TUBERCULOSIS IN INDIA: A HUMAN RIGHTS APPROACH TO HEALTHCARE

Dipika Jain & Brian Tronic***

ABSTRACT:

India has the highest burden of Tuberculosis (TB) in the world. By some estimates, over 600 Indians die each day from the disease. But it does not affect everyone equally—poor and marginalized communities are more likely to be exposed and become infected, progress from latent to active TB, and experience serious health consequences, including death. Despite these important human rights implications, India, like many countries, has based its Revised National Tuberculosis Program (RNTCP) on a bio-medical approach to the disease rather than a human rights approach. However, India has a strong tradition of health-rights litigation, which provides an opportunity for advocates to move beyond the bio-medical paradigm to claim specific rights. In the context of HIV/AIDS, for example, the Supreme Court and several High Courts have issued groundbreaking judgments protecting the rights of persons living with HIV, including their right to non-discrimination, their right to affordable (or free) medication, and their right to assistance in accessing treatment (e.g., through reduced fares on trains). Courts have also held the government accountable for inadequate health infrastructure and equipment and insufficient budgetary allocations for healthcare. These cases could allow advocates and activists to challenge the numerous shortcomings of India's

* Dipika Jain, Associate Professor & Executive Director of the Centre for Health Law, Ethics and Technology; Associate Professor at Jindal Global Law School, O.P. Jindal Global University; L.L.B. (Delhi), L.L.M. (Dalhousie), L.L.M. (Harvard).

** Brian Tronic, Teaching Fellow & Supervising Attorney, Georgetown University Law Center, former Assistant Professor & Assistant Director, Centre for Health Law, Ethics and Technology, Jindal Global Law School, O.P. Jindal Global University; J.D. (Penn Law School); B.A. in Math and Philosophy (University of Virginia).

The authors would like to thank Prajwal Aradhya, Vandita Khanna, Mitakshara Goyal, and Saumya Maheshwari who worked as Research Assistants on this article. They would also like to thank Brian Citro for his invaluable feedback and comments. They are also grateful to Dr. C. Rajkuamr for his support.

TB control program as not mere policy failures, but rather as human rights violations. The importance of doing so cannot be overstated—the stigma associated with TB, the lack of testing equipment and drugs, and the government's near total failure to address drug-resistant TB, contribute to unnecessary sickness, poverty, and death.

We argue that India should incorporate a human rights approach into the RNTCP because doing so would both protect stakeholders' rights and make the program more effective. A human rights approach would provide adherence support so that poor patients can afford the frequent travel to clinics; effectively regulate medical providers to reduce misdiagnosis and improper treatment; combat TB-related stigma, which delays care-seeking; dedicate adequate funding so that drugs, testing equipment, and trained staff are widely available; provide enforceable rights so that patients can hold the government accountable; address potential concerns relating to privacy of medical data and coercive measures; and involve patients in the design and implementation of TB programs in order to better address their needs. A human rights approach would also have to address the socio-economic determinants of TB—a crucial issue in India—given that it has the highest number of malnourished persons in the world, a growing slum population that is projected to soon exceed 104 million, and over 720 million people living in poverty.

I. INTRODUCTION

India has the highest burden of tuberculosis (TB) in the world.[1] Twenty-three percent of all persons with TB live in India, and every day, approximately 602 Indians die from the disease.[2] However, it does not affect all segments of the population equally. Rather, it thrives on the most vulnerable—the marginalized, the ostracized, and the poor.[3] The UN Committee on the Elimination of Racial Discrimination, for example, has noted that India's scheduled castes and tribes (historically disadvantaged groups that are entitled to affirmative action) are "disproportionately affected" by TB and that healthcare facilities are either unavailable or substantially worse where such people live.[4] The disproportionate effect that TB has on marginalized communities raises important human rights concerns, especially in light of the traumatic stigma associated with the medical condition, which can further isolate and marginalize groups that already face discrimination.[5]

Despite the clear connection between TB and human rights, many world governments have constructed their TB programs based on a bio-medical approach rather than a human rights approach. India, for example, has a strong health-rights jurisprudence dating back to the 1980s,[6] but it has yet to be meaningfully applied in the context of TB. There have been individual court cases, but they do not fully

---

1. T. Jacob John, *Tuberculosis Control in India: Why Are We Failing?*, 51 INDIAN PEDIATRICS 523, 523 (2014) (citing WORLD HEALTH ORG., GLOBAL TUBERCULOSIS REPORT (2013), http://apps.who.int/iris/bitstream/handle/10665/91355/9789241564656_eng.pdf?sequence=1); *see* WORLD HEALTH ORG., GLOBAL TUBERCULOSIS REPORT 17-18, 170-71, 230 (2017), http://apps.who.int/iris/bitstream/handle/10665/259366/9789241565516-eng.pdf;jsessionid=170471FA1C17B831DE012A9AB8105BB4?sequence=1.

2. WORLD HEALTH ORG., GLOBAL TUBERCULOSIS REPORT 2, 132 (20th ed. 2015) [hereinafter WHO REPORT], http://apps.who.int/iris/bitstream/handle/10665/191102/9789241565059_eng.pdf?sequence=1 (noting that, in 2014, 220,000 people died from TB in India).

3. JILL HANNUM & HEIDI LARSON, WORLD HEALTH ORG., A HUMAN RIGHTS APPROACH TO TUBERCULOSIS: GUIDELINES FOR SOCIAL MOBILIZATION 1 (Karen Reynolds ed., 2001), www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf.

4. Comm. on the Elimination of Racial Discrimination [CERD], Consideration of Reports Submitted by States Parties Under Art. 9 of the Convention: Concluding Observations of the CERD: India, ¶ 24, U.N. Doc. CERD/C/IND/CO/19 (May 5, 2007).

5. *See* Kounteya Sinha, *Fighting TB and Taboo*, TIMES INDIA (Jan. 30, 2010, 2:26 PM), https://timesofindia.indiatimes.com/life-style/spotlight/Fighting-TB-and-taboo/articleshow/5517099.cms (describing the social stigma associated with the diagnosis of TB in India).

6. Ravi Duggal, *Right to Health and Health Care- Theoretical Perspective*, *in* HEALTH CARE CASE LAW IN INDIA 1, 3, (Mihir Desai & Kamayani B. Mahabal eds., 2007) [hereinafter HEALTH CARE] (first citing Ravi Duggal et al., *Special Statistics-10: Health Expenditure across States: Part I*, 30 ECON. & POL. WKLY. 834 (1995); then citing Ravi Duggal et al., *Special Statistics-11: Health Expenditure across States: Part II: Regional Disparity in Expenditure*, 30 ECON. & POL. WKLY. 901 (1995); and then citing RAVI DUGGAL, THE PRIVATE HEALTH SECTOR IN INDIA

address the human rights issues surrounding TB in India. For example, in December 2016, the father of a minor girl with multi-drug resistant TB filed a writ petition in the Delhi High Court seeking treatment with the drug Bedaquiline, which had been denied.[7] The case ended in a settlement, memorialized in a court order, in which the girl would be given access to the drug.[8] In addition, in a different case, the Supreme Court ordered the government to change the dosing schedule of TB treatment.[9]

This is unfortunate, because a human rights approach to TB in India could both uphold patients' dignity and lead to better public health outcomes by increasing the accessibility of and demand for treatment and reducing loss to follow up.[10] The potential of a human rights approach can be seen in the context of HIV—by framing access to HIV treatment in rights-based language, advocates in India have secured important court victories (discussed throughout this article), which have helped reduce annual AIDS-related deaths from 148,309 in 2007 to 67,612 in 2015.[11]

This article seeks to demonstrate specific benefits of a human-rights approach to TB in India. Towards this end, it will first review the legal framework relating to the right to health, both in international and domestic law. It will then provide a brief overview of India's TB programs. Finally, it will make specific recommendations on how to implement a human rights approach to TB in India, locating support for each in domestic and international law.

– NATURE, TRENDS AND A CRITIQUE (2000)); Mihir Desai, *Trends in Judicial Outcomes and Consequences for Health Care*, *in* HEALTH CARE, *supra* note 6, at 163, 165.

7. *See Update on Litigation in Delhi High Court Regarding Treatment of XDR TB with Bedaquiline through the Conditional Access Programme*, LAWYERS COLLECTIVE, http://www.lawyerscollective.org/wp-content/uploads/2014/12/Bedaquiline-TB-Writ-Note.pdf (last visited Apr. 30, 2018).

8. Kaushal Tripathi v. Lal Ram Sarup TB Hospital, the W.P.(C) 11879/2016 (order dated Jan. 20, 2017) (on file with author).

9. *See Indian Supreme Court Orders Daily TB Treatment for Millions*, EXPRESS TRIB. (Jan. 23, 2017), https://tribune.com.pk/story/1304564/indian-supreme-court-orders-daily-tb-treatment-millions/.

10. *See generally Factsheet: Human Rights and the Three Diseases*, STOP TB PARTNERSHIP, http://www.stoptb.org/assets/documents/global/hrtf/Partnership%20Forum%20Fact%20Sheet%20-%20Human%20Rights%20June%202011%20FINAL%20COPY%20logos.pdf (last visited Feb. 3, 2018); *Tuberculosis and Human Rights*, STOP TB PARTNERSHIP, www.stoptb.org/assets/documents/global/hrtf/Briefing%20note%20on%20TB%20and%20Human%20Rights.pdf (last visited Feb. 3, 2018).

11. NAT'L AIDS CONTROL ORG. (NACO) & NAT'L INST. OF MED. STATISTICS, INDIA HIV ESTIMATIONS 2015: TECHNICAL REPORT 17–19 (2015), http://www.naco.gov.in/sites/default/files/India%20HIV%20Estimations%202015.pdf.

This discussion is timely for several reasons. First, the RNTCP has completed twenty years, making it a suitable time to reflect upon both its successes and failures. Second, the Indian government's landmark proposal to implement universal health care is currently receiving unprecedented attention, making it a good time to discuss improvements to the public health system. In fact, some of the reforms needed to implement universal health care in India would directly address shortcomings in the RNTCP. Third, given the troubling increase of drug-resistant (and extremely drug-resistant) TB in India, it is essential that India strengthen the RNTCP immediately. This discussion also provides useful guidance amidst renewed concerns over other communicable diseases in India, including dengue fever and drug-resistant malaria.

