushes them into environments where the risk of infectious disease transmission and other harms are increased.²⁰⁸ Drug policy that results in criminalization, arbitrary detention, and over-incarceration of drug users needs to be reoriented to consider its health and rights implications.

Health Systems Strengthening

Strengthening the facilities and systems in which people access health services is an essential component of the response to TB control. As the Global Fund notes, "Poor quality of care hampers global TB control efforts. Inadequate training and supervision of health workers, inconsistent drug supplies, inadequate diagnostic tests and limited resources inhibit early detection and appropriate treatment resulting in increased transmission and poor health outcomes. By tailoring services to meet the needs of patients and communities, a human rights focus will improve service delivery, ensure that resources used match community priorities and provide evidence that can be used to mobilize additional resources."²⁰⁹ Relevant aspects of the health care system to be strengthened include health policy and regulation, mobilization and allocation of financial and human resources, improved laboratory capacity for diagnosis and detection of drug sensitivity, management and delivery of health services, management of medicines and medical technology, and data and information management.²¹⁰

²⁰⁵ See *Lee v. Minister for Correctional Services, Constitutional Court of South Africa*, Case CCT 20/12 [2012] ZACC 30. www.saflii.org/za/cases/ZACC/2012/30.html. See also the nongovernmental organization, Section 27, www.section27.org.za.

²⁰⁶ Todrys K and Amon J, "Criminal Justice Reform as HIV and TB Prevention in African Prisons," *PLoS Medicine* 9, no. 5 (2012). www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001215.

²⁰⁷ International Center for Science in Drug Policy, *The Vienna Declaration*, www.viennadeclaration.com.

²⁰⁸ International Center for Science in Drug Policy et al., *The Vienna Declaration: Leading the way to illicit drug policies based on evidence, not ideology* (2010). www.viennadeclaration.com/wordpress/wp-content/uploads/2010/11/The-Vienna-Declaration-Progress-thus-far.pdf.

²⁰⁹ Global Fund, *Global Fund Information Note: TB and Human Rights* (2011). <http://goo.gl/vyb6Z>.

²¹⁰ Keshavjee S et al., "Building Capacity for Multidrug-Resistant Tuberculosis Treatment: Health Systems Strengthening in Lesotho," *Innovations* 2, no. 4 (2007): 87-106. www.mitpressjournals.org/doi/abs/10.1162/itgg.2007.2.4.87?journalCode=itgg.

2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO TB?

How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to TB. The tables are organized as follows:

Human right or fundamental freedom	
Examples of Human Rights Violations	
Human rights standards	UN treaty body interpretation This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.
Human rights standards	Case law This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.
Other interpretations: This section references other relevant interpretations of the issue. It includes interpretations by: <ul style="list-style-type: none"> • UN Special Rapporteurs • UN working groups • International and regional organizations • International and regional declarations 	

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on human rights and TB.

Abbreviations

In the tables, we use the following abbreviations to refer to the twelve treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights (UDHR)	None
International Covenant on Civil and Political Rights (ICCPR)	Human Rights Committee (HRC)
International Covenant on Economic, Social, and Cultural Rights (ICESCR)	Committee on Economic, Social and Cultural Rights (CESCR)
Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)	Committee on the Elimination of Discrimination Against Women (CEDAW Committee)
International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)	Committee on the Elimination of Racial Discrimination (CERD)
Convention on the Rights of the Child (CRC)	Committee on the Rights of the Child (CRC Committee)
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)	Committee against Torture (CAT Committee)
African Charter on Human and Peoples' Rights and Protocols (ACHPR)	African Commission on Human and Peoples' Rights (ACHPR Commission)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)	European Court of Human Rights (ECtHR)
1996 Revised European Social Charter (ESC)	European Committee of Social Rights (ECSR)
American Convention on Human Rights (ACHR)	Inter-American Court of Human Rights (IACHR)
American Declaration of the Rights and Duties of Man (ADRDM)	Inter-American Court of Human Rights (IACHR)

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**).

Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms

	UDHR	ICCPR	ICESCR	CEDAW	ICERD	CRC
Non-discrimination and Equality	Arts. 1, Art. 2	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2
Life	Art. 3	Art. 6(1)				Art. 6(1)
Health	Art. 25		Art. 12	Art. 12	Art. 5(e)(iv)	Art. 24
Bodily Integrity						
Freedom of Movement	Art. 13	Art. 12			Art. 5(d)(i)	
Arbitrary Arrest and Detention	Art. 9	Art. 9				Art. 37(b)
Fair Trial	Art. 8, Art. 10, Art. 11	Art. 9, Art. 14, Art. 15			Art. 5(a), Art. 6	Art. 40
Persons Deprived of Liberty Treated with Humanity		Art. 10.1				Art. 37
Torture or Cruel, Inhuman or Degrading Treatment	Art. 5	Art. 7				Art. 37(a)
Privacy	Art. 12	Art. 17			Art. 22	Art. 16
Expression and Information	Art. 19	Art. 19(2)			Art. 5(d)(viii)	Art. 12, Art. 13, Art. 17
Assembly and Association	Art. 20	Art. 21, Art. 22			Art. 5(d)(ix)	Art. 15
Enjoy Benefits of Scientific Progress	Art. 27		Art. 15			
Women	Art. 16, Art. 25(2)	Art. 3, Art. 23	Art. 3, Art. 10(1), Art. 10(2)	All		
Children	Art. 25(2)	Art. 24	Art. 10(3), Art. 12(2)(a)	Art. 5(b)		All

*See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.

Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADRDM	Americas: ACHR
Non-discrimination and Equality	Art. 2, Art. 19	Art. 14	Art. E	Art. II	Art. 1(1)
Life	Art. 4	Art. 2		Art. I	Art. 4
Health	Art. 16		Art. 11, Art. 13	Art. XI	
Bodily Integrity					
Freedom of Movement	Art. 12(1), Art. 12(2)			Art. VIII	Art. 22
Arbitrary Arrest and Detention	Art. 6	Art. 5		Art. XXV	Art. 7(3)
Fair Trial	Art. 7	Art. 6		Art. XVIII	Art. 8
Persons Deprived of Liberty Treated with Humanity				Art. XXV	Art. 5
Torture or Cruel, Inhuman or Degrading Treatment	Art. 5	Art. 3			Art. 5(2)
Privacy		Art. 8		Art. V	Art. 11
Expression and Information	Art. 9	Art. 10		Art. IV	Art. 13
Assembly and Association	Art. 10, Art. 11	Art. 11		Art. XXI, Art. XXII	Art 15, Art. 16
Enjoy Benefits of Scientific Progress				Art. XIII	
Women	Art. 18(3)		Art. 8	Art. VII	Art. 17
Children	Art. 18(3)		Art. 7, Art. 17	Art. VII	Art. 19

Table I: TB and Rights to Non-discrimination and Equality

Examples of Human Rights Violations	
<ul style="list-style-type: none"> Persons with TB are refused medical treatment or given a lower standard of care Persons with TB are prohibited from participating in the local market 	
Human Rights Standards	Treaty Body Interpretation
<p>ICERD 2(1) States Parties condemn racial discrimination and undertake to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its forms and promoting understanding among all races.</p> <p>ICERD 2(2) States Parties shall, when the circumstances so warrant, take, in the social, economic, cultural and other fields, special and concrete measures to ensure the adequate development and protection of certain racial groups or individuals belonging to them, for the purpose of guaranteeing them the full and equal enjoyment of human rights and fundamental freedoms.</p> <p>ICERD 5(e)(iv) States Parties undertake to prohibit and to eliminate racial discrimination in the right to public health, medical care, social security and social services.</p>	<p>CERD: Expressing concern to India about “reports that members of scheduled castes and scheduled and other tribes are disproportionately affected by ... tuberculosis ... and that health care facilities are either unavailable in tribal areas or substantially worse than in non-tribal areas” and recommending that the State ensure adequate health care facilities for members of scheduled castes and scheduled and other tribes and “to increase the number of doctors and of functioning and properly equipped primary health centres and health sub-centres in tribal and rural areas.” CERD/C/IND/CO/19 (2007).</p>

Other Interpretations

WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):

Overarching goals and objectives. ...[A]ll persons with TB should be treated the same way.... TB patients have the right to receive advice and treatment that meets international quality standards, be free of stigmatization and discrimination, establish and join peer support networks, and benefit from accountable representation.

The obligation to provide access to TB Services. TB programmes should take into account the needs of all patients, and in particular, the special needs of socially vulnerable groups for whom tailored interventions should be proactively developed.... Such groups include, but are not limited to, people living in extreme poverty, indigenous populations, refugees, asylum seekers, migrants, mine workers, prisoners, substance users (including alcohol), and homeless people. In addition, the needs of women, children, and people coinfectd with HIV warrant special consideration.

Resolution WHA 62.15, Prevention and control of multidrug-resistant tuberculosis and extensively drug-resistant tuberculosis (WHO, 2009):

Para. 1(j). Undertake “effective advocacy, communication and social mobilization, avoiding stigmatization and discrimination, and spreading community awareness about policies and plans for prevention and control of tuberculosis including multidrug-resistant and extensively drug-resistant tuberculosis”. *Resolution WHA 62.15.*

Beijing Call for Action on Tuberculosis control and patient care: together addressing the global MDR-TB and XDR-TB epidemic (WHO, 2009):

Para. 1(c). Ensuring a comprehensive framework for management and care of M/XDR-TB is developed, including community-based care, and identifying the groups most vulnerable to, and at risk of, drug-resistant TB and its impact, including people living with HIV, prisoners, mine workers, mobile populations, drug users, alcohol dependents, the poor and other vulnerable groups; and ensuring that services to prevent and treat drug-resistant TB are targeted to their needs”.

Recommendations to ensure the diagnosis and treatment of tuberculosis in undocumented migrants (Int'l Union Against Tuberculosis and Lung Disease, 2008):

Recommendation 1. Health authorities and/or health staff should: a) ensure easy access to low-threshold facilities where undocumented migrants who are tuberculosis suspects can be diagnosed and treated without giving their names and without fear of being reported to the police or migration officials, b) remind health staff that they have an obligation to respect confidentiality,

Table 1 (cont.)

Recommendation 2. Each country should ensure that undocumented migrants with tuberculosis are not deported until completion of treatment, and

Recommendation 3. Authorities and the non-governmental sectors should raise awareness among undocumented migrants about tuberculosis, emphasising that diagnosis and treatment should be free of charge and wholly independent of migratory status.

Berlin Declaration on Tuberculosis (WHO European Ministerial Forum, 2007)

Para. 5(2). We will adopt the Stop TB Strategy in all its components, thereby... empowering people with TB and their communities, and removing stigma.... EUR/o7/5061622/5 (2007).

Patients' Charter for Tuberculosis Care (World Care Council, 2006):

Care. The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness.

Dignity. The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination by health providers and authorities. The right to quality healthcare in a dignified environment, with moral support from family, friends, and the community.

Abuja Call for Accelerated Action Towards Universal Access to HIV/AIDS, Tuberculosis and Malaria Services in Africa (African Union, 2006):

Protection of Human Rights. Adapting national legislation to take cognizance of HIV and AIDS and TB issues specifically discrimination and stigmatization... Sp/Assembly/ATM/2 (I) Rev.3 (2006).

Security. The right to job security after diagnosis or appropriate rehabilitation upon completion of treatment.

Abuja Call for Accelerated Action Towards Universal Access to HIV/AIDS, Tuberculosis and Malaria Services in Africa (African Union, 2006):

Protection of Human Rights. Adapting national legislation to take cognizance of HIV and AIDS and TB issues specifically discrimination and stigmatization... Sp/Assembly/ATM/2 (I) Rev.3 (2006).

Table 2: TB and the Right to Life

Examples of Human Rights Violations

- Institutionalized persons face a disproportionate risk of TB infection, disease and death

Human Rights Standards	Treaty Body Interpretation
ICCPR 6(1) Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.	HRC: Expressing concern to Georgia at the “the still very large number of deaths of detainees in police stations and prisons, including suicides and deaths from tuberculosis” and urging the State to “ensure that every case of death in detention is promptly investigated by an independent agency.” CCPR/CO/74/GEO (2002)

Table 3: TB and the Right to the Highest Attainable Standard of Physical and Mental Health

Examples of Human Rights Violations	
<ul style="list-style-type: none"> Persons with TB are denied access to quality TB treatment and care in prison Persons with MRD-TB are denied tailored therapies of second-line drugs Government's failing to utilize donor resources to construct isolation wards 	

Human Rights Standards	Treaty Body Interpretation
<p>ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</p>	<p>CESCR: Expressing concern to Estonia about the high rate of cases of tuberculosis and recommending that “the State party intensify its efforts to combat the spread of tuberculosis.” E/C.12/1/ADD.85 (2002).</p> <p>CESCR: Expressing concern to Moldova about the “rising incidence of tuberculosis in the State party and notes with particular concern the acuteness of this problem in prisons where the infection rate is more than 40 times higher than the national average” and recommending that “the State party intensify its efforts under the National Programme on Tuberculosis Prophylaxis and Control to combat the spread of tuberculosis, including by ensuring the availability of medicines and adequate sanitary conditions in prisons.” E/C.12/1/ADD.91 (2003).</p> <p>CESCR: Expressing concern to Kyrgyzstan that new health threats such as the “reemergence of communicable and vaccine-preventable diseases such as tuberculosis” and urging “the State party to continue its efforts to address the prevailing health threats, and to target progressively resources to health services.” E/C.12/1/ADD.49 (2000).</p> <p>CESCR: Expressing concern to Russian Federation “about the spread of drug addiction, including by way of injection, which is the main factor for the growing epidemic of HIV/AIDS, hepatitis C and tuberculosis in the Russian Federation” and urging “the State party to apply a human rights-based approach to drug users so that they do not forfeit their basic right to health.” E/C.12/RUS/CO/5 (CESCR, 2011).</p> <p>CESCR: Expressing concern to Russian Federation about “the high incidence of tuberculosis in the State party, particularly in prisons, in the Republic of Chechnya and in the regions of the Far North, in particular among indigenous communities” and recommending that “the State party intensify its efforts to combat tuberculosis, under the special federal programme ‘Urgent measures to tackle tuberculosis in Russia for the period 1998-2004’, including by ensuring the availability of medicines and adequate sanitary conditions in prisons, and by taking special measures to combat the epidemic in the worst affected regions.” E/C.12/1/Add.94 (2003).</p>

Table 3 (cont.)