II. Legal framework: The right to health

The right to health is enshrined in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which recognizes "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."[12] The same provision requires states to take steps necessary for "the prevention, treatment and control of epidemic, endemic, occupational and other diseases" and "the creation of conditions which would assure to all medical service and medical attention in the event of sickness."[13] States are obligated to respect, protect, and fulfill the right to health—that is, they must refrain from taking actions that would interfere with the right to health, prevent third parties from impairing the right to health of others, and adopt appropriate measures towards the full realization of the right to health.[14] International law also prohibits discrimination "in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement."[15]

The right to health is not explicitly mentioned in India's Constitution.[16] However, the Supreme Court has read the right to health into

12. G.A. Res. 2200A (XXI), art. 12(1), International Covenant on Economic, Social and Cultural Rights (Dec. 16, 1966) [hereinafter G.A. Res. 2200A (XXI)].

13. *Id.* art. 12(c)-(d).

14. *See* Comm. on Econ., Soc. & Cultural Rights, Econ., & Soc. Council, Substantive Issues Arising in the Implementation of the Int'l Covenant on Econ., Soc. & Cultural Rights: General Comment No. 14: The Right to the Highest Attainable Standard of Health (Article 12 of the Int'l Covenant on Econ., Soc. & Cultural Rights), ¶¶ 33, 50-52, U.N. Doc. E/C.12/2000/4 (Aug. 11, 2000) [hereinafter Highest Attainable Standard].

15. *Id.* ¶ 18.

16. *See* India Const.

the right to life contained in Article 21.[17] In the landmark case *Francis Mullen v. Union Territory of Delhi*, the Court held that the right to life includes more than the right to be alive—it includes "the right to live with human dignity and all that goes along with it, namely, the bare necessities of life, such as adequate nutrition, clothing and shelter . . . ."[18] More specifically, in a series of cases dealing with the substantive content of the right to life, the Supreme Court has found that the right to live with human dignity includes the right to health.[19] *State of Punjab and Others v. Mohinder Singh* reiterated the settled position wherein right to health is regarded as an integral aspect of right to life under Article 21, and the government has a constitutional obligation to provide health facilities.[20] The Supreme Court in *Consumer Education and Research Centre v. Union of India* explicitly held that the right to life meant a right to a meaningful life, which was not possible without having a right to healthcare.[21] Furthermore, the Supreme Court has indicated that international human rights law should be "read into" the fundamental rights enumerated in the Indian Constitution in the absence of domestic statutory law on a given issue.[22]

III. India's TB program

India's Revised National Tuberculosis Control Program (RNTCP) was inaugurated in 1997 based on the World Health Organization's (WHO) recommended strategy of Directly Observed Treatment, Short Course (DOTS).[23] Patients are initially tested for TB using sputum smear microscopy and then given TB treatment by a trained DOTS provider who observes the patient consume the medication.[24] For the initial "intensive phase" of treatment (normally two months), patients must take observed treatment at a DOTS provider

17. *Id.* art. 21.

18. Francis Mullen v. Union Territory of Delhi, AIR 1981 SC 746, 747 (India); *see also* Consumer Educ. and Research Ctr. v. Union of India, AIR 1995 SC 922, 938-39 (India).

19. *See* Sheetal Shah, *Illuminating the Possible in the Developing World: Guaranteeing the Human Right to Health in India*, 32 Vand. J. Transnat'l L. 435, 467 (1999).

20. State of Punjab and Others v. Mohinder Singh, AIR 1997 SC 1225 (India).

21. Consumer Education and Research Centre v. Union of India, (1995) 3 SCC 42 (India).

22. *See* Vishaka v. Rajasthan, AIR 1997 SC 3011, 3012 (India); *see also* Writ Petition (Civil) Judgment of Apr. 17, 2014 at para. 54, Mohd. Ahmed v. Union of India, No. 7279 of 2013 (Delhi HC) (India).

23. *Revised National Tuberculosis Control Programme (RNTCP): Guidelines for TB Control in India*, World Health Org., www.searo.who.int/india/tuberculosis/topic/tb_rntcpguidelines/en/ (last visited Aug. 5, 2016).

24. Cent. TB Div., Ministry of Health & Family Welfare, Gov't of India, Technical and Operational Guidelines for Tuberculosis Control 12, 28 (2005), http://health.bih.nic.in/Docs/Guidelines/Guidelines-TB-Control.pdf [hereinafter Guidelines].

three times a week, and in the "continuation phase" (four months), the patient takes observed treatment once per week and is given the two other weekly doses to take at home.[25] In more complicated cases, such as those involving drug-resistant TB, the treatment period can extend to over two years, including up to nine months in the intensive phase.[26]

Since the RNTCP was initiated, India has made remarkable progress in TB diagnosis and treatment.[27] The RNTCP is now the world's largest DOTS program, covering over 1.2 billion people, with a treatment success rate around 88% for registered cases.[28] However, there are also numerous well-documented problems with India's TB programs, which will be discussed in more detail below.[29]

IV. Specific recommendations: How to implement a human rights approach to TB in India

The meaning and importance of a human rights approach to TB has been thoroughly explained by public health advocates and scholars.[30] In this article, we will not repeat this discussion by attempting to cover all the aspects of human rights approach to TB in India, but rather will focus on key areas where India is currently falling short. For now, we will simply note that, in conceptualizing a human rights-based approach, UN agencies have used the acronym PANEL—Participation, Accountability, Non-discrimination, Empowerment, and Legality.[31] These components will be discussed in the context of specific recommendations below.

---

25. *Id.* at 19; World Health Org., Standards for TB Care in India 38 (2014) [hereinafter TB Care in India], http://www.searo.who.int/india/mediacentre/events/2014/stci_book.pdf.

26. *See* Christoph Lange et al., *Management of Patients with Multidrug-Resistant/Extensively Drug-Resistant Tuberculosis in Europe: A TBNET Consensus Statemen*t, 44 Eur. Respiratory J. 23, 39, 53 (2014).

27. Fifth Joint Monitoring Mission, Revised Nat'l Tuberculosis Control Programme, Report of the Joint TB Monitoring Mission, India 12 (2015), www.tbonline.info/media/uploads/documents/jmmdraft2015.pdf; *Fighting Tuberculosis in India*, World Bank, web.worldbank.org/archive/website01291/WEB/0__CO-85.HTM (last visited Feb. 6, 2018).

28. Cent. TB Div., Ministry of Health & Family Welfare, Gov't of India, TB India 2015: Revised National TB Control Programme Annual Status Report 28, 66 (2015), http://www.tbcindia.nic.in/showfile.php?lid=3166 [hereinafter Revised National]; *see* WHO Report, *supra* note 2.

29. *See generally* Fifth Joint Monitoring Mission, *supra* note 27, at 6.

30. *See, e.g.*, FXB Ctr. for Health & Human Rights, Harvard Sch. of Pub. Health, Health and Human Rights Resource Guide 3.2 (5th ed. 2013), http://cdn2.sph.harvard.edu/wp-content/uploads/sites/25/2014/03/HHRRG_Chapter-3.pdf; Hannum & Larson, *supra* note 3.

31. *See* Gabrielle Berman, U.N. Educ., Sci., & Cultural Org., Undertaking a Human Rights-Based Approach: A Guide for Basic Programming 13 (2008); World

A. Address the Socio-Economic Determinants of TB

Malnutrition, crowding, poor air circulation, and poor sanitation—all of which are associated with poverty—increase one's risk both of becoming infected with TB and of developing active TB.[32] This is of particular concern in India because it has the highest number of malnourished persons in the world, a growing slum population that was projected to exceed 104 million by 2017, and, as of 2011, over 720 million people living in poverty.[33] The impact of these socio-economic determinants is likely immense—recent data suggests that half of the active TB cases among adolescents and adults in India could be attributable to the effects of undernutrition, and people living in housing made from low-quality materials are two and a half times more likely to have TB.[34] More generally, social protection spending is "strongly associated" with lower TB case notifications, incidence, and mortality rates, and research in India specifically has confirmed the

---

HEALTH ORG., ENSURING A HUMAN RIGHTS-BASED APPROACH FOR PEOPLE LIVING WITH DEMENTIA 1 (2015), http://www.ohchr.org/Documents/Issues/OlderPersons [hereinafter LIVING WITH DEMENTIA].

32. HANNUM & LARSON, *supra* note 3, at 9 (citing P. Kamolratanakul et al., *Economic Impact of Tuberculosis at the Household Level*, 3 INT'L J. TUBERCULOSIS & LUNG DISEASE 596, 599 (1999)).

33. MINISTRY OF HOUS. & URBAN POVERTY ALLEVIATION NAT'L BLDG. ORG., GOV'T OF INDIA, REPORT OF THE COMMITTEE ON SLUM STATISTICS/CENSUS 32 (2010); HIMANSHU, ASIAN DEV. BANK, POVERTY AND FOOD SECURITY IN INDIA 1 (2013); *see Population, Total*, WORLD BANK, http://data.worldbank.org/indicator/SP.POP.TOTL?locations=IN (last visited Feb. 6, 2018) [hereinafter *Total Population*] (India's population in 2011 was 1.247 billion); *Poverty Headcount Ratio at $3.10 a Day (2011 PPP) (% of Population),* DATAMARKET, https://datamarket.com/data/set/15nh/poverty-headcount-ratio-at-2-a-day-ppp-of-population#!ds=15nh!ho4=4t.4p&display=line (last visited Feb. 6. 2018) [hereinafter *Poverty Headcount*] (as of 2011, 58% of Indians lived in poverty).

34. Anurag Bhargava et al., *Undernutrition and the Incidence of Tuberculosis in India: National and Subnational Estimates of the Population-Attributable Fraction Related to Undernutrition*, 27 NAT'L MED. J. INDIA 128, 130 (2014); M. Muniyandi et al., *The Prevalence of Tuberculosis in Different Economic Strata: A Community Survey from South India*, 11 INT'L J. TUBERCULOSIS & LUNG DISEASE 1042, 1043 (2007) (first citing M. Muniyandi, *Tuberculosis Control Programme – is it Pro Poor?*, 1 SAARC J. TUBERCULOSIS, LUNG DISEASES & HIV/AIDS 14 (2004); and then citing CENT. TB DIV., MINISTRY OF HEALTH & FAMILY WELFARE, GOV'T OF INDIA, RNTCP STATUS REPORT (2007)) ("[W]e found that TB prevalence was 2.5 times higher among people living in katcha houses as compared to pucca houses . . . ."); *see also* Baskaran Dhanaraj et al., *Prevalence and Risk Factors for Adult Pulmonary Tuberculosis in a Metropolitan City of South India*, 10 PLOS ONE e0124260, at 13 (Apr. 23, 2015) (first citing N. Shetty et al., *An Epidemiological Evaluation of Risk Factors for Tuberculosis in South India: A Matched Case Control Study*, 10 INT'L J. TUBERCULOSIS & LUNG DISEASE 80 (2006); and then citing X. Kan et al., *Indoor Solid Fuel Use and Tuberculosis in China: A Matched Case-Control Study*, 11 BMC PUB. HEALTH 498 (2011)) ("The study observed that slum dwellers had a 1.6 times higher risk of both culture and bacteriologically positive PTB than non-slum dwellers."), http://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0124260&type=printable.