Human Rights Standards	Treaty Body Interpretation
<p>12(2) The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . . (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases.</p>	<p>CESCR: Expressing concern to the Ukraine that “information from the State party that in 2006, 70 persons out of 100,000 (80 out of 100,000 in rural areas) were suffering from tuberculosis, which has become the leading cause of death among persons with HIV/AIDS and is particularly prevalent among the prison population” and recommending that “the State party take urgent measures to improve tuberculosis prevention and accessibility of specialized tuberculosis treatment and medication, in particular in prisons, detention centres and police stations, and reduce delays in screening detainees for tuberculosis.” E/C.12/UKR/CO/5 (CESCR, 2008).</p> <p>CESCR: Expressing concern to Azerbaijan “about overcrowding and sub-standard conditions in prisons in Azerbaijan which have given rise to a disproportionately high rate of tuberculosis and other health problems among prisoners” and recommending “that the State party continue to take measures to improve the sanitary and hygienic conditions in prisons and to ensure that the right to mental and physical health of all prisoners in Azerbaijan is respected.” E/C.12/1/Add.104 (2004).</p> <p>CESCR: Expressing concern to India at the “high incidences of tuberculosis” and recommending that “the State party significantly increase its health-care expenditure, giving the highest priority to ... treating serious communicable diseases, including HIV/AIDS.” E/C.12/IND/CO/5 (2008).</p> <p>CESCR: Expressing concern to India about the “overcrowding and sub-standard conditions in prisons which are operating at 200-300 per cent of their maximum capacity, which have given rise to a disproportionately high rate of tuberculosis and other health problems affecting the prisoners” and recommending that “the State party strengthen its measures to improve the sanitary and hygienic conditions in prisons and to ensure that the right to mental and physical health of all prisoners is respected” E/C.12/IND/CO/5 (2008).</p> <p>CESCR: Expressing concern to Uzbekistan “about the absence of adequate health care and the poor hygienic conditions in prisons that lead to frequent tuberculosis infections of detainees” and recommending that the “State party to take measures to improve the hygienic conditions in prisons and to ensure that the right to health of all detainees in the State party is respected” E/C.12/UZB/CO/1 (2006).</p>
<p>CRC 24(1) States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p>	<p>CRC: Expressing concern that malaria and TB were re-emerging in Malaysia and recommended that the government “[p]revent and reduce the spread of tuberculosis and malaria.” CRC/C/MYS/CO/1 (2007).</p> <p>CRC: Expressing concern in Latvia at increasing rates of TB and recommended that the government “[offer] HIV-related care and treatment... including for the prevention and treatment of health problems related to HIV/AIDS, such as tuberculosis and opportunistic infections.” CRC/C/LVA/CO/2 (2006).</p> <p>CRC: Recommending that Turkmenistan “[a]ddress the issue of underreporting of communicable and infectious diseases, particularly HIV/AIDS and tuberculosis.” CRC/C/TKM/CO/1 (2006).</p> <p>CRC: Recommending that Lithuania “[strengthen] its efforts to implement the National Tuberculosis Prevention and Control Programme for 2003–2006.” CRC/C/LTU/CO/2 (2006).</p> <p>CRC: Expressing concern in Russia “that the number of tuberculosis cases remains high” and recommending that the government “continue efforts to reduce morbidity due to tuberculosis.” CRC/C/RUS/CO/3 23 (2005).</p> <p>CRC: Recommending that the Central African Republic “strengthen its efforts to combat HIV/AIDS infection, including through efforts to combat tuberculosis.” CRC/C/15/Add.138 (2000).</p>

Table 3 (cont.)

Other Interpretations

Policy on Collaborative TB/HIV activities: Guidelines for national programmes and other stakeholders (WHO, 2012). Extensive discussion of TB prevention, treatment and care options.

WHO Guidelines for the programmatic management of drug-resistant tuberculosis (WHO, 2011):

Recommendation 6. Patients with MDR-TB should be treated using mainly ambulatory care rather than models of care based principally on hospitalization....

WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):

The obligation to provide access to TB Services. Governments' ethical obligation to provide universal access to TB care is grounded in their duty to fulfil the human right to health.... The obligation to provide universal access to TB care implies a duty to ensure the quality of that care.

All aspects of TB care should be provided free of charge.... It is also important to remove non-TB-specific financial barriers to accessing the health-care system, such as user fees that prevent poor people from receiving health-care services, or charges imposed on TB patients for the care of related conditions (e.g. HIV)....

As WHO has recognized, "community-based care provided by trained lay and community health workers can achieve comparable results [to hospitalization] and, in theory, may result in decreased nosocomial spread of the disease". In addition, community-based care reduces burdens on health-care facilities and is more cost effective than facility-based treatment, thereby enabling governments with limited resources to serve the greatest proportion of those in need.

Resolution WHA 62.15, Prevention and control of multidrug-resistant tuberculosis and extensively drug-resistant tuberculosis (WHO, 2009):

Para. 1. Achieve "universal access to diagnosis and treatment of multidrug-resistant and extensively drug-resistant tuberculosis as part of the transition to universal health coverage".

Para. 1(a). Develop "a comprehensive framework for management and care of [MDR- and XDR-TB] that includes directly-observed treatment, community-based and patient-centred care, and which identifies and addresses the needs of persons living with HIV, the poor and other vulnerable groups, such as prisoners, mineworkers, migrants, drug users, and those dependent on alcohol, as well as the underlying social determinants of tuberculosis".

Para. 1(b). Strengthen "health information and surveillance systems to ensure detection and monitoring of the epidemiological profile of [MDR- and XDR-TB] and monitor achievement in its prevention and control".

Para. 1(d). Make "available sufficiently trained and motivated staff in order to enable diagnosis, treatment and care of tuberculosis".

Para. 1(e). Strengthen "laboratory systems, through increasing capacity and adequate human resources, and accelerating access to faster and quality-assured diagnostic tests".

Para. 1(f). Engage "all relevant public and private health-care providers in managing tuberculosis... and tuberculosis-HIV coinfection according to national policies, and strengthening primary health care in early detection, effective treatment and support to patients".

Para. 1(g). Ensure "that national airborne infection-control policies are developed... and implemented in every health-care facility and other high-risk settings...".

Para. 1(h). Ensure "an uninterrupted supply of first- and second-line medicines for tuberculosis treatment... and that quality-assured fixed-dose combination medicines of proven bioavailability are prioritized within a system that promotes treatment adherence".

Para. 1(i). Strengthen "mechanisms to ensure that tuberculosis medicines are sold on prescription only and that they are prescribed and dispensed by accredited public and private providers".

Para. 1(k). Establish "national targets in order to accelerate access to treatment, according to WHO guidelines, for [MDR- and XDR-TB] patients". *Resolution WHA 62.15.*

Table 3 (cont.)

Beijing Call for Action on Tuberculosis control and patient care: together addressing the global MDR-TB and XDR-TB epidemic (WHO, 2009):

Para. 1(l). Identifying and addressing the underlying social determinants of TB and M/XDR-TB. This needs action both within and outside the health system, and should be linked to broader national initiatives to ensure “health in all policies”.

Para. 1(b). Ensuring the removal of financial barriers to allow all TB patients equitable access to TB care, that their rights are protected, and that they are treated with respect and dignity.

WHO Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users (WHO, 2008):

Recommendation 10. All services dealing with drug users should collaborate locally with key partners to ensure universal access to comprehensive TB and HIV prevention, treatment and care as well as drug treatment services for drug users in a holistic person-centred way that maximizes access and adherence: in one setting, if possible.

SR Health (2006): Commenting that the “socio-economic consequences of stigmatization and discrimination can have devastating consequences” for marginalized individuals in **Uganda**: “stigma related to tuberculosis can be greater for women: it may lead, inter alia, to ostracism, rejection and abandonment by family and friends, as well as loss of social and economic support” and recommending that all relevant actors “urgently consider whether or not the national and international programmes in relation to HIV/AIDS, tuberculosis and malaria could also enhance interventions for other diseases”. E/CN.4/2006/48/Add.2 (2006)

Patients’ Charter for Tuberculosis Care (World Care Council, 2006):

Care. The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness. The right to receive medical advice and treatment... centering on patient needs, including those with multidrug-resistant tuberculosis (MDR-TB) or tuberculosis-human immunodeficiency virus (HIV) coinfections and preventative treatment for young children and others considered to be at high risk. The right to benefit from proactive health sector community outreach, education, and prevention campaigns as part of comprehensive care programs.

Security. The right to nutritional security or food supplements if needed to meet treatment requirements.

International Standards for Tuberculosis Care (Tuberculosis Coalition for Technical Assistance, 2006):

Standard 9. To foster and assess adherence, a patient-centered approach to administration of drug treatment, based on the patient’s needs and mutual respect between the patient and the provider, should be developed for all patients. Supervision and support should be gender-sensitive and age-specific and should draw on the full range of recommended interventions and available support services, including patient counseling and education.

Political Declaration on HIV/AIDS (UN General Assembly, 2006):

Para. 33. Emphasize the need for accelerated scale-up of collaborative activities on tuberculosis and HIV, in line with the Global Plan to Stop TB 2006–2015, and for investment in new drugs, diagnostics and vaccines that are appropriate for people with TB-HIV co-infection.

Para. 34. Commit ourselves to expanding...our capacity to deliver comprehensive HIV/AIDS programmes in ways that strengthen existing national health and social systems, including by integrating HIV/AIDS intervention into [programmes for tuberculosis].

Abuja Call for Accelerated Action Towards Universal Access to HIV/AIDS, Tuberculosis and Malaria Services in Africa (African Union, 2006):

Protection of Human Rights. To continue promoting an enabling policy, legal and social environment that promotes human rights particularly for women, youth and children and ensure the protection of people infected and affected by HIV and AIDS, TB and Malaria and to reduce vulnerability and marginalization including conflict-affected and displaced persons, refugees and returnees.

Access to Affordable Medicines and Technologies. To... ensure the availability of medicines and commodities at affordable prices as well as technologies for the treatment, care and prevention of HIV and AIDS, TB and malaria including vaccines, medicines and Anti-retrovirus Therapy (ART). Sp/Assembly/ATM/2 (I) Rev.3 (2006).

Cairo Programme of Action of the United Nations International Conference on Population and Development (UN, 1994):

HIV/AIDS. 8.31. The links between the prevention of HIV infection and the prevention and treatment of tuberculosis should be assured.

Table 4: TB and the Right to Bodily Integrity**Examples of Human Rights Violations**

- A patient is involuntarily hospitalized for treatment even though it has not been shown that she has failed to adhere to her treatment regimen.

Note: The right to bodily integrity is not specifically recognized under the ICCPR or ICESCR, but has been interpreted to be part of the right to security of the person, to freedom from torture and cruel, inhuman, and degrading treatment, and the right to the highest attainable standard of health.

Similarly, the right to bodily integrity is not specifically recognized in CEDAW, although CEDAW has been widely interpreted to include the right to protection from violence against women. (See concluding observations to Thailand, CEDAW/C/1999/I/L.1/Add.6 (1999) stating that “sexual harassment, rape, domestic violence and marital rape, whether in the family, the community or the workplace, constitute violations of women’s right to personal security and bodily integrity.”)

Other Interpretations**WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):**

Overarching goals and objectives. Autonomy can be defined in many ways, but is generally seen as guaranteeing individuals the right to make decisions about their own lives, including health care.... For example, respecting autonomy means that patients generally should have the right to choose among treatment options.

Information, counselling and the role of consent. There are several reasons to ensure that individuals undergoing TB testing and treatment receive complete and accurate information about the risks, benefits, and alternatives available to them. First, at the most basic level, people have a right to know what is being done to their bodies, and why it is being done.

Supporting adherence to TB treatment. Directly observed therapy should be seen as a process for providing support, motivation, and understanding to patients. It is a necessary part of TB care, but is not intended to be a method for “forcing” patients to do something against their will.... In rare instances, if all reasonable efforts to promote adherence have failed and the patient still remains infectious, involuntary isolation or detention may be considered.

Involuntary isolation and detention as last-resort measures. While contagious TB patients who do not adhere to treatment or who are unable or unwilling to comply with infection control measures pose significant risks to the public, those risks can be addressed by isolating the patient. Patients who are isolated should be offered the opportunity to receive treatment, but if they do not accept, their informed refusal should be respected, as the isolated patient no longer presents a public health risk. Forcing these patients to undergo treatment over their objection would require a repeated invasion of bodily integrity.

Beijing Call for Action on Tuberculosis control and patient care: together addressing the global MDR-TB and XDR-TB epidemic (WHO, 2009):

Para. 1(b). Ensuring the removal of financial barriers to allow all TB patients equitable access to TB care, that their rights are protected, and that they are treated with respect and dignity.

Patients’ Charter for Tuberculosis Care (World Care Council, 2006):

Dignity. The right to be treated with respect and dignity, including the delivery of services without stigma, prejudice, or discrimination by health providers and authorities. The right to quality healthcare in a dignified environment, with moral support from family, friends, and the community.

Choice. The right to accept or refuse surgical interventions if chemotherapy is possible and to be informed of the likely medical and statutory consequences within the context of a communicable disease. The right to choose whether or not to take part in research programs without compromising care.

Table 5: TB and Freedom of Movement

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • TB patients under quarantine or isolation or in detention are unable to freely move or reside in a country, or to leave and return. • People exercising freedom of movement for work are denied TB services because they lack identity documents. 	
Human Rights Standards	Treaty Body Interpretation
<p>ICCPR 12(1) Everyone lawfully within the territory of a State shall, within that territory, have the right to liberty of movement and freedom to choose his residence.</p> <p>12 (2) Everyone shall be free to leave any country, including his own.</p> <p>12 (4) No one shall be arbitrarily deprived of the right to enter his own country.</p>	None.

Other Interpretations

WHO Guidelines for the programmatic management of drug-resistant tuberculosis (WHO, 2011):

Recommendation 6. Patients with MDR-TB should be treated using mainly ambulatory care rather than models of care based principally on hospitalization ...

WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):

Involuntary isolation and detention as last-resort measures. Isolation or detention should be limited to exceptional circumstances... Isolation or detention should never be implemented as a form of punishment. Patients who decline treatment and who pose a risk to others should be made aware in advance that their continued refusal may result in compulsory isolation or detention....

If, in a rare individual case, a judgement is made that involuntary isolation or detention is the only reasonable means of safeguarding the public, it is essential to ensure that the manner in which isolation or detention is implemented complies with applicable ethical and human rights principles. As set forth in the Siracusa Principles, this means that such measures must be:

- *in accordance with the law;*
- *based on a legitimate objective;*
- *strictly necessary in a democratic society;*
- *the least restrictive and intrusive means available; and*
- *not arbitrary, unreasonable, or discriminatory....*

In order to make sure that these principles are followed, countries should review their public health laws to ensure that they carefully limit the scope of government authority and provide due process protections for individuals whose liberty may be restricted. In addition, in order to minimize the danger of arbitrary enforcement, countries and TB programmes should develop clear criteria and procedures for the use of non-voluntary measures, with involvement from TB patients and civil society.

Recommendations to ensure the diagnosis and treatment of tuberculosis in undocumented migrants (Int'l Union Against Tuberculosis and Lung Disease, 2008):

Recommendation 1. Health authorities and/or health staff should: a) ensure easy access to low-threshold facilities where undocumented migrants who are tuberculosis suspects can be diagnosed and treated without giving their names and without fear of being reported to the police or migration officials, b) remind health staff that they have an obligation to respect confidentiality,

Recommendation 2. Each country should ensure that undocumented migrants with tuberculosis are not deported until completion of treatment, and

Recommendation 3. Authorities and the non-governmental sectors should raise awareness among undocumented migrants about tuberculosis, emphasising that diagnosis and treatment should be free of charge and wholly independent of migratory status.

Table 5 (cont.)

WHO Guidance on human rights and involuntary detention for XDR-TB control (WHO, 2007):

In this regard, if a patient wilfully refuses treatment and, as a result, is a danger to the public, the serious threat posed by XDR-TB means that limiting that individual's human rights may be necessary to protect the wider public. Therefore, interference with freedom of movement when instituting quarantine or isolation for a communicable disease such as MDR-TB and XDR-TB may be necessary for the public good, and could be considered legitimate under international human rights law. *This must be viewed as a last resort, and justified only after all voluntary measures to isolate such a patient have failed.* A key factor in determining if the necessary protections exist when rights are restricted is that each one of the five criteria of the Siracusa Principles must be met, but should be of a limited duration and subject to review and appeal.

General Comment No. 27: Freedom of movement (Art.12) (UN Human Rights Committee, 1999):

Para. 16. States have often failed to show that the application of their laws restricting the rights enshrined in [ICCPR article 12] are in conformity with all requirements referred to... The application of restrictions in any individual case must be based on clear legal grounds and meet the test of necessity and the requirements of proportionality.

Para. 18. The application of the restrictions permissible under article 12, paragraph 3, needs to be consistent with the other rights guaranteed in the Covenant and with the fundamental principles of equality and non-discrimination. Thus, it would be a clear violation of the Covenant if [these rights] were restricted by making distinctions of any kind, such as on the basis of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. CCPR/C/21/Rev.1/Add.9 (1999).

Siracusa Principles (UN Economic and Social Rights Council, 1985):

Article 25. Public health may be invoked as a ground for limiting certain rights in order to allow a state to take measures dealing with a serious threat to the health of the population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care for the sick and injured.

Article 26. Due regard shall be had to the international health regulations of the World Health Organization.

Article 39. A state party may take measures derogating from its obligations under [ICCPR Art. 4] only when faced with a situation of exceptional and actual or imminent danger which threatens the life of the nation.

Article 70. Although protections against arbitrary arrest and detention (Art. 9) and the right to a fair and public hearing in the determination of a criminal charge (Art. 14) may be subject to legitimate limitations if strictly required by the exigencies of an emergency situation, the denial of certain rights fundamental to human dignity can never be strictly necessary in any conceivable emergency. E/CN.4/1985/4 (1985).

Table 6: TB and Freedom from Arbitrary Arrest and Detention

Examples of Human Rights Violations	
<ul style="list-style-type: none"> Persons diagnosed with TB, who have been declared to be noncompliant with TB treatment, are arrested. Persons arrested for noncompliance with TB treatment are not provided with treatment while in detention. 	

Human Rights Standards	Treaty Body Interpretation
<p>ICCPR 9(1) Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.</p>	<p>HRC: Noting that in Moldova "under a regulation promulgated in August 2009, persons with tuberculosis may be subjected to forcible detention in circumstances where he or she is deemed to have 'avoided treatment'. In particular, the regulation is unclear as to what constitutes the avoidance of treatment and fails to provide, inter alia, for patient confidentiality or for the possibility for the judicial review of a decision to forcibly detain a patient." Recommending that the State "should urgently review this measure to bring it into line with the Covenant, ensuring that any coercive measures arising from public health concerns are duly balanced against respect for patients' rights, guaranteeing judicial review and patient confidentiality and otherwise ensuring that persons with tuberculosis are treated humanely." CCPR/C/MDA/CO/2 (2009).</p>
<p>CAT 16(1) Each State Party shall undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article I, when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.</p>	<p>CAT: Expressing concern in Moldova over legislation providing for forcible detention of persons with tuberculosis deemed to have "avoided treatment," including lack of clarity "as to what constitutes the avoidance of treatment" and failure to provide adequate safeguards and procedural rights with respect to access to legal representation, "regular review of the reasons for detention or for maintaining continued detention, privacy, family and correspondence, confidentiality, data protection, non-discrimination and non-stigmatization." Recommending that the State "should urgently review the regulation on forcible detention of persons with tuberculosis and related policies, and bring them into compliance with the Convention, in particular guaranteeing independent regular review of detention measures, patient confidentiality and privacy, as well as non-discrimination in their application." CAT/C/MDA/CO/2 (2010).</p>

Human Rights Standards	Case Law
<p>ECHR 5(1) Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:</p> <p>(e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants.</p>	<p>ECtHR: Holding that the involuntary placement in the hospital of an HIV-positive gay man to prevent him from spreading HIV to others violated Art. 5. The Court developed criteria for determining whether a State Party's compulsory isolation of an individual to control infectious disease satisfies ECHR 5: "The detention of an individual is such a serious measure that it is only justified where other, less severe measures have been considered and found to be insufficient to safeguard the individual or the public interest which might require that the person concerned be detained. That means that it does not suffice that the deprivation of liberty is in conformity with national law, it must also be necessary in the circumstances . . . and in accordance with the principle of proportionality ..." Case of <i>Enhorn v. Sweden</i>, 56529/00 (Jan. 25, 2005).</p>

Table 6 (cont.)

Other Interpretations

Joint Statement on compulsory drug detention and rehabilitation centres (ILO et al., 2012):

Compulsory drug detention and rehabilitation centres raise human rights issues and threaten the health of detainees, including through increased vulnerability to HIV and [TB] infection.... [S]uch detention often takes place without the benefit of sufficient due process, legal safeguards or judicial review. The deprivation of liberty without due process is an unacceptable violation of internationally recognised human rights standards.

WHO Guidelines for the programmatic management of drug-resistant tuberculosis (WHO, 2011):

Recommendation 6. Patients with MDR-TB should be treated using mainly ambulatory care rather than models of care based principally on hospitalization....

WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010): *Involuntary isolation and detention as last-resort measures.* Isolation or detention should be limited to exceptional circumstances.... Isolation or detention should never be implemented as a form of punishment. Patients who decline treatment and who pose a risk to others should be made aware in advance that their continued refusal may result in compulsory isolation or detention....

If, in a rare individual case, a judgement is made that involuntary isolation or detention is the only reasonable means of safeguarding the public, it is essential to ensure that the manner in which isolation or detention is implemented complies with applicable ethical and human rights principles. As set forth in the Siracusa Principles, this means that such measures must be:

- in accordance with the law;
- based on a legitimate objective;
- strictly necessary in a democratic society;
- the least restrictive and intrusive means available; and
- not arbitrary, unreasonable, or discriminatory....

In order to make sure that these principles are followed, countries should review their public health laws to ensure that they carefully limit the scope of government authority and provide due process protections for individuals whose liberty may be restricted. In addition, in order to minimize the danger of arbitrary enforcement, countries and TB programmes should develop clear criteria and procedures for the use of non-voluntary measures, with involvement from TB patients and civil society.

WHO Guidance on human rights and involuntary detention for XDR-TB control (WHO, 2007):

In this regard, if a patient willfully refuses treatment and, as a result, is a danger to the public, the serious threat posed by XDR-TB means that limiting that individual's human rights may be necessary to protect the wider public. Therefore, interference with freedom of movement when instituting quarantine or isolation for a communicable disease such as MDR-TB and XDR-TB may be necessary for the public good, and could be considered legitimate under international human rights law. *This must be viewed as a last resort, and justified only after all voluntary measures to isolate such a patient have failed.* A key factor in determining if the necessary protections exist when rights are restricted is that each one of the five criteria of the Siracusa Principles must be met, but should be of a limited duration and subject to review and appeal.

Patients' Charter for Tuberculosis Care (World Council, 2006): *Justice.* The right to make a complaint through channels provided for this purpose by the health authority and to have any complaint dealt with promptly and fairly. The right to appeal to a higher authority if the above is not respected and to be informed in writing of the outcome.

Siracusa Principles (UN Economic and Social Rights Council, 1985):

Article 25. Public health may be invoked as a ground for limiting certain rights in order to allow a state to take measures dealing with a serious threat to the health of the population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care for the sick and injured.

Article 26. Due regard shall be had to the international health regulations of the World Health Organization.

Article 39. A state party may take measures derogating from its obligations under [ICCPR Art. 4] only when faced with a situation of exceptional and actual or imminent danger which threatens the life of the nation....

Article 70. Although protections against arbitrary arrest and detention (Art. 9) and the right to a fair and public hearing in the determination of a criminal charge (Art. 14) may be subject to legitimate limitations if strictly required by the exigencies of an emergency situation, the denial of certain rights fundamental to human dignity can never be strictly necessary in any conceivable emergency. E/CN.4/1985/4 (1985).

Table 7: TB and the Right to a Fair Trial

Examples of Human Rights Violations	
<ul style="list-style-type: none"> Individuals with TB are detained without adequate justification that it is the least restrictive alternative, strictly necessary or a measure of last resort 	
Human Rights Standards	Treaty Body Interpretation
<p>ICCPR 14(1) All persons shall be equal before the courts and tribunals. In the determination of any criminal charge against him, or of his rights and obligations in a suit at law, everyone shall be entitled to a fair and public hearing by a competent, independent and impartial tribunal established by law...</p> <p>14(3) In the determination of any criminal charge against him, everyone shall be entitled to... minimum guarantees, in full equality...</p>	None.

Other Interpretations

Joint Statement on compulsory drug detention and rehabilitation centres (ILO et al., 2012):

Compulsory drug detention and rehabilitation centres raise human rights issues and threaten the health of detainees, including through increased vulnerability to HIV and [TB] infection.... [S]uch detention often takes place without the benefit of sufficient due process, legal safeguards or judicial review. The deprivation of liberty without due process is an unacceptable violation of internationally recognised human rights standards.

WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):

Involuntary isolation and detention as last-resort measures. In order to make sure that these principles are followed, countries should review their public health laws to ensure that they carefully limit the scope of government authority and provide due process protections for individuals whose liberty may be restricted. In addition, in order to minimize the danger of arbitrary enforcement, countries and TB programmes should develop clear criteria and procedures for the use of non-voluntary measures, with involvement from TB patients and civil society.