"significant association" between standard of living and the prevalence of TB.[35]

To combat malnutrition, India needs to strengthen the Public Distribution System (PDS), which provides subsidized food to hundreds of millions of people.[36] Corruption, low-quality grains, poor targeting (many poor families do not receive benefits), and a lack of accountability have greatly reduced its effectiveness.[37] India should fully implement the National Food Security Act, 2013, which mandates needed reforms—including an improved grievance redressal mechanism, creation of state level monitoring bodies, and increased transparency—and allows the number of beneficiaries to be significantly increased.[38] In February 2016, the Supreme Court reproached some states for failing to implement the Act.[39] India should also include persons with TB in the Antyodaya Anna Yojana (AAY) scheme, which provides additional foodgrains to the "poorest of the poor."[40] In 2008, the Right to Food Commissioners appointed by the Supreme Court recommended that patients undergoing treatment for TB or HIV be included in the AAY scheme, which was accomplished for HIV patients in 2009.[41] Given that TB can lead to malnutrition, the

35. Muniyandi, *supra* note 34; Katrina F. Ortblad et al., *Stopping Tuberculosis: A Biosocial Model for Sustainable Development*, 386 LANCET 2354, 2356 (2015).

36. *See* ANIKET BAKSY ET AL., CENT. FOR CIVIL SOC'Y, THE PDS, CASH TRANSFERS AND NUTRITION IN URBAN INDIA, 8–9 (2013), https://ccsinternship.files.wordpress.com/2013/05/291_pds-and-cash-transfer_aniket-aashna-aayushi.pdf; SAKSHI BALANI, PRS LEGISLATIVE RESEARCH, FUNCTIONING OF THE PUBLIC DISTRIBUTION SYSTEM: AN ANALYTICAL REPORT 1 (2013).

37. *See* BALANI, *supra* note 36, at 7; RAJITA VARMA, CENT. FOR CIVIL SOC'Y, THE 'LAST MILE' CRITIQUE: IMPLEMENTATION AND ACCESSIBILITY OF PDS IN DELHI 5 (2012), ccs.in/internship_papers/2012/269_implimentation-accessiblity-of-pds-in-delhi_rajita-verma.pdf.

38. National Food Security Act, 2013, No. 20, §§ 3(2), 14-16, 27-29, Acts of Parliament, 2013 (India).

39. Utkarsh Ananda, *SC Raps Govt for Not Implementing Food Security Law: Is Gujarat Not a Part of India?*, INDIAN EXPRESS (Feb. 2, 2016, 4:08 AM), indianexpress.com/article/india/india-news-india/is-gujarat-not-part-of-india-sc-questions-failure-in-implementing-mnrega-food-act/.

40. National Food Security Act, 2013, No. 20, Acts of Parliament, 2013 (India) (indicating that the Act's purpose is to "provide for food and nutritional security in human life cycle approach, by ensuring access to adequate quantity of quality food at affordable prices to people to live a life with dignity . . . ."); *see also Targeted Public Distribution System*, DEP'T FOOD & PUB. DISTRIBUTION, http://dfpd.nic.in/public-distribution.htm (last updated June 27, 2017).

41. COMM'RS OF THE SUPREME COURT, EIGHTH REPORT OF THE COMMISSIONERS OF THE SUPREME COURT: A SPECIAL REPORT ON MOST VULNERABLE SOCIAL GROUPS AND THEIR ACCESS TO FOOD 9 (2008), http://www.hrln.org/hrln/pdf/rtf/reports/Eight%20report%20.harsh%20tanveer%20final%20aug%2020%2008.pdf; M.V.S Prasad, *Antyodaya Anna Yojana*, PRESS INFO. BUREAU (Apr. 26, 2013, 5:38 PM), http://www.pib.nic.in/newsite/mbErel.aspx?relid=95141.

government should include TB patients as well.[42] Regarding housing, India should upgrade slums through the new Housing for All by 2022 scheme, which is specifically directed at addressing the housing needs of the urban poor, including slum dwellers.[43] In doing so, the government should follow a participatory approach that ensures slum residents are actively engaged and their rights and needs are considered.[44]

Tying domestic programs to international human rights standards is required under the Legality component of the PANEL approach,[45] and under international law, India must address the socio-economic determinants of TB.[46] The right to health in international law includes "a wide range of socio-economic factors that promote conditions in which people can lead a healthy life," and the right to housing requires dwellings must have access to heating, lighting, sanitation, and adequate space and be able to protect the inhabitants from health hazards and disease vectors.[47]

Within India, the Supreme Court has recognized that the right to life, enshrined in Article 21 of the Constitution, includes both the right to food and the right to a shelter with adequate living space, clean and decent surroundings, sufficient light, pure air and water, and sanitation.[48] Even persons living in illegal settlements have the right to these minimum standards—for example, in 2014, the Bombay High Court held that, since the right to life includes the right to water, the government cannot deny the water supply to a person on the ground that he is residing in a structure which was illegally erected.[49] The Court has also issued numerous interim orders in the ongoing "right

42. WORLD HEALTH ORG., GUIDELINE: NUTRITIONAL CARE AND SUPPORT FOR PATIENTS WITH TUBERCULOSIS 10, 19 (2013).

43. MINISTRY OF HOUS. & URBAN POVERTY ALLEVIATION, GOV'T OF INDIA, PRADHAN MANTRI AWAS YOJANA: HOUSING FOR ALL (URBAN): SCHEME GUIDELINES i (2015).

44. *See generally* REINHARD SKINNER ET AL., U.N. HABITAT, A PRACTICAL GUIDE TO DESIGNING, PLANNING, AND EXECUTING CITYWIDE SLUM UPGRADING PROGRAMMES (Jane Reid et al. eds., 2014).

45. *See, e.g.*, LIVING WITH DEMENTIA, *supra* note 31, at 4.

46. *See* Highest Attainable Standard, *supra* note 14, ¶ 2.

47. *Id.* ¶ 4; Comm. on Econ., Soc. & Cultural Rights, Rep. on the Sixth Session, annex III, ¶ 8(b), U.N. Doc. E/1992/23 E/C.12/1991/4 (Nov. 25, 1991–Dec. 13, 1991).

48. *See* Shantistar Builders v. Narayan Khimalal Totame, AIR 1990 SC 630, 633 (India); Chameli Singh v. State of U. P., AIR 1996 SC 1051, 1052-1053 (India).

49. Public Interest Litigation Oral Order of Dec. 15, 2014, Pani Haq Samiti v. Mumbai Muni. Corp., No. 10 of 2014, paras. 11, 19 (Bombay HC) (India).

to food" case, *PUCL v. Union of India*, indicating that the government must provide subsidized food to the infirm and destitute.[50]

B. Provide Adherence Support

There are a variety of physical, financial, social, and cultural obstacles that can prevent a person who has started TB treatment from completing the entire course.[51] In several studies, TB patients in India cited the distance to DOTS providers as a reason for discontinuing treatment.[52] For example, one study in rural Maharashtra found that 34% of respondents lived more than five kilometers from a DOTS health facility and 17% lived more than ten kilometers away, and another study in a tribal area in Nagaland reported that the average time for rural residents to reach a Designated Microscopy Centre to obtain free treatment was three hours.[53] A related issue is the cost of transportation—in some areas, more than half of TB patients have to spend money to reach a DOTS centre.[54] While the amounts involved may be relatively small (between ten to thirty rupees), the repeated visits required for proper treatment (three times per week) and the widespread poverty in India (over 720 million people live on less than $3.10 [Rs. 212] per day) can make this a serious barrier to obtaining treatment.[55] Inconvenient clinic hours, especially in conflict with working hours, make it difficult for some patients to adhere to the treatment schedule, and for those who continue treatment at the ex-

50. Interim Order of May 2, 2003, People's Union for Civil Liberties v. Union of India, (2003) 2 SCR 1136 (India).

51. *See* Rony Zachariah et al., *Language in Tuberculosis Services: Can We Change to Patient-Centred Terminology and Stop the Paradigm of Blaming the Patients?*, 16 INT'L J. TUBERCULOSIS & LUNG DISEASE 714, 715 (2012).

52. Sudipta Basa & Srinivas Venkatesh, *Study on Default and Its Factors Associated among Tuberculosis Patients Treated under DOTS in Mayurbhanj District, Odisha*, 2 J. HEALTH RES. & REVIEWS 25, 26 (2015); P.G. Gopi et al., *Risk Factors for Non-Adherence to Directly Observed Treatment (DOT) in a Rural Tuberculosis Unit, South India*, 54 INDIAN J. TUBERCULOSIS 66, 69 (2007); Nirmalya Roy et al., *Risk Factors Associated with Default among Tuberculosis Patients in Darjeeling District of West Bengal, India*, 4 J. FAM. MED. & PRIMARY CARE 388, 390 (2015).

53. Shilpa Bawankule et al., *Delay in DOTS for New Pulmonary Tuberculosis Patient from Rural Area of Wardha District, India*, 9 ONLINE J. HEALTH & ALLIED SCI., no. 1, 2010, at 5, http://cogprints.org/6991/1/2010-1-5.pdf; Mrinalini Das et al., *Self-Administered Tuberculosis Treatment Outcomes in a Tribal Population on the Indo-Myanmar Border, Nagaland, India*, PLOS ONE e108186, Sept. 2014, at 3.

54. Srivastav Shalini et al., *Indirect Cost as Hindrance in Availing DOTS for Tuberculosis: Is the Treatment Truly Free of Cost?*, 2 NAT'L J. MED. RES. 35, 35 (2012).