WHO Guidance on human rights and involuntary detention for XDR-TB control (WHO, 2007):

... [I]nterference with freedom of movement when instituting quarantine or isolation for a communicable disease such as MDR-TB and XDR-TB may be necessary for the public good, and could be considered legitimate under international human rights law. *This must be viewed as a last resort, and justified only after all voluntary measures to isolate such a patient have failed.* A key factor in determining if the necessary protections exist when rights are restricted is that each one of the five criteria of the Siracusa Principles must be met, but should be of a limited duration and subject to review and appeal.

Patients' Charter for Tuberculosis Care (World Care Council, 2006):

Justice. The right to make a complaint through channels provided for this purpose by the health authority and to have any complaint dealt with promptly and fairly. The right to appeal to a higher authority if the above is not respected and to be informed in writing of the outcome.

Siracusa Principles (UN Economic and Social Rights Council, 1985):

Article 25. Public health may be invoked as a ground for limiting certain rights in order to allow a state to take measures dealing with a serious threat to the health of the population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care for the sick and injured.

Article 26. Due regard shall be had to the international health regulations of the World Health Organization.

Article 39. A state party may take measures derogating from its obligations under [ICCPR Art. 4] only when faced with a situation of exceptional and actual or imminent danger which threatens the life of the nation....

Article 70. Although protections against arbitrary arrest and detention (Art. 9) and the right to a fair and public hearing in the determination of a criminal charge (Art. 14) may be subject to legitimate limitations if strictly required by the exigencies of an emergency situation, the denial of certain rights fundamental to human dignity can never be strictly necessary in any conceivable emergency. E/CN.4/1985/4 (1985).

Table 8: TB and the Right of All Persons Deprived of Their Liberty to be Treated with Humanity

Examples of Human Rights Violations	
<ul style="list-style-type: none"> Prisoners diagnosed with TB are not provided medical treatment or medicines. Prisoners are detained in facilities that are overcrowded and/or have poor hygiene. Prisoners diagnosed with TB are not provided adequate nutrition. 	
Human Rights Standards	Treaty Body Interpretation
ICCPR 10(1) All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.	<p>HRC: Expressing concern to Moldova at the conditions in detention facilities, including the prevalence of disease. The Committee “reminds the State party of its obligation to ensure the health and life of all persons deprived of their liberty. Danger to the health and lives of detainees as a result of the spread of contagious diseases and inadequate care amounts to a violation of article 10 of the Covenant and may also include a violation of articles 9 and 6.” The Committee recommends that Moldova prevent the spread of disease in detention facilities and provide “appropriate medical treatment to persons who have contracted diseases, either in prison or prior to their detention.” CCPR/CO/75/MDA (2002).</p> <p>HRC: Expressing concern to Georgia about the large number of cases of tuberculosis reported in prisons and specifically urges the State to “improve the hygiene, diet and general conditions of detention of and provide appropriate medical care to detainees as provided for in article 10 of the Covenant.” CCPR/CO/74/GEO (2002).</p> <p>HRC: Expressing concern to Ukraine at the “high incidence of HIV/AIDS and tuberculosis among detainees in facilities of the State party is also a cause for concern, along with the absence of specialized care for pre-trial detainees” and recommending that the State “should guarantee the right of detainees to be treated humanely and with respect for their dignity, particularly by relieving overcrowding, providing hygienic facilities, and assuring access to health care and adequate food.” CCPR/C/UKR/CO/6 (2006).</p>

Other Interpretations

Joint Statement on compulsory drug detention and rehabilitation centres (ILO et al., 2012):

Compulsory drug detention and rehabilitation centres raise human rights issues and threaten the health of detainees, including through increased vulnerability to HIV and [TB] infection....

The UN entities... call on States that operate compulsory drug detention and rehabilitation centres to close them without delay and to release the individuals detained. Upon release, appropriate health care services should be provided to those in need of such services, on a voluntary basis, at community level [including] HIV and TB prevention, treatment, care and support....

Where a State is unable to close the centres rapidly, without undue delay, we urge... [the] provision of health care services pending closure of the centres, including for treatment of HIV and other sexually transmitted infections (STIs), TB and opportunistic infections...

Time to act to prevent and control tuberculosis among inmates (International Union Against Tuberculosis and Lung Disease, 2012):

Urging health authorities, technical agencies, civil society organisations and donor agencies to:

- i) adapt and implement the... Stop TB strategy in penitentiary settings;
- ii) conduct screening of new inmates, periodic screening of prisoners and penitentiary services staff to detect active TB in a timely manner, and ensure contact tracing;
- iii) ensure airborne infection control, including protective measures for staff,⁸ and promote provider-initiated HIV testing and counselling to detect HIV and TB-HIV co-infected individuals...;
- iv) provide access to early diagnosis and effective treatment of all types of TB, including ensure early initiation of antiretroviral therapy for people living with HIV who have active TB;
- vi) ... provide preventive therapy both for those individuals who become infected with TB in penitentiary services and for those found to be infected while in penitentiary services;

- vii) ensure a continuum of care for released prisoners... and for individuals who are on treatment for either infection or disease before entering the penitentiary services;
- viii) monitor the TB and TB-HIV situation in the penitentiary services... and link recording and reporting in the penitentiary services to the national health information system;
- ix) encourage and facilitate collaborative efforts between the penitentiary and civilian health services;
- x) provide psychological counselling and support for prisoners to improve TB and HIV treatment adherence;
- xi) ... rais[e] awareness about TB among prisoners and penitentiary medical and non-medical staff through continuing education;
- xii) and promote operational research to build evidence for enhanced TB prevention, control and care in penitentiary services.

Women's health in prison: Action guidance and checklists to review current policies and practices (WHO, UNODC, 2011):

Para. 1. The underlying importance of human rights should underpin all thinking and all policy development for all those in compulsory detention.

Para. 3. Key services to be provided should include... specialist health care, which is readily provided and adjusted to meet the needs of women, such as for... chronic health conditions, HIV and AIDS (including counselling and support), hepatitis, tuberculosis (TB) and other infectious diseases.

WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):

Involuntary isolation and detention as last-resort measures. Isolation or detention should never be implemented as a form of punishment.... In the rare event that isolation or detention is to be used, it must take place in adequate settings, with appropriate infection control measures, as specified more fully in WHO guidance. In addition, reasonable social supports should be provided to isolated patients and their dependants, taking into account the local system's capacity.

The Madrid Recommendation (WHO, 2010): Recognizing the urgent need in all prison systems for “measures to use alternatives to imprisonment where possible and to reduce overcrowding in prisons”, “counselling, screening and treatment programmes for infectious diseases, including HIV/AIDS, tuberculosis, hepatitis B and C and sexually transmitted infections”; “guaranteed throughcare for prisoners upon entry and after release from prison” and “training of all prison staff in the prevention, treatment and control of communicable diseases”.

Guidelines for control of tuberculosis in prisons (USAID, Tuberculosis Coalition for Technical Assistance, International Committee of the Red Cross, 2009).

WHO Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users (WHO, 2008):

Recommendation 11. Medical examination upon entry and any time thereafter, conforming to internationally accepted standards of medical confidentiality and care, should be available for all prisoners. Prisoners should obtain health care equivalent to that provided for the civilian population, and care should be continuous on transfer in and out of places of detention.

Principles and Best Practices on the Protection of Persons Deprived of Liberty in the Americas (IACHR, 2008):

Principle X. Persons deprived of liberty shall have the right to health, understood to mean the enjoyment of the highest possible level of physical, mental, and social well-being, including... special measures to meet the particular health needs of persons deprived of liberty belonging to vulnerable or high risk groups, such as... people living with HIV-AIDS, tuberculosis...

Patients' Charter for Tuberculosis Care (World Care Council, 2006):

Care. The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness. The right to receive medical advice and treatment which fully meets the new International Standards for Tuberculosis Care, centering on patient needs, including those with [MDR-TB] or [TB-HIV] coinfections and preventative treatment for young children and others considered to be at high risk.

Table 9: TB and Freedom from Torture or Cruel, Inhuman or Degrading Treatment or Punishment

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • Institutional settings are overcrowded and unhygienic, making it more likely for individuals to contract TB. • Prisoners cannot access medical treatment and care for a TB diagnosis. • Prisoners are not screened or tested for TB. 	

Human Rights Standards	Treaty Body Interpretation
<p>CAT 16(1) Each State Party shall undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article I, when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.</p>	<p>CAT: Expressing concern to Zambia at the prevalence of tuberculosis and the high contamination rate of inmates and prison officers due to overcrowding and the lack of adequate health care. Recommending that the State speed up the establishment of health care services in prisons including the recruitment of medical personnel, as established under the Prisons Act of 2004. CAT/C/ZMB/CO/2 (2008).</p> <p>CAT: Urging Ethiopia to “take urgent measures to bring the conditions of detention in police stations, prisons and other places of detention into line with the Standard Minimum Rules for the Treatment of Prisoners, as well as with other relevant standards, in particular by... Improving the quality and quantity of food and water as well as the health care provided to detainees and prisoners, including ... tuberculosis patients.” CAT/C/ETH/CO/1 (2011).</p> <p>CAT: Expressing concern to Russia about the distressing conditions of pre-trial detention, including the prevalence of tuberculosis and other diseases, as well as the poor and unsupervised conditions of detention in IVS (temporary police detention), and SIZOs (pre-trial establishment) facilities, and recommending “Urgent consideration should be given to making a medical examination compulsory for persons when they enter IVS and SIZOs.” CAT/C/CR/28/4 (2002).</p> <p>CAT: Recommending that Estonia “should provide adequate food to all detainees and improve the health and medical services in detention facilities, including by making available appropriate treatments, especially to HIV and tuberculosis infected detainees.” CAT/C/EST/CO/4 (2008).</p> <p>CAT: Expressing concern to South Africa and Ukraine about the high rate of tuberculosis amongst detainees and recommending that the State should “adopt effective measures to improve the conditions in detention facilities, reduce the current overcrowding and meet the fundamental needs of all those deprived of their liberty, in particular regarding health care” CAT/C/ZAF/CO/1 (2006); CAT/C/UKR/CO/5 (2007).</p> <p>CAT: Expressing concern to Georgia about the “high number of deaths reported from tuberculosis” and encouraging the State to “continue its cooperation with the International Committee of the Red Cross and non-governmental organizations with regard to the implementation of programmes related to the treatment of tuberculosis and distribution and monitoring of the medicines taken in penitentiary facilities throughout its territory.” CAT/C/GEO/CO/3 (2006).</p>

Table 9 (cont.)

Human Rights Standards	Treaty Body Interpretation
	SPT: Recommending to Paraguay and Honduras “that all prisoners should have the opportunity to be X-rayed for tuberculosis using mobile X-ray units and that treatment should commence for inmates who have tested positive. Prisoners sharing a cell with a person infected with tuberculosis should be allowed to undergo a second X-ray and the Mantoux test (for prisoners who have not been vaccinated) three months later. This procedure should be repeated periodically to prevent the outbreak of further cases.” CAT/OP/PRY/1 (2010), CAT/OP/HND/1 (2010).
Human Rights Standards	Case Law
ECHR 3 No one shall be subjected to torture or to inhuman or degrading treatment or punishment.	<p>ECtHR: Finding a violation of Article 3 because “the applicant had to spend twenty three hours per day in an overcrowded cell”. However, the Court noted that contracting TB in detention alone would not necessarily establish an Article 3 violation and dismissed this portion of the applicant’s claim due to a lack of evidence establishing inadequate medical care for his TB. <i>Asyanov v. Russia</i>, Application No. 25462/09 (Jan. 9, 2013).</p> <p>ECtHR: Finding a violation of Article 3 because “the applicant did not receive comprehensive, effective and transparent medical assistance in respect of his HIV and tuberculosis in detention. It believes that, as a result of this lack of adequate medical treatment, the applicant was exposed to prolonged mental and physical suffering diminishing his human dignity. The authorities’ failure to provide the applicant with the requisite medical care amounted to inhuman and degrading treatment within the meaning of Article 3 of the Convention.” <i>Koryak v. Russia</i>, Application No. 24677/10 (Nov. 13, 2012).</p> <p>ECtHR: Finding a violation of Article 3 on account of the authorities’ failure to duly diagnose the applicant with tuberculosis and comply with their responsibility to ensure adequate medical assistance for him during his detention in a correctional colony before September 2004. <i>Vasyukov v. Russia</i>, Application No. 2974/05 (April 5, 2011).</p> <p>ECtHR: Finding that the authorities violated their obligations under Article 3 because there was a “lack of a comprehensive approach to the applicant’s medical supervision and treatment for tuberculosis and HIV and failure to ensure physical conditions reasonably adapted for his recovery process.” <i>Logvinenko v. Ukraine</i>, Application No. 13448/07 (Oct. 14, 2010).</p> <p>ECtHR: Finding a violation of Article 3 on account of detention conditions in a pretrial detention center (e.g., overcrowding, sleep deprivation and lack of natural light and air) and the authorities’ failure to provide timely and appropriate medical assistance to the applicant in respect of his HIV and TB infections. <i>Yakovenko v Ukraine</i>, Application No. 15825/06 (Oct. 25, 2007) (adapted from Human Rights in Patient Care: A Practitioner Guide, www.health-rights.am/practitioner-guide)</p>

Other Interpretations

SR Torture (2013): Noting that compulsory detention of TB patients, as is reported in certain countries, constitutes a form of abuse in the health care setting: “Medical care that causes severe suffering for no justifiable reason can be considered cruel, inhuman or degrading treatment or punishment, and if there is State involvement and specific intent, it is torture.” *Paras. 39–40. A/HRC/22/53* (2013).

Joint Statement on compulsory drug detention and rehabilitation centres (ILO et al., 2012):

Compulsory drug detention and rehabilitation centres raise human rights issues and threaten the health of detainees, including through increased vulnerability to HIV and [TB] infection.... [S]uch detention often takes place without the benefit of sufficient due process, legal safeguards or judicial review. The deprivation of liberty without due process is an unacceptable violation of internationally recognised human rights standards.

Table 10: TB and the Right to Privacy

Examples of Human Rights Violations	
<ul style="list-style-type: none"> Information about a patient's TB status is disclosed 	
Human Rights Standards	Treaty Body Interpretation
ICCPR 17(1) No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.	None.

Other Interpretations

Recommendations to ensure the diagnosis and treatment of tuberculosis in undocumented migrants (Int'l Union Against Tuberculosis and Lung Disease, 2008):

Recommendation 1. Health authorities and/or health staff should: a) ensure easy access to low-threshold facilities where undocumented migrants who are tuberculosis suspects can be diagnosed and treated without giving their names and without fear of being reported to the police or migration officials, b) remind health staff that they have an obligation to respect confidentiality.

Patients' Charter for Tuberculosis Care (World Care Council, 2006):

Confidence. The right to have personal privacy, dignity, religious beliefs, and culture respected. The right to have information relating to the medical condition kept confidential and released to other authorities contingent upon the patient's consent.

Table 11: TB and Freedom of Expression and the Right to Information

Examples of Human Rights Violations	
<ul style="list-style-type: none"> People who are illiterate may have less knowledge of TB and its signs and symptoms Health care workers fail to give adequate information to patients on the importance of adhering to TB medicine and the possible side effects 	
Human Rights Standards	Treaty Body Interpretation
<p>ICCPR 19(1) Everyone shall have the right to hold opinions without interference.</p> <p>19(2) Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.</p>	None.

Table II (cont.)

Other Interpretations

WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):

Information, counselling and the role of consent. Individuals who undergo TB testing should receive basic information about the nature of TB and why they are being tested. Individuals who are offered TB treatment should be given information about the risks and benefits of the proposed interventions (for both the patient and others in the community), the importance of completing the full course of treatment and of infection control measures, and available support to help patients complete the full course of treatment.

The gap between the availability of drug susceptibility testing and access to M/XDR-TB treatment. For countries that are still scaling up their capacity to supply rapid drug susceptibility testing, decisions about how to treat patients should be made on an individualized basis, taking into account both the local epidemiology and patient-specific factors. These decisions should ideally be made in a consultative process, involving multiple practitioners and, when available, a patient advocate. Education and counselling should be offered to patients.

Resolution WHA 62.15, Prevention and control of multidrug-resistant tuberculosis and extensively drug-resistant tuberculosis (WHO, 2009):

Para. 1(j). Undertake “effective advocacy, communication and social mobilization, avoiding stigmatization and discrimination, and spreading community awareness about policies and plans for prevention and control of tuberculosis including [MDR- and XDR-TB]”.
Resolution WHA 62.15.

WHO Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users (WHO, 2008):

Recommendation 6. All services dealing with drug users should have a case-finding protocol for TB and HIV so that personnel are aware of the symptoms of TB and HIV and can ensure that drug users have access to appropriate TB and HIV testing and counselling, preferably at the service where they initially present.

Recommendation 9. All personnel working with TB suspects and patients, people living with HIV and drug users should be able to assess risk factors for HIV infection and transmission and should provide comprehensive HIV prevention information and services to their clients to minimize these risks. Personnel should also be aware of how to protect themselves from occupational exposure to HIV and TB.

Patients’ Charter for Tuberculosis Care (World Care Council, 2006):

Care. The right to benefit from proactive health sector community outreach, education, and prevention campaigns as part of comprehensive care programs.

Choice. The right to a second medical opinion, with access to previous medical records. The right to accept or refuse surgical interventions if chemotherapy is possible and to be informed of the likely medical and statutory consequences within the context of a communicable disease. The right to choose whether or not to take part in research programs without compromising care.

Information. The right to information about what healthcare services are available for tuberculosis and what responsibilities, engagements, and direct or indirect costs are involved. The right to receive a timely, concise, and clear description of the medical condition, with diagnosis, prognosis (an opinion as to the likely future course of the illness), and treatment proposed, with communication of common risks and appropriate alternatives. The right to know the names and dosages of any medication or intervention to be prescribed, its normal actions and potential side-effects, and its possible impact on other conditions or treatments. The right of access to medical information which relates to the patient’s condition and treatment and to a copy of the medical record if requested by the patient or a person authorized by the patient. The right to meet, share experiences with peers and other patients and to voluntary counseling at any time from diagnosis through treatment completion.

International Standards for Tuberculosis Care (Tuberculosis Coalition for Technical Assistance, 2006):

Standard 9. To foster and assess adherence, a patient-centered approach to administration of drug treatment, based on the patient’s needs and mutual respect between the patient and the provider, should be developed for all patients. Supervision and support should be gender-sensitive and age-specific and should draw on the full range of recommended interventions and available support services, including patient counseling and education....

Table 12: TB and Freedom of Assembly and Association

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • TB patients under quarantine or isolation or in detention are from association with others 	
Human Rights Standards	Treaty Body Interpretation
<p>ICCPR 21. The right of peaceful assembly shall be recognized. No restrictions may be placed on the exercise of this right other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (ordre public), the protection of public health or morals or the protection of the rights and freedoms of others.</p> <p>22(1). Everyone shall have the right to freedom of association with others, including the right to form and join trade unions for the protection of his interests.</p>	None.

Other Interpretations**WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):**

Overarching goals and objectives. TB patients have the right to receive advice and treatment that meets international quality standards, be free of stigmatization and discrimination, establish and join peer support networks, and benefit from accountable representation.

The obligation to provide access to TB services. Focusing on patients as part of their larger communities—Patients should be encouraged to form support groups and to work with their communities to address the social determinants of TB.

Resolution WHA 62.15, Prevention and control of multidrug-resistant tuberculosis and extensively drug-resistant tuberculosis (WHO, 2009):

Para. 1(j). Undertake “effective advocacy, communication and social mobilization, avoiding stigmatization and discrimination, and spreading community awareness about policies and plans for prevention and control of tuberculosis including [MDR- and XDR-TB]”.

Resolution WHA 62.15.

Patients’ Charter for Tuberculosis Care (World Care Council, 2006):

Care. The right to benefit from proactive health sector community outreach, education, and prevention campaigns as part of comprehensive care programs.

Information. The right to meet, share experiences with peers and other patients and to voluntary counseling at any time from diagnosis through treatment completion.

Organization. The right to join, or to establish, organizations of people with or affected by tuberculosis and to seek support for the development of these clubs and community-based associations through the health providers, authorities, and civil society. The right to participate as “stakeholders” in the development, implementation, monitoring, and evaluation of tuberculosis policies and programs with local, national, and international health authorities.

Table 13: TB and the Right to Enjoy the Benefits of Scientific Progress and its Applications

Examples of Human Rights Violations	
<ul style="list-style-type: none"> TB patients in resource-constrained settings may have limited access to high-quality diagnostic services and first- and second-line medicines for treatment Restrictive intellectual property regimes limit access to quality, affordable anti-TB medicines 	
Human Rights Standards	Treaty Body Interpretation
ICESCR 15(1)(b) The States Parties to the present Covenant recognize the right of everyone... [t]o enjoy the benefits of scientific progress and its applications...	None.

Other Interpretations

SR Cultural Rights (2012): *Para. 61.* The Special Rapporteur notes that new incentives have been proposed to ensure innovation and access to medicines at affordable costs, in particular for those living in extreme poverty. Importantly, the WTO Doha Declaration on the TRIPS Agreement and public health explicitly recognizes that the TRIPS Agreement “can and should be interpreted and implemented in a manner supportive of WTO Members’ right to protect public health”, and reaffirmed the right to use the flexibilities included in the Agreement for this purpose. A/HRC/20/26 (2012).

WHO Guidelines for the programmatic management of drug-resistant tuberculosis (WHO, 2011): Extensive discussion of prevention, treatment and care options for MDR- and XDR-TB, including HIV-coinfection.

WHO Model List of Essential Medicines (WHO, 2011).

WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):

The gap between the availability of drug susceptibility testing and access to M/XDR-TB treatment. Countries that implement diagnostic testing in the absence of treatment should do so only as a temporary measure, and should establish a timetable for when treatment for M/XDR-TB will be made available.... As emphasized above, countries and TB programmes should provide universal, free access to drug susceptibility testing; for resource-constrained countries that cannot meet this obligation on their own, the international community should give financial and other support.

Research on TB care and control. There is an urgent need to develop an enhanced evidence base for TB prevention and treatment, and to improve the standard of care. Achieving these goals will be impossible without a greater commitment to research.... The international community should cooperate to develop incentives to encourage this kind of research and development. It is also important to ensure that, as evidence is developed, it is made publicly available and integrated into practice.

WHO Guidance on human rights and involuntary detention for XDR-TB control (WHO, 2007):

WHO places prevention and care of XDR-TB as a priority through the strengthening of basic TB control and the necessary interventions to cure existing cases.... [This] includes ensuring that the capacity to identify and treat drug-resistant TB is in place, with a secure supply of second-line anti-TB drugs required for treating multidrug-resistant TB obtained through the Green Light Committee (in resource-limited settings).... WHO strongly recommends that governments must ensure, as their top priority, that every patient has access to high quality TB diagnosis and treatment for TB and drug-resistant forms of TB.

Berlin Declaration on Tuberculosis (WHO European Ministerial Forum, 2007)

Para. 5(2). We will adopt the Stop TB Strategy in all its components, thereby... allowing and promoting research into and the development of new diagnostics, drugs and vaccines, as well as programme-based operational research. EUR/07/5061622/5 (2007).

Access to medication in the context of pandemics such as HIV/AIDS, tuberculosis and malaria, Resolutions 2005/23, 2004/26, 2003/29 & 2002/32 (UN Commission on Human Rights).

General Comment No. 17: The right of everyone to benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author (art. 15 (1) (c)) (CESCR, 2006):

States parties should ensure that their intellectual property regimes constitute no impediment of their ability to comply with their core obligations in relation to the right to health ... States thus have a duty to prevent that unreasonably high license fees or royalties for access to essential medicines ... undermine the right ... of large segments of the population to health E/C.12/GC/17 (2006).

Table 13 (cont.)

Other Interpretations

Political Declaration on HIV/AIDS (UN General Assembly, 2006):

Para. 33. Emphasize the need for accelerated scale-up of collaborative activities on tuberculosis and HIV, in line with the Global Plan to Stop TB 2006–2015, and for investment in new drugs, diagnostics and vaccines that are appropriate for people with TB-HIV co-infection.

Abuja Call for Accelerated Action Towards Universal Access to HIV/AIDS, Tuberculosis and Malaria Services in Africa (African Union, 2006):

Research and Development. To promote and support research and development of microbicides, vaccines, diagnostics and treatment for HIV and AIDS, TB and malaria, including traditional medicine. Sp/Assembly/ATM/2 (I) Rev.3 (2006).

Doha Declaration on the TRIPS Agreement and Public Health (World Trade Organization, 2001):

Para. 4. [T]he TRIPS agreement does not and should not prevent Members from taking measures to protect public health ... in particular to promote access to medicines for all.... Each member has the right to grant compulsory licences and the freedom to determine the grounds upon which such licences are granted...[and] the right to determine what constitutes a national emergency or other circumstances of extreme urgency, it being understood that public health crises, including those relating to HIV/AIDS, tuberculosis, malaria and other epidemics, can represent a national emergency or other circumstances of extreme urgency. WT/MIN(01)/DEC/2 (2001).

Amsterdam Declaration to Stop TB (WHO Ministerial Conference on “TB and Sustainable Development”, 2000):

Part V. [A]ccelerate basic & operational research for the development & delivery of new tools, including diagnostics, drugs & vaccines, & pay attention to the need for improved incentives for drug & vaccine development in a manner consistent with affordability & accessibility of such new products

Table 14: TB and the Rights of Women

Examples of Human Rights Violations	
<ul style="list-style-type: none"> • Women have less decision-making power over the use of household resources • Women may not leave the house to seek care without the company of a male relative 	
Human Rights Standards	Treaty Body Interpretation
CEDAW 12(1) States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.	<p>CEDAW: Recommending that Kyrgyzstan “strengthen measures to reduce ... the spread of tuberculosis and other diseases among women.” CE-DAW/C/KGZ/CO/3 (2008).</p> <p>CEDAW: Expressing concern to the increase of tuberculosis among women to Estonia A/57/38(SUPP) (2002), Vietnam A/56/38(SUPP) (2001), and Lithuania A/55/38(SUPP) (2000).</p>

Other Interpretations

UN Commission on the Status of Women (2011): Calls on Governments to integrate HIV prevention, voluntary counselling and voluntary testing of HIV into other health services, including sexual and reproductive health, family planning, maternity and tuberculosis services. *Resolution 55/2* (2011).

Women’s health in prison: Action guidance and checklists to review current policies and practices (WHO, UNODC, 2011):

Para. 1. The underlying importance of human rights should underpin all thinking and all policy development for all those in compulsory detention.