55. *Id.* at 37; Suparna Bagchi et al., *Determinants of Poor Adherence to Anti-Tuberculosis Treatment in Mumbai, India*, 1 INT'L J. PREVENTIVE MED. 223, 230 (2010); *Poverty Headcount*, *supra* note 33; *Total Population*, *supra* note 33.

pense of work, lost wages can result in significant financial burden.[56] This is most acutely an issue for the poor since manual labourers are hired on a daily basis, and attending a clinic visit, however brief, will cost them the entire day's wages.[57]

The behaviour of health providers is also problematic. Rude treatment has been reported, leading patients to switch to the more expensive private sector.[58] Some providers "weed out" patients who might not be able to complete the treatment (e.g., alcoholics) to avoid diminishing the centre's results.[59] Others require patients who have previously discontinued treatment to produce a "guarantor" who can vouch for them before they are allowed to resume treatment.[60] Furthermore, government health staff do not routinely follow up with patients that have stopped coming for treatment—data from 2008 in Ahmedabad found that, out of 123 TB patients who missed a dose of medication, only one third received a home visit.[61] Poor support by health staff is a significant predictor of interrupted treatment.[62]

India should provide free (or, at least, reduced fare) transport to patients accessing TB treatment in government health centres. This is currently provided to HIV patients in several states, either through free transport upon the showing of proper documentation (e.g., a certificate from an HIV treatment centre) or through reimbursement af-

56. Ramya Ananthakrishnan et al., *Socioeconomic Impact of TB on Patients Registered within RNTCP and Their Families in the Year 2007 in Chennai, India*, 29 LUNG INDIA 221, 222–23 (2012); Basa & Venkatesh, *supra* note 52, at 27; Rajesh D. Deshmukh et al., *Patient and Provider Reported Reasons for Lost to Follow Up in MDRTB Treatment: A Qualitative Study from a Drug Resistant TB Centre in India*, 10 PLOS ONE e0135802, at 5–6 (Aug. 24, 2015); Bhuwan Sharma et al., *Indirect Costs in the Treatment of Tuberculosis under DOTS*, 2 INT'L ARCHIVES INTEGRATED MED. 90, 92 (2015); Sonia Tiwari & R. R. Wavare, *Reasons for Non-Compliance and Profile of Tuberculosis Patients in Urban Area of Indore*, 6 NAT'L J. COMMUNITY MED. 55, 56 (2015).

57. K. R. John et al., *Costs Incurred by Patients with Pulmonary Tuberculosis in Rural India*, 13 INT'L J. TUBERCULOSIS & LUNG DISEASE 1281, 1285 (2009).

58. Deshmukh et al., *supra* note 56, at 5.

59. Peter D.O. Davies, *Multi-Drug-Resistant Tuberculosis*, *in* TUBERCULOSIS 809, 813 (M. Monir Madkour ed., 2004).

60. A. Jaiswal et al., *Adherence to Tuberculosis Treatment: Lessons from the Urban Setting of Delhi, India*, 8 TROPICAL MED. & INT'L HEALTH 625, 629 (2003); Nerges Mistry et al., *Drug-Resistant Tuberculosis in Mumbai, India: An Agenda for Operations Research*, 1 OPERATIONS RES. FOR HEALTH CARE 45, 49 (2012).

61. Bhavna Puwar et al., *A Record Based Study on Paediatric Tuberculosis in Ahmedabad City, India*, 3 NAT'L J. COMMUNITY MED. 153, 154 (2012); *see also* S. Gupta et al., *Patient Satisfaction Towards RNTCP: A Study of Patient Satisfaction Towards RNTCP in Meerut District, Uttar Pradesh*, 42 NAT'L TUBERCULOSIS INST. BULL. 9, 10 (2006) (indicating that when patients missed a dose, only 28% were contacted by the DOTS provider).

62. Sophia Vijay et al., *Risk Factors Associated with Default Among New Smear Positive TB Patients Treated under DOTS in India*, PLOS ONE e10043, Apr. 2010, at 3.

ter the fact.[63] The government should also help reduce the impact of lost wages by creating TB specific pensions and including persons living with TB in existing social protection schemes meant for, e.g., widows and the elderly, both of which have already been done for HIV patients in some states.[64] More generally, TB patients should be able to access government welfare programs and services through a single forum and a liaison should be provided to facilitate access.[65] Some states are experimenting with routing social protection schemes through HIV treatment centres; this should be explored as a possibility for TB as well.[66] The government should expand access to DOTS through community volunteers as an alternative to going to government health centres—there appears to be great variation in availability of community providers, with 89% of public sector TB patients doing this in Andhra Pradesh, but only 29% in Mizoram.[67] The government should also train health providers to be sensitive to the needs and challenges of TB patients, expand clinic timings, and ensure appropriate follow-up (such as SMS reminders and home visits) with patients who have missed a dose of medication or other treatment.

International law requires states to take "positive measures that enable and assist individuals and communities to enjoy the right to health."[68] The Indian Constitution similarly states that the government must provide public assistance in cases of unemployment and other cases of undeserved want.[69] The Delhi High Court recognized the importance of this in *Love Life Society v. Union of India*, in which it ordered a meeting between the Ministry of Health and the Railway Ministry to discuss giving persons living with HIV a reduced train fare to travel to distant treatment centres.[70] Indian Railways subsequently

63. VIMLA NADKAMI ET AL., U.N. DEV. PROGRAMME, HIV SENSITIVE SOCIAL PROTECTION: A FOUR STATE UTILIZATION STUDY 31 (2011), http://www.undp.org/content/dam/india/docs/hiv_sensitive_social_protection_a_four_state_utilisation_study.pdf; *see* NAT'L AIDS CONTROL ORG. (NACO), GOVERNMENT ORDERS / CIRCULARS ON HIV SENSITIVE SOCIAL PROTECTION ISSUED BY STATE GOVERNMENTS 16, 62, 93, 96, 139, 159, 198, 211, 215, 222, 228, 240, 261, 263, 279, 313, 315 (n.d.), indiahivinfo.naco.gov.in/sites/default/files/media-gallery/718%20_%20Social%20Protection%20Compendium.pdf.

64. NADKAMI ET AL., *supra* note 63, at 4; *see* NACO, *supra* note 63, at 10, 94, 271.

65. FIFTH JOINT MONITORING MISSION, *supra* note 27, at 36–37.

66. NADKAMI ET AL., *supra* note 63, at viii.

67. MINISTRY OF HEALTH & FAMILY WELFARE, GOV'T OF INDIA, TB INDIA 2016: REVISED NATIONAL TB CONTROL PROGRAM ANNUAL STATUS REPORT 103 (2016), http://tbcindia.nic.in/index1.php?lang=1&level=2&sublinkid=4569&lid=3174.

68. Highest Attainable Standard, *supra* note 14, ¶ 37.

69. INDIA CONST. art. 41.

70. Writ Petition (Civil) Decision at 1, Love Life Society v. Union of India, No. 8700 of 2006 (Dehli HC) (India); *Love Life Society vs. Union of India & Ors*, HUM. RTS. L. NETWORK,

announced that it would offer a 50% concession.[71] In addition, India's current TB policies recommend reimbursement of travel expenses; home visits or use of information technology to follow up with patients who have missed treatment; and making treatment available at locations and times so as to minimize workday disruptions.[72]

C. Ensure Quality Treatment

The majority of Indians seek TB treatment in the private sector (at least initially), which is largely unregulated.[73] Unqualified practitioners with limited medical knowledge are able to "prescribe" TB medications because they are widely available over the counter (despite the law's requirement of a prescription).[74] Although India banned the use of serological tests for diagnosis of TB in 2012, private providers continue to use them for diagnosis.[75] Private providers also commonly prescribe inappropriate medication regimens, which contributes to drug resistance.[76] A 2010 study in Mumbai, for example, found that only six out of 106 private medical practitioners prescribed an appropriate drug regimen for TB with correct drugs, dosage, and

hrln.org/hrln/hiv-aids/pils-a-cases/207-love-life-society-vs-union-of-india-a-ors.html (last updated Mar. 3, 2008).

71. *Indian Railways To Offer 50% Concession To HIV-Positive People Traveling to NACO Treatment Centers*, KAISER HEALTH NEWS (June 11, 2009), khn.org/morning-breakout/dr00051191/.

72. CENT. TB DIV., MINISTRY OF HEALTH & FAMILY WELFARE, GOV'T OF INDIA, GUIDELINES ON PROGRAMMATIC MANAGEMENT OF DRUG RESISTANT TB (PMDT) IN INDIA 61, 63 (May 2012), https://tbcindia.gov.in/WriteReadData/l892s/8320929355Guidelines%20for%20PMDT%20in%20India%20-%20May%202012.pdf [hereinafter PROGRAMMATIC]; TB CARE IN INDIA, *supra* note 25, at 54–55, 69, 71.

73. *See* HEALTH CARE, *supra* note 6, at 3.

74. Ramesh Kumar, *Empirical Use of Antituberculosis Drugs Should Not Be Equated to Their Inappropriate and Indiscriminate Use*, 43 INDIAN J. PHARMACOLOGY 363, 363–64 (2011); Ekatha Ann John, *Over-Counter Drugs Fuel TB Threat*, TIMES INDIA (July 10, 2014, 5:51 AM), timesofindia.indiatimes.com/city/chennai/Over-counter-drugs-fuel-TB-threat/articleshow/38109005.cms.

75. Virander S. Chauhan, *Can India Defeat Tuberculosis and Save Three Lakh Lives?*, DNA (Mar. 24, 2015, 8:00 AM), www.dnaindia.com/analysis/standpoint-can-india-defeat-tuberculosis-and-save-three-lakh-lives-2071438; *Diagnosis of Tuberculosis*, GOV'T INDIA PRESS INFO. BUREAU (Nov. 30, 2012, 4:57 PM), pib.nic.in/newsite/PrintRelease.aspx?relid=89739; Sarman Singh, *Serology Testing Ban Needs To Be Enforced*, HINDU (Mar. 23, 2014, 12:41 AM), www.thehindu.com/opinion/open-page/serology-testing-ban-needs-to-be-enforced/article5820021.ece.