Para. 3. Key services to be provided should include... specialist health care, which is readily provided and adjusted to meet the needs of women, such as for... chronic health conditions, HIV and AIDS (including counselling and support), hepatitis, tuberculosis (TB) and other infectious diseases....

WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):

The obligation to provide access to TB services. Interventions should be gender-sensitive and address different types of vulnerabilities.... In addition, the needs of women, children, and people coinfected with HIV warrant special consideration.

Table 14 (cont.)

Other Interpretations

Agreed Conclusions of the Commission on the Status of Women on the Critical Areas of Concern of the Beijing Platform for Action 1996-2009 (UN DESA, 2010): Recommending that governments, the UN system and civil society undertake measures to: “[i]ncrease the preventive, as well as the therapeutic, measures against **tuberculosis** and malaria”; intensify “support of national efforts against HIV/AIDS, particularly in favour of women and young girls, including efforts to provide affordable antiretroviral drugs, diagnostics and **drugs to treat tuberculosis** and other opportunistic infections”; “incorporate gender perspectives and human rights in health-sector policies and programmes”; and “recognize that the lack of economic empowerment and independence increased women’s vulnerability to a range of negative consequences, involving the risk of contracting HIV/AIDS, malaria, **tuberculosis** and other poverty-related diseases” ST/ESA/327 (2010).

Resolution WHA 62.15, Prevention and control of multidrug-resistant tuberculosis and extensively drug-resistant tuberculosis (WHO, 2009):

Para. 4. Urging member states “to increase investment by countries and all partners substantially in operational research and research and development for new diagnostics, medicines and vaccines to prevent and manage tuberculosis including multidrug-resistant and extensively drug-resistant tuberculosis”. *Resolution WHA 62.15.*

Beijing Call for Action on Tuberculosis control and patient care: together addressing the global MDR-TB and XDR-TB epidemic (WHO, 2009):

Para. 1(i). ...[S]upporting developing countries to establish manufacturing plants to produce combined preparations of anti-TB medicines ... to ensure adequate drug supply for the prevention and control of M/XDR-TB.

Table 15: TB and the Rights of Children

Examples of Human Rights Violations

- Children are malnourished and at risk of TB infection
- Children live in households affected by TB

Human Rights Standards

CRC 24(1) States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

Treaty Body Interpretation

CRC: Expressing concern to **Portugal** that “Infant mortality, under-5 mortality and child tuberculosis rates remain higher than the regional average, particularly in some northern rural areas, and are also too high in the Azores” and recommending that the State “[i]ncrease investment in public health care facilities, including investments by civil society” and “[e]nsure the equal access of all children to the highest attainable standard of health care in all areas of the country.” CRC/C/15/Add.162 (2001).

Table 15 (cont.)

Human Rights Standards	Treaty Body Interpretation
<p>CRC 24(1) States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.</p>	<p>CRC: Expressing concern to Uzbekistan “at the increasing number of children infected with preventable diseases, such as Tuberculosis ...” and recommending that the State “[c]ontinue its reform of the health sector and its efforts to strengthen the primary care centres and the preventive health services.” CRC/C/ UZB/CO/2 (2006).</p> <p>CRC: Expressing concern in Armenia about “the continuous growth in tuberculosis morbidity among children” and recommending that the government “[t]ake measures to reduce child and infant mortality rates and combat tuberculosis.” CRC/C/15/Add.225 (2004).</p> <p>CRC: Expressing concern Gabon that it continues “to be threatened by early childhood diseases such as ... tuberculosis” and recommending that it “[r]einforce its efforts to allocate appropriate resources and develop and implement comprehensive policies and programmes to improve the health situation of children, particularly in rural areas” and “[f]acilitate greater access to primary health service.” CRC/C/15/Add.171 (2002).</p> <p>CRC: Expressing concern to Uzbekistan at the “high incidence of infectious diseases, such as tuberculosis, despite high rates of immunization” and recommending the State “[i]mplement the 2000 Amsterdam Declaration to Stop TB.” CRC/C/15/Add.167 (2001).</p> <p>CRC: Expressing concern to Ethiopia “at the high incidence of malaria and tuberculosis and their effects upon children, at the fragile health infrastructure, limited health awareness among the public and the limited implementation of the 1993 Health Policy and the 1994 Social Policy” and urging the State to “ensure that access to primary health care services is increased, that national health infrastructure is strengthened and that public health education programmes are used to lower infant mortality rates and raise life expectancy in the State party.” CRC/C/15/Add.144 (2001).</p> <p>CRC: Expressing concern to Lithuania “at the high rates of child morbidity, in particular the increase in cases of tuberculosis” and recommending that the State “allocate appropriate resources and develop comprehensive policies and programmes to improve the health situation of all children.” CRC/C/15/Add.146 (2001).</p> <p>CRC: Noting that Mauritania has a “resurgence of tuberculosis” and recommending that the State “[a]llocate appropriate resources and develop comprehensive policies and programmes to improve the health situation of all children without discrimination, in particular by focusing more on primary care and further decentralizing the health care system.” CRC/C/15/ADD.159 (2001).</p> <p>CRC: Noting that Moldova has a “high incidence of tuberculosis ... in schoolchildren” and recommending that the State “[d]efine sustainable financing mechanisms for the health care system, including adequate salaries for child health care professionals, in order to ensure that all children, in particular children from the most vulnerable groups, have access to free basic health care of good quality.” CRC/C/15/Add.192 (2002).</p>

Table 15 (cont.)

Other Interpretations

WHO Model List of Essential Medicines, Children (WHO, 2011).

WHO Guidance on ethics of tuberculosis prevention, care and control (WHO, 2010):

The obligation to provide access to TB services. Interventions should be gender-sensitive and address different types of vulnerabilities.... In addition, the needs of women, children, and people coinfectd with HIV warrant special consideration.

WHO Guidelines for the programmatic management of drug-resistant tuberculosis: Emergency Update (WHO, 2008): Extensive discussion of TB prevention, treatment and care options for children. Select recommendations:

9.5 *Children.* ...Anecdotal evidence suggests that adolescents are at high risk for poor treatment outcomes. Early diagnosis, strong social support, individual and family counselling and a close relationship with the medical provider may help to improve outcomes in this group.

WHO Guidance for national tuberculosis programmes on the management of tuberculosis in children (WHO, 2006).

Abuja Call for Accelerated Action Towards Universal Access to HIV/AIDS, Tuberculosis and Malaria Services in Africa (African Union, 2006):

Protection of Human Rights. To continue promoting an enabling policy, legal and social environment that promotes human rights particularly for women, youth and children and ensure the protection of people infected and affected by HIV and AIDS, TB and Malaria....

Prevention, Treatment, Care and Support. To invest heavily in evidence-based prevention as the most cost-effective intervention with focus on young people, women, girls and other vulnerable groups. Sp/Assembly/ATM/2 (I) Rev.3 (2006).

Patients' Charter for Tuberculosis Care (World Care Council, 2006):

Care. The right to free and equitable access to tuberculosis care, from diagnosis through treatment completion, regardless of resources, race, gender, age, language, legal status, religious beliefs, sexual orientation, culture, or having another illness.

CRC, General Comment 3 (2003): "In the context of HIV/AIDS and taking into account the evolving capacities of the child, States parties are encouraged to ensure that health services employ trained personnel who fully respect the rights of children to privacy (art. 16) and non-discrimination in offering them... HIV-related care and treatment if and when needed, including for the prevention and treatment of health problems related to HIV/AIDS, e.g. tuberculosis and opportunistic infections." CRC/GC/2003 (2003)

3. WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION AND PROGRAMMING?

What is a human rights-based approach?

“Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans.”²¹¹

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

- The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights.
- Human rights principles include: “universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law.”²¹² They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.
- Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States).²¹³ With respect to programming, this requires “[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights.”²¹⁴

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

²¹¹ Yamin AE, “Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care,” *Health and Human Rights* 10, no. 1 (2008).

²¹² For a brief explanation of these principles, see UN Development Group (UNDG), *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies* (May 2003), available at: www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf.

²¹³ Ibid

²¹⁴ Ibid

What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- **Participation:** Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- **Accountability:** Does the activity identify both the entitlements of claim-holders and the obligations of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors involved held accountable for their actions? Are both outcomes and processes monitored and evaluated?
- **Non-discrimination:** Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment:** Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights:** Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability:** Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.²¹⁵ Other benefits to implementing a human rights-based approach include:

- **Participation:** Increases and strengthens the participation of the local community.
- **Accountability:** Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- **Empowerment:** Capacity building.
- **Linkage to rights:** Promotes the realization of human rights and greater impact on policy and practice.
- **Sustainability:** Promotes sustainable results and sustained change.

²¹⁵ Gauri V & Gloppen S, *Human Rights Based Approaches to Development: Concepts, Evidence, and Policy*, World Bank Policy Research Working Paper 5938 (Jan. 2012). <http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938>.

How can a human rights-based approach be used?

- A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:
- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- Develop guidelines and standards.
- Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.

4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS-BASED WORK IN THE AREA OF TB?

This section contains **four examples** of effective human rights-based work in the area of TB and human rights. These are:

1. Defining the grounds for compulsory isolation of a patient with an infectious disease
2. Development of a Patient Network to fight TB in Peru
3. Advocating for the constitutional rights of TB patients in Kenya
4. Litigating for prisoners exposed to TB in South African prisons

Example I: Defining the grounds for compulsory isolation of a patient with an infectious disease

Enhorn v. Sweden, app. No. 56529/00 (Jan. 25, 2005).

Available at: <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-68077>

Project Type

Litigation

Actor

Mr. Eie Enhorn suffered from an infectious disease that Swedish law listed as a threat to public health (HIV/AIDS). Pursuant to a national public health law drafted to stem the spread of infectious disease, Sweden ordered the compulsory isolation of Mr. Enhorn. Mrs. E. Hagstrom, a legal aid attorney practicing in Stockholm, represented the interests of Mr. Enhorn before the European Court of Human Rights.

Problem

Although the petitioner in this case suffered from HIV, the main issue the Court considered concerned the powers of a State Party to the European Convention on Human Rights to order compulsory isolation of an individual with an infectious disease.

Legality of Involuntary Detention of TB Patients in Select European States

	Detention	Isolation on grounds of exposure	Exclusion from activities	Number of control measures
<i>Spain</i>	N	N	N	0
<i>France</i>	N	N	Y	2
<i>Germany</i>	Y	N	N	2
<i>Israel</i>	Y	N	Y	2
<i>Netherlands</i>	N	N	N	2
<i>Finland</i>	N	N	Y	3
<i>Poland</i>	N	N	Y	3
<i>England</i>	Y	N	Y	4
<i>Estonia</i>	Y	N	N	4
<i>Hungary</i>	N	N	Y	4
<i>Switzerland</i>	Y	N	N	4
<i>Czech</i>	Y	N	Y	5
<i>Norway</i>	Y	Y	Y	6
<i>Russia</i>	Y	N	Y	6

Adapted from Coker R, *Public Health Law and Tuberculosis Control in Europe*, Public Health 121, no. 4 [2007]: 266-73).

This case is centrally important to Europeans who suffer from TB and who are at risk of involuntary detention. Extensively drug-resistant tuberculosis (XDR-TB) and multi-drug resistant tuberculosis (MDR-TB)—in particular—raise the question of whether involuntary detention is justified where voluntary measures have failed or where the patient poses a danger to public health. A number of countries in Europe currently allow for involuntary detention of TB patients (see chart, above)

Legal Conflict

ECHR, Article 5 § 1

1. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:

(e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants.

The 1988 Infectious Diseases Act (Sweden)

Section 38: “The County Administrative Court, on being petitioned by the county medical officer, shall make an order for the compulsory isolation of a person infected with a disease dangerous to society if that person does not voluntarily comply with the measures needed in order to prevent the infection from spreading. An order of this kind shall also be made if there is *reasonable cause* to suppose that the infected person is not complying with the practical instructions issued and this omission entails a *manifest risk* of the infection being spread. Compulsory isolation shall take place in a hospital run by a county council. (emphasis supplied).

Procedure

An Administrative Court in Sweden tasked with hearing section 38 actions (see side box) ordered the compulsory isolation of Mr. Enhorn. The Administrative Court of Appeals upheld Mr. Enhorn’s compulsory isolation. Having exhausted his domestic remedies, Mr. Enhorn brought a human-rights claim before the European Court of Human Rights to challenge his compulsory isolation.

Arguments & Holdings

Existence of “*reasonable cause*” and “*manifest risk*” as required under the domestic law. The state ordered compulsory isolation of the applicant pursuant to section 38 of the Infectious Disease Act (Sweden), which requires *reasonable cause* to suppose that the infected person is not complying with the practical instructions issued. It further requires that this omission entails a *manifest risk* of the infection being spread. did not create the manifest risk of spreading the disease. The Court, however, found that the applicant’s sexual history, which included the infection of a 19-year-old man, misuse of alcohol and failure to follow instructions of medical professionals provided “*reasonable cause*” to believe that the applicant would not follow future healthcare orders and that his likely omission to follow orders would create a manifest risk of spreading his infection. Therefore, the Court found that the Government satisfied its obligations under section 38, and Mr. Enhorn’s compulsory isolation was legal under Swedish law.

Whether detention and deprivation of liberty was justified under Article 5 § 1(e). The Court itself noted that it had scant jurisprudence on the issue of detaining a person “for the prevention of the spreading of infectious diseases.” The Court, therefore, outlined the criteria for determining whether a State Party’s compulsory isolation of an individual to control infectious disease satisfied Article 5 § 1(e) of the European Convention on Human Rights:

The detention of an individual is such a serious measure that it is only justified where other, less severe measures have been considered and found to be insufficient to safeguard the individual or the public interest which might require that the person concerned be detained. That means that it does not suffice that the deprivation of liberty is in conformity with national law, it must also be necessary in the circumstances . . . and in accordance with the principle of proportionality . . . (citations omitted).

The Court found that the Government never provided examples of less severe measures that were shown to be insufficient to safeguard the public health from the risk of infection. Therefore, the Court held that the compulsory isolation of Mr. Enhorn violated Article 5 § 1 of the ECHR.

Commentary & Analysis

This case is important because it establishes criteria for determining whether the compulsory isolation of an individual with an infectious disease is justified under the ECHR. Isolation in accordance with the national law of a State Party is not sufficient to pass scrutiny under the ECHR. To justify isolation of a TB patient or any other patient on the basis of the health threat posed by their infectious disease, a State Party must show that isolation of the patient is:

- *Necessary*—that the State Party considered less severe measures and found them to be insufficient to safeguard the health of the individual or public; and
- *Proportional*—that the degree and length of isolation is proportional to the threat to the individual's health or public health.

Compulsory detention statutes in Europe, as outlined in the chart above, are susceptible to challenges made on human rights grounds.

The applicant argued that the statute's required showing of "reasonable cause" and "manifest risk" were too vague. The statute lacked clearness and foreseeability, which would allow him to understand what constituted prohibited conduct. In the alternative, he argued that his actions did not create the manifest risk of spreading the disease. The Court, however, found that the applicant's sexual history, which included the infection of a 19-year-old man, misuse of alcohol and failure to follow instructions of medical professionals provided "reasonable cause" to believe that the applicant would not follow future healthcare orders and that his likely omission to follow orders would create a manifest risk of spreading his infection. Therefore, the Court found that the Government satisfied its obligations under section 38, and Mr. Enhorn's compulsory isolation was legal under Swedish law.

Whether detention and deprivation of liberty was justified under Article 5 § 1(e). The Court itself noted that it had scant jurisprudence on the issue of detaining a person "for the prevention of the spreading of infectious diseases." The Court, therefore, outlined the criteria for determining whether a State Party's compulsory isolation of an individual to control infectious disease satisfied Article 5 § 1(e) of the European Convention on Human Rights:

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- *Proportional*—that the degree and length of isolation is proportional to the threat to the individual's health or public health.

Compulsory detention statutes in Europe, as outlined in the chart above, are susceptible to challenges made on human rights grounds.

WHO Opinion

Interference with freedom of movement when instituting quarantine or isolation for a communicable disease such as MDR-TB and XDR-TB may be necessary for the public good, and could be considered legitimate under international human rights law. **This must be viewed as a last resort, and justified only after all voluntary measures to isolate such a patient have failed.**

A key factor in determining if the necessary protections exist when rights are restricted is that each one of the five criteria of the Siracusa Principles must be met, but should be of a limited duration and subject to review and appeal. The Siracusa principles are:

- The restriction is provided for and carried out in accordance with the law;
- The restriction is in the interest of a legitimate objective general interest;
- The restriction is strictly necessary in a democratic society to achieve the objective;
- There are no less intrusive and restrictive means available to reach the same objective;
- The restriction is based on scientific evidence and not drafted or imposed arbitrarily i.e. in an unreasonable or otherwise discriminatory manner.

Source: www.who.int/tb/features_archive/involuntary_treatment

Additional Sources: World Health Organization, Report of the Meeting of the WHO Global Task Force on XDR-TB (Oct. 9-10 2006). www.who.int/tb/challenges/xdr/globaltaskforcereport_octo6.pdf; Geneviève Pinet, World Health Organization, Good Practice in Legislation and Regulations for TB Control: An Indicator of Political Will (2001). http://apps.who.int/iris/bitstream/10665/68708/1/WHO_CDS_TB_2001.290.pdf

Example 2: Development of a Patient Network to fight TB in Peru

Project Type

Advocacy

Organization

The Peruvian Patient Network (PPN) formed in 2007 after several months of intense mobilization by patient organizations, human rights groups, and civil society organizations in Peru. PPN has a small staff and an annual budget under USD \$1,000, but it is supported by the Ombudsman of Peru, the Ombudsman at the Ministry of Health, the Peruvian Medical Association and the Pan American Health Organization.

Problem

Peru has long struggled with tuberculosis (TB). In the 1960s, Peru was estimated to have the highest case rates of TB in Latin America. Incidence and mortality rates fell in the early 1990s, largely due to Peru's implementation of directly observed treatment short (DOTS), the internationally recommended strategy for TB control. But these gains were ephemeral. According to a 2009 report by USAID, "[i]n the past few years, Peru's National TB Program (NTP) has been hindered by serious administrative and funding problems in the Ministry of Health (MOH). These problems led to deterioration of the TB situation"

Actions Taken

With ongoing threats to health and human rights in Peru, PPN believes in vigilance, advocacy and the training of advocates:

- *Vigilance.* Helping to guarantee constant access to medicine and to ensure the regulation of patents.
- *Advocacy.* Lobbying the government to promote policies that promote health and prevent illness; seeking additional resources for the first level of health care and leading a declaration of a state of emergency in the health system for non-contagious diseases.
- *Capacity building and training.* Training activists to engage—at the community level—in the decentralization of the health care system, assist in health promotion and access to medicines.

PPN works with other patient organizations, including the National Coalition of Cancer Patients, Mental health Patients and Patients Living with HIV/AIDS. Importantly, PPN also integrates groups of patients with TB and others who have suffered adverse consequences from the health care system. Working together with the government, patients and patient organizations, PPN advocates for human rights within the context of health care.

Results & Lessons Learned

In 2004, a reorganization of the MOH created the National Sanitary Strategy for the Prevention and Control of Tuberculosis (ESNTBC) to replace the failed NTP. Universal access to multi-drug resistant tuberculosis (MDR TB) diagnosis and treatment is now a reality in Peru.

PPN faced a range of challenges in their interactions with stakeholders and government leaders. Among those challenges were a lack of time and resources. In addition, PPN often found it difficult to compete for the attention of and then convince influential administrators and government leaders who sometimes had conflicting interests. To overcome these challenges, PPN learned that it is important to build and encourage development of regional, national and international networks of patients. Doing so develops information and knowledge, builds capacity, lets voices be heard and increases the status of the organization. A network promotes quality health care services that respect human rights.

Peruvian Network for Patients and Users

(PROSA, Program for the Self-Help and Support of Seropositive Persons)

Lima, PeruE-mail: prosa@prosa.org.pe

Website: <http://prosa.org.pe>

Example 3: Advocating for the constitutional rights of TB patients in Kenya

Project Type

Advocacy

Organization

KELIN is a national network that responds to human rights concerns relating to health, including TB and HIV.

Problem

In October 2012, a patient at Kenyatta National Hospital in Nairobi was diagnosed with “extensively drug-resistant” tuberculosis (XDR-TB). The patient—known as “Mrs. X” to protect her anonymity—is one of about 600 people confirmed to be living with drug-resistant TB in Kenya. Fewer than half of these patients receive the treatment they need to get better and prevent further spread of the infectious disease. XDR-TB, which has been reported in 69 countries globally, describes strains of tuberculosis that are resistant to the two most powerful anti-TB medicines and at least three of the six classes of secondary medicines. Because of this resistance, treatment can take longer than two years and patients must take medicines that are very difficult for the body to tolerate.

At a policy level, the Kenyan government is committed to giving its citizens the highest attainable standard of health, as enshrined in Article 43(1) of the Constitution. As part of this commitment, the country adopted the WHO’s international standards of TB care and patients’ charter for tuberculosis care, which endorse free TB treatment as a government responsibility. Despite this, Mrs. X was left for four months without receiving proper treatment. She was finally prescribed three expensive medicines, but was forced to pay for two of these herself. The third medicine, Viomycin, is not registered for use in Kenya and was therefore inaccessible to Mrs. X and other patients.

Mrs. X says the situation has put tremendous financial and psychological stress on her and her family. “The way in which I have been treated by the public health service is making it very difficult to survive,” she said. “My family has to find 16,000 shillings (approx. \$200) for drugs every week. All I want is for the government to provide me with the medicine that I need without making me pay for it myself.”

Actions Taken

Advocates at KELIN have taken on Mrs. X’s case. Working with 15 other civil society organizations, KELIN delivered an advisory note to government ministers and Kenya’s Attorney General outlining the facts of the cause and urging immediate action. In an official statement, KELIN attorney Allan Maleche said, “One of Kenya’s Millennium Development Goals is to reduce the incidence and mortality due to TB by 2015 and to eradicate it completely by 2050, but the Government is not addressing TB with the level of seriousness it deserves, particularly as it is a matter concerning the individual, community, national and global public health.”

Results & Lessons Learned

Following the civil society action, the Kenyan government agreed in 2012 to provide Mrs. X with the two available TB drugs at no cost, but it stressed that it is unable to guarantee the supply of these drugs beyond a few weeks. Mrs. X needs at least several months of treatment to overcome XDR-TB. She also needs the third medicine, Viomycin, but that remains unavailable in Kenya.

At last report in January 2013, Mrs. X's health was improving. She was responding well to the medication, although she remained concerned about receiving refunds from the Government for the costs of laboratory tests that she has incurred.

Although government efforts to provide some of the necessary drugs are a positive development, concrete actions are needed to improve policies and programs to detect and treat drug-resistant TB and realize the commitments in Kenya's Constitution. Civil society organizations, like those coordinated by KELIN, play an important role to hold governments accountable for designing and implementing policies that meet patients' needs. Without them, it is unlikely that patients like Mrs. X will receive the medications and support needed to get well.

KELIN

Nairobi, Kenya

Email: info@kelinkenya.org

Website: www.kelinkenya.org

Example 4: Litigating for prisoners exposed to TB in South African prisons

*Lee v. Minister for Correctional Services, Constitutional Court of South Africa, Case CCT 20/12 [2012] ZACC 30.*²¹⁶ www.saflii.org/za/cases/ZACC/2012/30.html.

Project Type
Litigation

Actor

Mr. Dudley Lee was incarcerated in Pollsmoor Maximum Security Prison outside Cape Town, South Africa, from 1999 to 2004 on charges of counterfeiting, fraud and money laundering, among others. The prison was at over 200% occupancy and notoriously crowded, with 3 men in single cells and 40 to 60 men in communal cells. Inmates were confined in close contact for as much as 23 hours every day.

Mr. Lee was 53 years old when he entered Pollsmoor and he did not have TB. In June 2003, he was diagnosed with pulmonary TB. According to SECTION27, a public interest law center providing amicus support: “In September 2004—over four years after entering prison—he was acquitted of the charges against him and released. He then sued the Minister of Correctional Services in the Western Cape High Court in Cape Town for negligently causing him to become infected with TB.”

The Problem

South Africa has one of the highest rates of TB incidence in the world. TB is the country’s leading cause of death and is often compounded by HIV co-infection and drug resistant strains of TB. The risk is especially high in prisons, which combine overcrowding, poor nutrition and sanitation, poor health care, and inadequate infection control measures.

Under the South African Constitution, all individuals—including prisoners—have the right to life, to freedom and security of the person, and to be detained in “conditions of detention that are consistent with human dignity, including at least exercise and the provision, at state expense, of adequate accommodation, nutrition, reading material and medical treatment”. Furthermore, Standing Correctional Orders require prison officials to screen, isolate, separate and treat prisoners infected with or at risk of TB.

In this case, Mr. Lee sued the South African government for negligence in its systemic failure to take preventive and precautionary measures in prison, causing him to be infected with TB. The lawsuit shows how litigation to enforce constitutional and statutory obligations can protect the rights of prisoners at risk of TB.

²¹⁶ This case study content is adapted from the case opinions, as well as content from Section 27 (www.section27.org.za). See *Lee v. Minister of Correctional Services* 2011 (6) SA 564 (WCC) (High Court Judgment), www.saflii.org/za/cases/ZAWCHC/2011/13.pdf; *Minister of Correctional Services v. Lee* 2012 (3) SA 617 (SCA) (Supreme Court of Appeal Judgment), www.saflii.org/za/cases/ZASCA/2012/23.pdf; and John Stephens, “Dudley Lee v Minister of Correctional Services, what will it mean for South Africa?”, *Health-e*, Aug. 28, 2012, www.health-e.org.za/news/article.php?uid=20033738.

South African Constitution Chapter 2, Bill of Rights

Section 10. Everyone has inherent dignity and the right to have their dignity respected and protected.

Section 11. Everyone has the right to life.

Section 12(1). Everyone has the right to freedom and security of the person, which includes the right:

- (a) not to be deprived of freedom arbitrarily or without just cause;
- (b) not to be detained without trial;
- (c) to be free from all forms of violence from either public or private sources;
- (d) not to be tortured in any way; and
- (e) not to be treated or punished in a cruel, inhuman or degrading way.

Section 35(2)(e). Everyone who is detained, including every sentenced prisoner, has the right... to conditions of detention that are consistent with human dignity, including at least exercise and the provision, at state expense, of adequate accommodation, nutrition, reading material and medical treatment....