76. Alpa Dalal et al., *Resistance Patterns Among Multidrug Resistant Tuberculosis Patients in Greater Metropolitan Mumbai: Trends Over Time*, 10 PLOS ONE e0116798, Jan. 21, 2015, at 6–7.

duration.[77] Wrong and delayed diagnoses and improper treatment contribute to the spread of both TB and drug-resistant TB.[78]

Another problem is that poor quality TB drugs are sold in the private sector.[79] This may be due to inadequate storage of properly formulated drugs or drugs that were not manufactured with the proper amount of active ingredients in the first place.[80] Regardless of the cause, this is a serious concern—in two studies, over 10% of certain TB medications failed quality testing.[81] Substandard drugs can lead to patient death and development of drug resistance.[82]

India needs to more thoroughly regulate the private health sector by enforcing the Clinical Establishments Act, 2010. The Act applies to both public and private health facilities and requires them to meet the Standard Treatment Guidelines issued by the government, which include the Standards for TB Care in India.[83] Under the Act, designated authorities can inspect any clinical establishment and give binding directions for improvement.[84] There are financial penalties for any violation of the Act, and if a clinical establishment is not complying with the conditions for registration, including the Standard Treatment Guidelines, the authorities can cancel its registration.[85] One key problem with the Clinical Establishments Act is that it does not provide for a separate body or budget to implement it, but rather assigns responsibilities for all inspections to a "district registering authority" led by existing government employees—the District Collector and the

77. Zarir F. Udwadia et al., *Tuberculosis Management by Private Practitioners in Mumbai, India: Has Anything Changed in Two Decades?*, PLOS ONE e12023, Aug. 9, 2010, at 2; *see also* Gyanshankar Mishra & Jasmin Mulani, *Tuberculosis Prescription Practices in Private and Public Sector in India*, 4 NAT'L J. INTEGRATED RES. MED. 71 (2013) (finding that only 9.52% of TB treatment prescriptions from private practitioners and 4.76% from government facilities were correct).

78. *See* Anurag Bhargava et al., *Mismanagement of Tuberculosis in India: Causes, Consequences, and the Way Forward*, 9 HYPOTHESIS 1, 3–6 (2011); Mistry et al., *supra* note 60, at 49; *Patients in India Suffer the Consequences of Poor Regulation of TB Drugs*, MEDECINS SANS FRONTIERS (Mar. 21, 2014), www.msfindia.in/patients-india-suffer-consequences-poor-regulation-tb-drugs.

79. R. Bate et al., *Substandard and Falsified Anti-Tuberculosis Drugs: A Preliminary Field Analysis*, 17 INT'L J. TUBERCULOSIS & LUNG DISEASE 308, 309-10 (2013).

80. *See id.* at 310.

81. *Id.* at 309 (noting a 10.1% failure rate in India); Roger Bate et al., *Pilot Study of Essential Drug Quality in Two Major Cities in India*, PLOS ONE e6003, June 23, 2009, at 2.

82. Bate et al., *supra* note 79; Bate et al., *supra* note 81, at 1.

83. Clinical Establishments (Registration and Regulation) Act, 2010, No. 23, § 2(c)(ii), Acts of Parliament, 2010 (India); *Standard Treatment Guidelines*, MINISTRY HEALTH & FAM. WELFARE, http://clinicalestablishments.gov.in/En/1068-standard-treatment-guidelines.aspx (last visited Feb. 6, 2018).

84. Clinical Establishments (Registration and Regulation) Act, 2010, § 33.

85. *Id.* §§ 32, 40–46.

District Health Officer—who are already overburdened.[86] Thus, oversight is lost. The Act also fails to provide a grievance mechanism for patients in the private sector (the public sector already has one, at least on paper, as will be discussed below).[87] The Clinical Establishments Act should be amended to provide a separately financed body to inspect and oversee all health facilities, including private ones, and to create a grievance redressal mechanism.

The government should also enforce The Drugs and Cosmetics Act, 1940,[88] to ensure that only accurate and reliable diagnostics are used. Such tests already fall under the Act, and the government is empowered to prohibit manufacture and sale of devices that make false or misleading claims, with criminal penalties for violations.[89] The Act also gives the government the authority to prohibit import, manufacture, and sale of non-standard, misbranded, adulterated, and spurious drugs, including drugs that contain ingredients in quantities for which there is no therapeutic justification.[90] In addition, the government should enact the Drugs and Cosmetics (Amendment) Bill, 2013, which would give the government additional regulatory authority over medical devices, including the power to prohibit medical devices for which there is no functional justification.[91]

The Committee on Economic, Social and Cultural Rights (CESCR) has stated that health facilities, goods, and services must be "scientifically and medically appropriate and of good quality."[92] Under international law, States must also ensure that the privatization of the health sector does not threaten the quality of health services, and that health professionals meet appropriate standards of education and skill.[93] The failure to sufficiently regulate the activities of individuals, groups, or corporations so as to prevent them from violating the right to health of others is a violation of international law.[94] Similarly, Indian courts have made clear that allowing private hospitals to "run a mock [sic]" would "defeat the very purpose and the meaning and ex-

86. *Id.* at §§ 2(a), 10(1), 33; Anant Phadke, *Regulation of Doctors and Private Hospitals in India*, 51 ECON. & POL. WKLY. 46, 51 (2016).

87. Phadke, *supra* note 86, at 52.

88. Drugs and Cosmetics Act, 1940, No. 23, Acts of Parliament, 1940 (India).

89. *Id.* §§ 3(b)(iv), 17(c), 18(a)(i), 27(d).

90. *Id.* §§ 10, 10A, 18, 26A.

91. *See* Drugs and Cosmetics (Amendment) Bill, 2013, No. LVIII, §§ 12–13(7I), Acts of Parliament, 2013 (India).

92. Highest Attainable Standard, *supra* note 14, ¶ 12(d).

93. *See id.* ¶ 35.

94. *See id.* ¶ 51.

tent of the right to health care which is embodied in Article 21."[95] The Supreme Court has explicitly stated that, in an appropriate case, it will give directions to even private employers to protect the right to life,[96] and it has ordered states to stop unqualified and unregistered persons from practicing medicine and making false claims.[97] Regarding poor quality drugs, the Supreme Court noted as far back as 1987 that "strict regulations" are needed to ensure that drugs maintain their quality, that "the process of regulation has to be strengthened," and that "constant and regular attention has to be bestowed in order that the flow into the market may be only of acceptable drugs."[98]

D. Combat Stigma

In India, stigma related to TB is rampant.[99] Many people refrain from telling anyone, even family members, that they have or suspect that they have TB.[100] In some cases, persons with TB have lost their jobs after disclosing this at the work place.[101] Some patients travel to distant clinics to avoid being seen taking treatment by their neighbours, or go to private clinics, which are perceived to offer more privacy,[102] both of which increase the likelihood that treatment will be discontinued for financial reasons.[103] Even health care workers and

95. Smt. Vandana Dixit v. Visitor S.G.P.G.I., (2010) ILR 3 All 1058, para. 25 (Allahabad HC) (India); *see also* Pt. Parmanand Katara v. Union of India, 1989 AIR 2039, para. 8 (India).

96. Consumer Educ. & Research Cent. v. Union of India, 1995 AIR 922, para. 30 (India).

97. D.K. Joshi v. State of U.P., (2000) 3 SCR 525 (India); Writ Petition of Mar. 27, 2007, Karnataka Network for People living with HIV/AIDS v. Balachandra K. Pagali, No. 8852 of 2006 (Karnataka HC) (India).

98. Vincent Parikurlangara v. Union of India, 1987 2 SCR 468 (India).

99. *See* Tanu Anand et al., *Perception of Stigma Towards TB Patients on DOTS and Patients Attending General OPD in Delhi*, 61 INDIAN J. TUBERCULOSIS 35, 35 (2014); D. Somma et al., *Gender and Socio-Cultural Determinants of TB-Related Stigma in Bangladesh, India, Malawi and Colombia*, 12 INT'L J. TUBERCULOSIS & LUNG DISEASE 856, 858-60 (2008) ("India had the highest item-adjusted stigma index (1.17) . . . .").

100. *See* V. K. Dhingra & Shadab Khan, *A Sociological Study on Stigma among TB Patients in Delhi*, 57 INDIAN J. TUBERCULOSIS 12, 17 (2010) ("here was an immense stigma observed at society level with 60% of the patients hiding their disease (P<0.5) from the friends or neighbours . . . ."); Priya Y. Kulkarni et al., *Treatment Seeking Behavior and Related Delays by Pulmonary Tuberculosis Patients in E-Ward of Mumbai Municipal Corporation, India*, 3 INT'L J. MED. & PUB. HEALTH 286, 289 (2013); C.M. Munegowda, *TB Stigma in India—A Harsh Reality Even After Five Decades of A TB Control Programme*, BMJ OPINION (Sept. 8, 2015), blogs.bmj.com/bmj/2015/09/08/tb-stigma-in-india-a-harsh-reality.

101. K. Jaggarajamma et al., *Psycho-Social Dysfunction: Perceived and Enacted Stigma among Tuberculosis Patients Registered under Revised National Tuberculosis Control Programme*, 55 INDIAN J. TUBERCULOSIS 179, 185 (2008).

102. Athar Parvaiz, *Running Away from TB Treatment*, INTER PRESS SERV. (July 22, 2013), http://www.ipsnews.net/2013/07/kashmiris-run-away-from-tb-treatment/; Sinha, *supra* note 5.

103. Parvaiz, *supra* note 102.

medical students are reluctant to work with TB patients.[104] This stigma is due, in part, to the widespread misunderstanding of the symptoms, cause, method of transmission, contagiousness, and even the curability of TB, at least in some parts of the country.[105]

TB-related stigma is a well-recognized barrier to timely screening, diagnosis, care seeking, and adherence to treatment.[106] However, advocacy, communication, and social mobilization, which could be used to educate and fight stigma, is currently a low priority in the RNTCP.[107] India should fully implement the Operational Handbook on Advocacy, Communication, and Social Mobilization developed in 2014 by the Central TB Division,[108] which provides guidance on how to create effective education and information campaigns at the local, state, and national levels, and also follow the recommendations relating to education and awareness raising made by the 2015 Joint TB Monitoring Mission.[109]

Under international law, states must address widespread stigmatization of persons on the basis of their health status (including disease), and must take "concrete, deliberate and targeted measures" to eliminate discrimination.[110] States must also ensure access to health facilities, goods, and services on a non-discriminatory basis, and this must be done immediately (i.e., is not subject to progressive realiza-

104. Sonal Mobar & A.K. Sharma, *Stigma and Social Exclusion among Tuberculosis Patients: A Study of Ladakh, India*, 1 INT'L J. HEALTH, WELLNESS & SOC'Y 119, 136 (2011); Manjulika Vaz et al., *Perceptions of Stigma among Medical and Nursing Students and Tuberculosis and Diabetes Patients at a Teaching Hospital in Southern India*, 13 INDIAN J. MED. ETHICS 8, 8 (2016).