Procedure

High Court. Mr. Lee filed suit in 2004. The case went to trial in 2009 and 2010. In 2011, the High Court ruled in his favor. It held that prison authorities failed to take adequate, or even any, steps to protect him against the risk of TB—including prevention, diagnosis and treatment measures, as well as adequate staffing, health care and nutrition.

Supreme Court of Appeal. In 2012, the Minister appealed to the Supreme Court of Appeal (SCA) which ruled against Mr. Lee. It found that prison authorities were in breach of their duties. However, Mr. Lee could not prove that their negligence caused his TB since he could not identify the “source” of his infection or show that reasonable precautions would have “altogether eliminated” the risk of infection.

Constitutional Court. Mr. Lee appealed to the Constitutional Court in 2012. The Treatment Action Campaign, Centre for Applied Legal Studies, and Wits Justice Project, represented by SECTION27, were admitted as amici curiae (friends of the court).

Arguments and Holdings

The Constitutional Court considered the following issues on the merits: (1) whether the Minister’s negligent conduct caused Mr. Lee to contract TB; (2) if not, whether the common law needed to be developed to give effect to his constitutional rights and to avoid injustice.

The Court found that the SCA applied an unduly inflexible standard in determining the issue of causation. The SCA should have simply considered whether the conditions of Mr. Lee’s incarceration were a more probable cause of his tuberculosis than if the conditions had been different. Instead, the SCA required Mr. Lee to prove that reasonable systemic measures by prison authorities would have totally eliminated the risk of TB—a standard no inmate could ever meet.

The Court upheld Mr. Lee's claim, noting that important democratic and constitutional issues were at stake:

The responsible authorities' function is to execute its duties in accordance with the purposes of the [Correctional Services Act] which include detaining all inmates in safe custody whilst ensuring their human dignity and providing adequate health care services for every inmate to lead a healthy life. The rule of law requires that all those who exercise public power must do so in accordance with the law and the Constitution. This, including the requirements of accountability and responsiveness, provides 'additional' reasons for finding in favour of the applicant and imposing delictual liability.

Analysis and Commentary

This case is an example of an individual bringing a successful claim for constitutional damages against his government for human rights violations in prison. It is also an examples of lawyers and civil society organizations taking an active role in developing jurisprudence on TB-related rights in South Africa.

The decision takes a humane and pragmatic approach to factual causation in cases of negligent omission by prison officials: instead of mechanistically requiring the applicant to prove that proper action would have eliminated all risk of TB, it simply requires him to show that his actual conditions were likely the cause of his TB infection. It takes a similar approach to legal causation as it relates to the positive duty of the state: proper action simply means taking “reasonable measures to reduce the risk of contagion”—here, complying with the statutory obligation to screen, isolate, examine, report, etc.

The decision illustrates a common theme in health and human rights: that flexibility is often essential to ensuring justice for vulnerable individuals, whether it's in the provision of tailored treatment for MDR-TB patients or in the provision of legal remedies for prisoners with TB. It is therefore very innovative and sets a precedent for developing favorable case law for prisoners with TB.

SECTION27

Braamfontein, South Africa

E-mail: info@section27.org.za

Website: www.section27.org.za

Treatment Action Campaign (TAC)

Cape Town, South Africa

Website: www.tac.org.za

Wits Justice Project

South Africa

Website: www.witsjusticeproject.com

5. WHERE CAN I FIND ADDITIONAL RESOURCES ON TB AND HUMAN RIGHTS?

A list of commonly used resources on TB and human rights follows.
It is organized into the following categories:

- A. International Instruments
- B. Regional Instruments
- C. Other Declarations and Statements
- D. Human Rights and TB – General Resources
- E. Right to Non-discrimination
- F. Right to Health
- G. Freedom from Arbitrary Arrest and Detention
- H. Right of All Persons Deprived of their Liberty to be Treated with Humanity
- I. Freedom from Torture or Cruel, Unusual or Degrading Punishment
- J. Right to Privacy
- K. Freedom of Assembly and Association
- L. Right to Enjoy the Benefits of Scientific Progress and its Applications
- M. Rights of Women
- N. Rights of Children
- O. Key Populations – People Living with HIV
- P. Key Populations – People Who Use Drugs
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6. WHAT ARE KEY TERMS RELATED TO TB AND HUMAN RIGHTS?

A variety of terms is used in TB and human rights work. All definitions are adapted from the WHO unless otherwise indicated.

A

Active TB

Tuberculosis disease associated with symptoms or signs, including findings on physical examination.

Adherence

Active, voluntary and collaborative involvement of the patient in a mutually acceptable course of behavior (including taking the prescribed dose of a particular medicine at the recommended time) to produce the desired therapeutic results.

Adherence support

Adherence support refers to medical, social and economic initiatives to help patients who face barriers to accessing TB treatment and care. Examples include providing travel vouchers or transportation to health care facilities, food packages, peer support, education and follow-up, and engaging community health workers to accompany patients as they access health care.²¹⁷

Anti-retroviral therapy (ART)

Anti-retroviral drugs inhibit various phases of the life-cycle of the human immunodeficiency virus (HIV), thus reducing HIV-related symptoms and prolonging life expectancy of people living with HIV.

B

BCG (Bacille-Calmette-Guérin) vaccine

A live vaccine against TB derived from an attenuated strain of *Mycobacterium bovis*. The vaccine protects against severe forms of TB in children (TB meningitis and miliary TB), but its efficacy in preventing pulmonary TB in adults is highly variable.

C

Community-based care

Activities conducted outside of formal health facilities (hospitals, health centres and clinics) using community-based structures (such as schools, places of worship and congregate settings, homes). Care is often provided by trained lay and community health workers in patients' homes.

Culture

Test to determine whether there are TB bacteria in a person's phlegm or other body fluids. This involves growing organisms on or in media (liquid or solid substances containing nutrients) so that they can be identified. Results can take 2 to 4 weeks in most laboratories.²¹⁸

²¹⁷ WHO, *Global Tuberculosis Control* 2012 (2012).

²¹⁸ CDC, *Core Curriculum on Tuberculosis: What the Clinician Should Know* (2013). www.cdc.gov/tb/education/corecurr/pdf/corecurr_all.pdf.

D**Directly observed therapy (DOT)**

An adherence-enhancing strategy in which a healthcare worker or other trained person watches a patient swallow each dose of medication and is accountable to the public health system. DOT is the preferred method of care for all patients with TB disease and is a preferred option for patients under treatment for latent infection.²¹⁹

Drug-resistant TB

TB disease caused by *Mycobacterium tuberculosis* organisms that are resistant to at least one first-line anti-tuberculosis drug.

Drug-susceptibility test (DST)

A laboratory determination to assess whether an *M. tuberculosis* complex isolate is susceptible or resistant to anti-TB drugs that are added to mycobacterial growth medium. The results predict whether a specific drug is likely to be effective in treating TB disease caused by that isolate.²²⁰

E**Extensively drug-resistant TB (XDR TB)**

A form of TB caused by bacteria resistant to all the most effective drugs (i.e. MDR-TB plus resistance to any fluoroquinolone and any of the second-line anti-TB injectable drugs: amikacin, kanamycin or capreomycin).

Extrapulmonary TB

Patient with tuberculosis of organs other than the lungs (e.g. pleura, lymph nodes, abdomen, genitourinary tract, skin, joints and bones, meninges).

H**Harm reduction**

Refers to a set of interventions designed to diminish the individual and societal harms associated with drug use, including the risk of HIV infection, without requiring the cessation of drug use. In practice, harm reduction programs include syringe exchange, drug substitution or replacement therapy using substances such as methadone, health and drug education, HIV and sexually transmitted disease screening, psychological counseling, and medical care.

High burden country

One of the 22 countries which together account for approximately 80% of all new TB cases arising each year. The WHO also identifies another 27 high MDR-TB burden countries that concentrate more than 85% of MDR-TB cases emerging globally.²²¹

HIV infection

Infection with the human immunodeficiency virus (HIV) the virus that causes AIDS (acquired immunodeficiency syndrome). A person with both latent TB infection and HIV infection is at very high risk for developing TB disease.²²²

²¹⁹ National Tuberculosis Curriculum Consortium (NTCC), "Tuberculosis Glossary". http://ntcc.ucsd.edu/NTCC_glossary.pdf.

²²⁰ NTCC, "Tuberculosis Glossary". http://ntcc.ucsd.edu/NTCC_glossary.pdf.

²²¹ Centers for Disease Control and Prevention, Core Curriculum on Tuberculosis: What the Clinician Should Know (2013). www.cdc.gov/tb/education/corecurr/pdf/corecurr_all.pdf.

²²² TB CARE I, Guidelines to Measure the Prevalence of Active TB Disease Among Health Care Workers, USAID (2012). www.tbcare1.org/publications/toolbox/tools/hss/HCW_TB_Prevalence_Measuring_Guidelines.pdf.

I**Infectious TB**

Active TB that is transmissible to others, i.e. contagious, usually determined by a positive sputum smear in case of pulmonary or laryngeal disease.

Isoniazid or INH

A medicine used to prevent TB disease in people who have latent TB infection. INH is also one of the four medicines often used to treat TB disease. It is a first-line agent for treatment of all forms of TB.²²³

Isolation

A state of separation between persons or groups to prevent the spread of disease. Isolation measures can be undertaken in hospitals or homes, as well as in alternative facilities. Once the diagnosis is made and treatment begun, isolation is usually neither necessary nor appropriate for patients who are willing to undergo treatment. Isolation has a very limited role to play in patients in whom treatment has failed.

L**Latent TB infection**

Infection where *M. tuberculosis* bacilli are present in the body but the disease is not clinically active. Not everyone who is infected with tuberculosis bacteria develops the disease. People who are infected may not feel ill and may have no symptoms. The infection can last for a lifetime, but the infected person may never develop the disease itself. People who are infected but who do not develop the disease do not spread the infection to others.

M***Mycobacterium tuberculosis***

The bacterium of the *M. tuberculosis* complex that is the most common causative infectious agent of TB disease in humans. The *M. tuberculosis* complex also includes *M. bovis* and five other related species.

Multidrug-resistant TB (MDR TB)

A form of TB that does not respond to the standard six month regimen using first line-drugs (i.e. resistant to isoniazid and rifampicin). It can take two years to treat with drugs that are more toxic, and 100 times more expensive. If the drugs to treat MDR-TB are mismanaged, further resistance can occur.

P**Preventive therapy**

The treatment of subclinical, latent infection with *M. tuberculosis* to prevent progression to active TB disease, usually based on 6–9 months of oral isoniazid.

Progression

Development of active tuberculosis disease from a state of latency.

Pulmonary TB

Patient with tuberculosis disease involving the lung parenchyma.

²²³ CDC, "TB Terms". www.cdc.gov/tb/topic/basics/glossary.htm.

Q**Quarantine**

The detention, isolation or distancing of healthy individuals who may have been exposed to an infectious disease for a given period to slow transmission of the disease.

R**Relapse case**

Patient previously declared cured but with a new episode of bacteriologically positive (sputum smear or culture) TB.

Rifampin or RIF

One of the four medicines often used to treat TB disease. It is considered a first-line drug.²²⁴

S**Smear**

Test to determine whether there are TB bacteria in phlegm. To perform this test, lab workers smear the phlegm on a glass slide, stain the slide with a special stain, and look for any TB bacteria on the slide. It usually takes a day to get the results.²²⁵

Sputum smear examination

A laboratory technique in which sputum is smeared on glass slides and stained with an acid-fast stain. Slides are subsequently examined by microscopy for the presence of acid-fast bacilli.

Sputum

Phlegm coughed up from deep inside the lungs. Sputum is examined for TB bacteria using a smear; part of the sputum can also be used to do a culture.²²⁶

Stop TB Strategy

The Stop TB Strategy aims to dramatically reduce the global burden of TB by 2015, and has six components: (1) pursue high-quality DOTS expansion and enhancement; (2) address TB-HIV, MDR-TB, and the needs of poor and vulnerable populations; (3) contribute to health system strengthening based on primary health care; (4) engage all care providers; (5) empower people with TB, and communities through partnership; and (6) enable and promote research.

T**Tuberculin**

Purified protein derivative (PPD) – a mixture of antigens from a culture filtrate extract of *M. tuberculosis* that is used for skin testing; many of its antigens are non-species specific.

Tuberculin skin test

Cutaneous (intradermal) injection of tuberculin to identify people who have been sensitized to mycobacterial antigens by infection with *M. tuberculosis*, non-tuberculous mycobacteria or vaccination with BCG.

²²⁴ Ibid.

²²⁵ Ibid.

²²⁶ Ibid.

Tuberculosis (TB)

Active disease attributable to *Mycobacterium tuberculosis* complex, typically affecting the lungs and airways in which case it is directly transmissible through droplet.²²⁷ TB spreads rapidly, especially in areas where people are living in crowded conditions, have poor access to health care, and are malnourished. People of all ages can contract tuberculosis. But the risk of developing TB is highest in children younger than three years old, in older people, and people with weakened immune systems (for example, people with HIV).

X

Xpert MTB/RIF

A test that employs automated real-time nucleic acid amplification technology for rapid and simultaneous detection of TB and rifampicin resistance.²²⁸

²²⁷ TB CARE I, Guidelines to Measure the Prevalence of Active TB Disease Among Health Care Workers, USAID (2012).

²²⁸ Ibid.