105. *See* Palash Das et al., *Perception of Tuberculosis among General Patients of Tertiary Care Hospitals of Bengal*, 29 LUNG INDIA 319, 320–21 (2012); S.N. Mani Devi Karampudi et al., *Awareness of Tuberculosis among Patients Attending RNTCP at Siddhartha Medical College, Vijayawada*, 1 ASIAN PAC. J. HEALTH SCI. 50, 50–53 (2014); P. Kulkarni et al., *Tuberculosis Knowledge and Awareness in Tribal-Dominant Districts of Jharkhand, India: Implications for ACSM*, 4 PUB. HEALTH ACTION 189, 189 (2014); Talha Saad & Abhay S. Tirkey, *Tuberculosis Associated Stigma among Patients Attending Outpatient in Medical College Hospital in Sagar (Madhya Pradesh) in Central India*, 3 J. MED. & HEALTH SCI. 126, 129 (2014).

106. FIFTH JOINT MONITORING MISSION, *supra* note 27, at 86; Kulkarni et al., *supra* note 105, at 189, 192; Saad & Tirkey, *supra* note 105, at 128–130 ("Patients who considered TB as a socially stigmatizing disease had a longer patient delay in seeking care for TB symptoms than those that did not.").

107. GUIDELINES, *supra* note 24, at 39–41.

108. CENT. TB DIV., MINISTRY OF HEALTH & FAMILY WELFARE, GOV'T OF INDIA, OPERATIONAL HANDBOOK ON ADVOCACY, COMMUNICATION, AND SOCIAL MOBILIZATION (Mar. 2014), http://www.nrhmhp.gov.in/sites/default/files/files/l%20Handbook%20on%20ACSM%20%20 2014_04_02.pdf.

109. GUIDELINES, *supra* note 24, at 40–41.

110. Comm. on Econ., Soc. & Cultural Rights, General Comment No. 20: Non-Discrimination in Economic, Social and Cultural Rights, ¶¶ 33, 36, U.N. Doc. E/C.12/GC/20 (July 2, 2009).

tion).[111] The Committee on Economic, Social and Cultural Rights has also noted that access to information is an integral component of the right to health[112] and that states have a positive obligation to conduct information campaigns and disseminate information relating to health.[113] This would address the Non-discrimination component of the PANEL principles.[114] Indian courts have acknowledged the importance of providing health-related information to the public—the Gujarat High Court noted in 2013 that "normalizing the presence of HIV/AIDS in society through public education is the only way to reduce discriminatory attitudes and practices," and that the government should undertake awareness programs directed towards both the public at large and HIV patients specifically.[115] Indian courts have also held that a public sector employee cannot be denied a position merely because they are living with HIV[116] and that doctors cannot refuse to treat patients simply because they are living with HIV.[117]

E. Dedicate Adequate Funding for TB

India's National Strategic Plan for Tuberculosis Control 2017–2025 states that Rs. 16,649 crore (Rs. 166 billion) is needed "over the next three years to transform TB control and achieve the national goal of ending TB as a major public health problem by 2025."[118] This is significantly lower than the WHO's estimate of $788 million (approximately Rs. 52 billion) needed for 2015 alone.[119] Regardless, the government is not fully funding even the lower amount.

111. *See* Comm. on Econ., Soc. & Cultural Rights, General Comment No. 13: The Right to Education (Art. 13), ¶¶ 43-44, U.N. Doc. E/C.12/1999/10 (Dec. 8, 1999).

112. Highest Attainable Standard, *supra* note 14, ¶ 3.

113. *Id.* ¶¶ 36–37.

114. *See generally* BERMAN, *supra* note 31.

115. Harshad J. Pabari v. Gujarat, 2013 GLR 3 (Gujarat) 258, paras. 30, 34(2), 34(5) (Gujarat HC) (India).

116. *See, e.g.*, MX v. ZY, 1997 AIR 406 (Bom.) para. 62 ("[D]enial of work to the petitioner as a casual labourer merely because of his HIV status is thoroughly unjustified and-illegal . . . ."); *see also* Atiya Bose & Kajal Bhardwaj, *Legal Issues that Arise in the HIV Context*, INFOCHANGE INDIA (Feb. 2008), http://infochangeindia.org/component/content/article/361-hiv-aids/hiv-a-human-rights/6899-legal-issues-that-arise-in-the-hiv-context (listing several "[d]iscrimination in the workplace" cases involving "[p]ersons living with HIV/AIDS").

117. *See, e.g.*, Oral Order of May 28, 2015 at 1, Sohila Kuwar v. Bihar, No. 8301 of 2015 (Patna HC) (India) ("[M]erely because a person is HIV positive no doctor can refuse to take care under Hypocretics [sic] oath . . . .").

118. CENT. TB DIV., MINISTRY OF HEALTH & FAMILY WELFARE, GOV'T OF INDIA, REVISED NATIONAL TUBERCULOSIS CONTROL PROGRAMME: NATIONAL STRATEGIC PLAN FOR TUBERCULOSIS CONTROL 2017–2025 97 (n.d.) [hereinafter STRATEGIC PLAN], https://tbcindia.gov.in/WriteReadData/NSP%20Draft%2020.02.2017%201.pdf.

119. WHO REPORT, *supra* note 2, at 91.

Of the Rs. 45 billion proposed in the National Strategic Plan, it is estimated that Rs. 1,998.87 crore (Rs. 19 billion) will come from external sources.[120] This leaves Rs. 2,501.28 crore (Rs. 25 billion) to be funded by the government. However, in the first three years of the National Strategic Plan, the government approved only Rs. 1,607 crore (Rs. 16 billion) and, of this, only Rs. crore 887.27 (Rs. 8.8 billion) was actually released to the states.[121] This has caused shortages of drugs and equipment and left some states unable to cover RNTCP staff salaries.[122] For example, the 2015 Joint TB Monitoring Mission noted that, in Andhra Pradesh, contractual staff suffered delayed remuneration of at least four months.[123]

A related problem is a lack of medication and equipment for drug-resistant TB. In 2013, for example, 248,000 cases of TB were tested for drug resistance and 35,400 were found to have multiple drug resistant or rifampicin-resistant TB.[124] However, only 20,700 received treatment that year.[125] Government doctors have reported such drug shortages for several years.[126] Also, while the WHO recommends one laboratory with drug-susceptibility testing for every five million people, the ratio in India, as of 2014, was 0.2 per five million.[127] The 2015 draft JMM report concluded that procurement of new testing equipment was "unaccountably delayed."[128] There are also shortages of other key supplies.[129] The Sewri TB Hospital in Mumbai—the largest TB hospital in Asia—has refused to perform lung surgeries on TB patients because they do not have adequate ventilation equipment in

120. *See* Savita Thakur, *Govt. Cuts Back Planned Funding for National Health Mission by 20 Percent*, MED. DIALOGUES (Nov. 25, 2017), https://medicaldialogues.in/govt-cuts-back-planned-funding-for-national-health-mission-by-20-percent/.

121. *See Need to Enhance Budget for TB Programme*, INDIA SAGA (Apr. 8, 2017), http://www.theindiasaga.com/saga-corner/need-to-enhance-budget-for-tb-programme.

122. C. Maya, *TB Control Scheme Gasping for Life*, HINDU, http://www.thehindu.com/news/cities/Thiruvananthapuram/tb-control-scheme-gasping-for-life/article8084492.ece (last updated Sept. 22, 2016); Kanchan Srivastava, *TB Epidemic Looms Large with Rs 2,000 Crore Fund Cut, Erred Policy*, DNA, www.dnaindia.com/mumbai/report-tb-epidemic-looms-large-with-rs-2000-crore-fund-cut-erred-policy-2051254 (last updated Jan. 10, 2015); Ranjana Diggikar, *Funds Crunch Hits Fight Against TB*, TIMES INDIA, http://timesofindia.indiatimes.com/city/aurangabad/Funds-crunch-hits-fight-against-TB/articleshow/45359806.cms/ (last updated Dec. 3, 2014).

123. GUIDELINES, *supra* note 24, at 32, 38–41.

124. FIFTH JOINT MONITORING MISSION, *supra* note 27.

125. Nishant Gupta et al., *Tuberculosis: A Man with Fever, Cough, and Mycobacterium*, SCI. INDIA, May–June 2016, at 25, 26.

126. *See, e.g.*, Swati Jha, *MDR-TB Drug Shortage Continues,* ASIAN AGE (Jan. 12, 2015, 2:33 AM), http://www.asianage.com/mumbai/mdr-tb-drug-shortage-continues-013.

127. WHO REPORT, *supra* note 2, at 72.

128. GUIDELINES, *supra* note 24, at 47.

129. FIFTH JOINT MONITORING MISSION, *supra* note 27, at 59, 79, 103, 116.

the operating rooms and even suffer critical shortages of breathing masks for the staff, leaving surgeons at risk of contracting TB.[130]

India should increase funding for the RNTCP in order to meet the targets set in the 2012-2017 National Strategic Plan.[131] International law requires states to ensure that there is a sufficient quantity of public healthcare facilities, goods, services, and programs.[132] Although this obligation is subject to progressive realization, states must take steps to the maximum of their available resources.[133] Providing essential drugs, as defined by the WHO, is a core obligation of the right to health, and states must make "every effort . . . to use all resources that are at its disposition" to provide essential drugs "as a matter of priority."[134] This includes both standard TB medications and those for drug-resistant TB.[135] Insufficient expenditure on health and misallocation of public resources, which results in the non-enjoyment of the right to health by individuals or groups, particularly the vulnerable or marginalized, constitute breaches of India's obligations under international law.[136]

Moreover, Indian courts have largely rejected financial limitations as an excuse in the context of the right to health. In *Paschim Banga Khet Majdoor Samity v. State of West Bengal*, the Supreme Court ordered the government to provide additional beds and facilities for patients needing emergency care.[137] The Court acknowledged that financial resources would be needed to provide these facilities, but noted "it is the constitutional obligation of the State to provide adequate medical services to the people" and "[w]hatever is necessary

130. *Lack of Equipment Hits TB Patients in Mumbai Civic Hospital*, DNA, http://www.dnaindia.com/mumbai/report-lack-of-equipment-hits-tb-patients-in-mumbai-civic-hospitals-1973109 (last updated Mar. 29, 2014, 7:17 AM); Maitri Porecha, *Fear Stalks Sewri TB Hospital as Mask Stocks Dwindle*, DNA, http://www.dnaindia.com/india/report-fear-stalks-sewri-tb-hospital-as-mask-stocks-dwindle-2103800 (last updated Jul. 12, 2015, 10:23 PM).

131. CENT. TB DIV., MINISTRY OF HEALTH & FAMILY WELFARE, GOV'T OF INDIA, REVISED NATIONAL TUBERCULOSIS CONTROL PROGRAMME: NATIONAL STRATEGIC PLAN FOR TUBERCULOSIS CONTROL 2012–2017 22–23 (n.d.), https://www.tbfacts.org/wp-content/uploads/2017/12/NSP-2012-2017.pdf.

132. Highest Attainable Standard, *supra* note 14, ¶ 12(a).

133. G.A. Res. 2200A (XXI), *supra* note 12, art. 2(1).

134. Highest Attainable Standard, *supra* note 14, ¶ 43(d); Comm. on Econ., Soc. and Cultural Rights, Annex III, General Comment No. 3, The Nature of States Parties' Obligations, ¶ 10, U.N. Doc. E/C.12/1990/8 (Dec. 14, 1990).

135. WORLD HEALTH ORG., WHO MODEL LIST OF ESSENTIAL MEDICINES 10–12 (19th ed. Nov. 2015).

136. Highest Attainable Standard, *supra* note 14, ¶ 52.

137. Paschim Banga Khet Mazdoor Samity of Ors. v. State of West Bengal., AIR 1996 SC 2426, paras. 10–11 (India).

for this purpose has to be done."[138] Similarly, the Delhi High Court, for example, held that the government "cannot cite financial crunch as a reason not to fulfill its obligation to ensure access of medicines," even if the medicines are extremely expensive (in that case, Rs. 600,000 [approximately $8,700] per month per person).[139] More recently, in holding that the government must provide second-line HIV treatment to all those who need it, the Supreme Court rejected the government's argument that it lacked funds to do so, stating, "It is a question of right to life guaranteed under Article 21 of the Constitution and the government cannot say finances are a constraint."[140] The Delhi High Court has been active in ensuring access to other medical products, including HIV testing equipment and Anti-Haemophilic Factor.[141]

F. Provide Enforceable Rights

India's TB guidelines and policies do not confer enforceable rights upon patients, but rather only set forth standardized protocols for healthcare providers.[142] For example, one of the core components of the RNTCP is an uninterrupted supply of quality assured drugs.[143] However, the RNTCP does not provide a legal or other mechanism for enforcing this. More generally, there are numerous problems with the existing grievance redressal procedures under the National Rural Health Mission (NRHM)[144]—a 2010 study described the complaint

138. *Id.* para. 16.

139. Writ Petition (Civil) Decision at paras. 1, 4, 69, Mohd Ahmed v. Union of India, No. 7229 of 2013 (Dehli HC) (India); *see also* Paschim Banga Khet Mazdoor Samity of Ors., AIR 1996 SC 2426.

140. *SC Forces Govt to Agree to Second-Line ART to All AIDS Patients*, TIMES INDIA (Dec. 11, 2010, 4:50 AM), https://timesofindia.indiatimes.com/india/SC-forces-govt-to-agree-to-second-line-ART-to-all-AIDS-patients/articleshow/7078375.cms.

141. *See, e.g.*, Writ Petition (Civil) at 1–2, Haemophiliacs Fed. v. Union of India, No. 16326 of 2006 (Delhi HC) (India); Writ Petition (Civil) Decision at 1, Love Life Society v. Union of India, No. 8700 of 2006 (Dehli HC) (India); DIPIKA JAIN & RACHEL STEVENS, THE STRUGGLE FOR ACCESS TO TREATMENT FOR HIV/AIDS IN INDIA 68–70 (Laya Medhini ed., 2008), http://www.hrln.org/hrln/publications/books/913-the-struggle-for-access-to-treatment-for-hivaids-in-india.html (discussing the *Love Life Society* case); *Haemophilia Federation India vs. Union of India*, HUM. RTS. L. NETWORK, www.hrln.org/hrln/disability-rights/pils-a-cases/129-haemophilia-federation-india-vs-union-of-india.html (last visited Jan. 28, 2018) (discussing the *Haemophiliacs Fed.* case); *Love Life Society vs. Union of India & Ors*, *supra* note 70.

142. MINISTRY OF HEALTH & FAMILY WELFARE, GOV'T OF INDIA, NATIONAL HEALTH POLICY 2015 DRAFT 56 (2014), https://www.nhp.gov.in/sites/default/files/pdf/draft_national_health_policy_2015.pdf [hereinafter HEALTH POLICY]; *see* PROGRAMMATIC, *supra* note 72; STRATEGIC PLAN, *supra* note 118; TB CARE IN INDIA, *supra* note 25.

143. REVISED NATIONAL, *supra* note 28, at 46; PROGRAMMATIC, *supra* note 72, at 5.

144. ARUNA KASHYAP, HUMAN RIGHTS WATCH, NO TALLY OF THE ANGUISH: ACCOUNTABILITY IN MATERNAL HEALTH CARE IN INDIA 103–07 (Oct. 2009).

handling mechanism as "abysmal" and, that same year, the Delhi High Court noted that, "despite the fact that under the NRHM there are service guarantees," there "does not also appear to be any inbuilt mechanism for corrective action, restitution and compensation in the event of the failure of any beneficiary to avail of the services."[145]

India should ensure that the RNTCP is held accountable for the health of its patients. Given the country's strong health rights jurisprudence (discussed throughout this article), an effective way to do this would be to provide free legal aid to TB patients. Some states are already doing this for HIV patients through state legal service authorities, bar associations, and partnerships with NGOs.[146] Tamil Nadu has created legal aid clinics inside of sixteen HIV Counseling and Testing Centres,[147] which could be replicated in select DOTS providers as well. More generally, the National Health Mission (NHM) needs to strengthen grievance redressal mechanisms at all levels—ASHA Grievance Redressal Committees; Village Health, Sanitation and Nutrition Committees; District and City Level Vigilance and Monitoring Committees; and Rogi Kalyan Samitis (Patient Welfare Committees).[148] India should also pass legislation making health a justiciable right, as suggested in the Ministry of Health and Family Welfare's 2015 Draft National Health Policy.[149]

Under international law, states must implement "accessible, transparent, and effective mechanisms of accountability" for rights violations.[150] Article 2(1) of the ICESCR requires states parties to take steps to achieve the right to health "by all appropriate means," and there is a strong presumption that these means include legal remedies

145. OM PRAKASH ARYA ET AL., CUTS CTR. FOR CONSUMER ACTION, RESEARCH & TRAINING, CASE STUDY: IMPROVING THE SERVICE DELIVERY BY MEASURING RATE OF ABSENTEEISM AND INITIATING COMMUNITY MONITORING IN 30 HEALTH CENTRES IN TONK DISTRICT OF RAJASTHAN, INDIA 4 (2010), http://www.cuts-international.org/Cart/pdf/CASE-Study-Improving_the_Service_Delivery_by_Measuring_Rate_of_Absenteeism.pdf; Writ Petition (Civil) Judgment of June 4, 2010 at 32, Laxmi Mandal v. Deen Dayal Harinagar Hospital, No. 8853 of 2008 (Delhi HC) (India).

146. NAT'L AIDS CONTROL ORG., *supra* note 63, at 72, 119, 173, 296; NADKAMI ET AL., *supra* note 63, at 33.

147. NADKAMI ET AL., *supra* note 63, at 77–78.

148. MINISTRY OF HEALTH & FAMILY WELFARE, GOV'T OF INDIA, 8TH COMMON REVIEW MISSION: REPORT 2014, at 15, 18, 20, 25, 57, 93, 96-97, 99-105, 151, 189 (2014), http://nhm.gov.in/images/pdf/monitoring/crm/8th-crm/Report/8th_CRM_Main_Report.pdf; NAT'L RURAL HEALTH MISSION, GUIDELINES FOR COMMUNITY PROCESSES 14, 45 (2013), http://nhsrcindia.org/sites/default/files/Community%20Processes%20Guidelines26.06.2013.pdf.

149. HEALTH POLICY, *supra* note 142.

150. U.N. Gen. Assembly, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, ¶ 8, U.N. Doc. A/63/263 (Aug. 11, 2008) [hereinafter Right of Everyone].

for violations.[151] Any person whose right to health has been violated should have access to effective judicial or other appropriate remedies at both the national and international levels, including both financial and equitable relief.[152] This requirement of accountability extends to both the public and private health sectors.[153] Under the PANEL approach, legal aid would promote accountability and empower patients to claim their rights rather than simply wait for policies, legislation, or the provision of services.[154] In India, the Supreme Court itself has created accountability mechanisms when needed. In the "right to food" case, the Supreme Court issued several orders relating to accountability—it empowered local government to conduct social audits, assigned responsibility for implementing schemes to specific public officials, created a grievance procedure, and gave extensive monitoring powers to independently appointed commissioners.[155]

G. Respect Patients' Privacy

In 2012, the Ministry of Health and Family Welfare made TB a notifiable disease, which requires healthcare providers to notify local government health authorities if a patient is diagnosed with it.[156] The reporting doctor has to submit the patient's name, age, sex, government ID number, address, phone number, the basis of the diagnosis, and certain medical information relating the disease (e.g., whether the patient's TB is drug resistant).[157] Given the strong stigma associated with TB in India, and reports that at least some TB patients in India have refused treatment from DOTS providers due to the "apprehension of disclosure," the government should explain and justify its use of patients' names in the notification system, given the possible alternatives of coded or unnamed notification.[158]

---

151. Econ., and Soc. Council, Comm. on Econ., Soc. and Cultural Rights, Substantive Issues Arising in the Implementation of the Int'l Covenant on Econ., Soc. and Cultural Rights: General Comment No. 9, ¶ 3, U.N. Doc E/C.12/1998/24 (Dec. 3, 1998); G.A. Res. 2200A (XXI), *supra* note 12, art. 2(1).

152. Highest Attainable Standard, *supra* note 14, ¶ 59.

153. Right of Everyone, *supra* note 150, ¶ 13.

154. LIVING WITH DEMENTIA, *supra* note 31, at 3.

155. RIGHT TO FOOD CAMPAIGN, SUPREME COURT ORDERS ON THE RIGHT TO FOOD: A TOOL FOR ACTION 9–10 (2008), http://www.righttofoodindia.org/data/scordersprimeratoolforaction.pdf.

156. MANOJ SINHA, MINISTRY OF HEALTH & FAMILY WELFARE, GOV'T OF INDIA, NOTIFICATION OF TB CASES (2012), https://tbcindia.gov.in/showfile.php?lid=3136.

157. CENT. TB DIV., MINISTRY OF HEALTH & FAMILY WELFARE, GOV'T OF INDIA, GUIDANCE FOR TB NOTIFICATION IN INDIA 3 (2012), https://tbcindia.gov.in/showfile.php?lid=3139.

158. RONALD BAYER & AMY FAIRCHILD, U.N. PROGRAMME ON HIV/AIDS (UNAIDS), THE ROLE OF NAME-BASED NOTIFICATION IN PUBLIC HEALTH AND HIV SURVEILLANCE 21–24,

This is supported by international law. The Committee on Economic, Social and Cultural Rights has recognized that the right to health is "closely related to and dependent on" the right to privacy.[159] Any limitations on the right to privacy based on public health concerns must be in accordance with international human rights standards and must be "strictly necessary."[160] According to the Siracusa Principles, this means that restrictions must respond to a pressing public or social need, pursue a legitimate aim, and be proportionate to that aim.[161] The burden of justifying a limitation upon the right to privacy lies with the state, and "[p]ublic health authorities must substantiate the need for a named identifier when collecting information."[162]

India should also develop clear policies and standards governing the non-consensual disclosure of a patient's TB status, as recommended by the WHO.[163] This is essential because, not only is TB-related stigma strong and widespread, but the Supreme Court has troubling precedent on this issue. In *X v. Hospital Z*, the Court found no violation of privacy where a hospital revealed X's HIV status to his uncle and, after X's fiancée and the fiancée's relatives found out (it is not clear how from the case), the wedding was called off.[164] The Court reasoned that disclosure was warranted to protect the fiancée's right to life,[165] and that since the Indian Penal Code criminalizes acts likely to spread "infection of any disease dangerous to life," the hospital would have participated in a crime if it did *not* disclose his HIV status.[166] While the WHO supports disclosure of a patient's HIV sta-

32 (July 2000), http://www.unaids.org/sites/default/files/media_asset/jc338-name-based_en_1.pdf; Mohd. Afzalul Haque et al., *A Study on Socio-Demographic Profile and Feasibility of DOTS Provider Registered Under RNTCP in Varanasi District Uttar Pradesh*, 26 INDIAN J. COMMUNITY HEALTH 107, 109 (2014).

159. Highest Attainable Standard, *supra* note 14, ¶ 3.

160. *Id.* ¶ 28.

161. U.N. Econ. and Soc. Council, Comm'n on Human Rights, The Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights, ¶ 10, U.N. Doc. E/CN.4/1985/4 (Sept. 28, 1984).

162. *Id.* ¶ 12; AMY L. FAIRCHILD ET AL., WORKING GRP. ON GLOB. HIV/AIDS & STI SURVEILLANCE, U.N. PROGRAMME ON HIV/AIDS/WORLD HEALTH ORG., GUIDING PRINCIPLES ON ETHICAL ISSUES IN HIV SURVEILLANCE 17 (2013), http://apps.who.int/iris/bitstream/10665/90448/1/9789241505598_eng.pdf?ua=1.

163. CARL COLEMAN ET AL., WORLD HEALTH ORG., GUIDANCE ON ETHICS OF TUBERCULOSIS PREVENTION, CARE AND CONTROL 14 (2010), http://apps.who.int/iris/bitstream/10665/44452/1/9789241500531_eng.pdf.

164. X v. Hospital Z, AIR 1999 SC 495 (India); *see also* X v. Hospital Z, AIR 2003 SC 664 (India).

165. *Hospital Z*, AIR 1999 SC 495, para. 44.

166. Indian Penal Code, Act No. 45 of 1860, PEN. CODE §§ 269–270; *Hospital Z*, AIR 1999 SC 495, para. 43.

tus over their objection in certain circumstances, it is only to the sexual partners of the patient.[167] In *X v. Hospital Z*, the Supreme Court went far beyond this by authorizing disclosure to X's relatives (his uncle) and the relatives of X's fiancée as well.[168]

H. Incorporate Explicit Limitations on Coercive Measures

India's TB policies do not discuss forced treatment or isolation for non-compliant patients, but merely state that when a patient has missed a dose of medication, the healthcare provider should "ensure that treatment is resumed promptly and effectively . . . in a sympathetic, friendly, and non-judgmental manner."[169] However, the government appears willing to consider more coercive measures. During the 2012 panic over "Totally Drug-Resistant" TB in Mumbai, the state and central governments announced that these patients would be isolated in a sanatorium (although it appears this did not actually end up happening).[170]

Indian law on this point is troubling. In 1989, the Bombay High Court upheld a provision of the Goa, Daman and Diu Public Health Act that allowed the government to isolate a person with HIV for "such period and on such conditions as may be considered necessary and in such Institution or ward thereof as may be prescribed."[171] The court noted that if there is a conflict between the right of an individual and the public interest, the former must yield to the latter.[172] Although this provision was removed from the statute in 1995,[173] this holding was never overruled, and other provisions are also problematic. The same Health Act still allows a health officer to forcibly take someone to a hospital or other place of treatment if it appears that

167. WORLD HEALTH ORG., GUIDANCE ON COUPLES HIV TESTING AND COUNSELLING INCLUDING ANTIRETROVIRAL THERAPY FOR TREATMENT AND PREVENTION IN SERODISCORDANT COUPLES: RECOMMENDATIONS FOR A PUBLIC HEALTH APPROACH 11 (2012), http://apps.who.int/iris/bitstream/10665/44646/1/9789241501972_eng.pdf?ua=1.

168. *See Hospital Z*, AIR 2003 SC 664, para. 44.

169. PROGRAMMATIC, *supra* note 72, at 63.

170. *See* Malathy Iyer, *New, Deadlier Form of TB Hits India*, TIMES INDIA, http://timesofindia.indiatimes.com/india/New-deadlier-form-of-TB-hits-India/articleshow/11396410.cms (last updated Jan. 7, 2012, 1:37 PM); Somita Pal, *TDR-TB Patients to Be Isolated, Say Centre and State Govt*, DNA, www.dnaindia.com/mumbai/report-tdr-tb-patients-to-be-isolated-say-centre-and-state-govt-1637699 (last updated Jan. 15, 2012); Theo Smart, *What Is Being Done About TDR-TB in Mumbai?*, AIDSMAP (May 8, 2012), http://www.aidsmap.com/What-is-being-done-about-TDR-TB-in-Mumbai/page/2271801.

171. Lucy R. D'Souza v. State of Goa, 1990 AIR 355 (Bom.), paras. 1, 4(vii) (India).

172. *Id.* paras. 8, 20.

173. Goa, Daman, and Diu Public Health Act, 1985 and Rules, 1987, at 977 (India), http://goaprintingpress.gov.in/uploads/Public%20Health%20Act%20and%20Rules.pdf.

they have an infectious disease (including TB) and the person is: (i) without proper lodging or accommodation, (ii) without medical supervision directed to the prevention of the spread of the disease, (iii) lodging in a place occupied by more than one family, or (iv) in a place where his presence is a danger to the people in the neighbourhood.[174] Moreover, a person taken to the hospital under this provision can leave only with the permission of the Medical Officer in-charge or the Health Officer, and leaving without permission is punishable by up to three months in prison.[175] Several other states have similar laws.[176]

India should incorporate explicit limitations on coercive measures into its TB policies. These should follow international law, as reflected in the Siracusa Principles and WHO guidance.[177] Restrictions in the name of public health must be strictly necessary, there must be no less intrusive means available, the restrictions must be based on scientific evidence, and they cannot be imposed in an unreasonable or discriminatory manner.[178] Forced isolation, in particular, must be the last resort and used "only after all voluntary measures to isolate [the] patient have failed."[179] This is a high burden—community-based treatment models for even MDR- and XDR-TB have been successful in numerous countries, including India, and treating TB patients at home with appropriate infection measures in place generally poses no substantial risk to other family members.[180] In addition, coercive treatment may actually undermine the government's public health goals by scaring people away from testing and treatment.[181] Finally,

174. *Id.* at 956, 973, 977.

175. *Id.* at 978.

176. *See* Tamil Nadu Public Health Act, No. 3 of 1939, at 667, 670 (India), http://www.lawsofindia.org/pdf/tamil_nadu/1939/1939TN3.pdf; Madhya Pradesh Public Health Act, No. 36 of 1949, at 273, 276, 279 (India), http://www.lawsofindia.org/pdf/madhya_pradesh/1949/1949MP36.pdf; Puducherry (Public) Health Act, 1973, No. 5 of 1974, at 50 (India), http://www.lawsofindia.org/pdf/puducherry/1974/1974Pondicherry5.pdf;Travancore Cochin Public Health Act, 1955, No. 16 of 1955 (India), http://www.sanchitha.ikm.in/node/2363.

177. *WHO Guidance On Human Rights And Involuntary Detention For XDR-TB Control*, World Health Org. (Jan. 24, 2007), http://www.who.int/tb/features_archive/involuntary_treatment/en/.

178. *Id.*

179. *Id.*

180. Coleman et al., *supra* note 163, at 22; *Drug Resistant TB: XDR-TB FAQ*, World Health Org., http://www.who.int/tb/areas-of-work/drug-resistant-tb/xdr-tb-faq/en/ (last visited Feb. 7, 2018).

181. *See generally* Thelma Narayan, A Study of Policy Process and Implementation of the National Tuberculosis Control Programme in India (1998).

forced treatment (above and beyond forced isolation) should never be allowed.[182]

I. Ensure Patient Participation

As reflected in the PANEL principles, a human rights approach to TB must ensure that TB patients are able to *participate* in all decisions that directly affect them.[183] Although not specifically listed in the major human rights treaties, the right to participate is implicit in a variety of other rights, including the right to self-determination, the right against medical experimentation, and the right to dignity.[184] The right to participate means that TB patients should be recognized as key actors in the health system, rather than passive recipients of commodities and services.[185] A key component of this is sharing information in an accessible format.[186] However, a significant number of patients using government TB services (at least in some areas) lack basic knowledge about the disease itself (as discussed above) and also the logistics of treatment, including the dosage schedule, the duration of treatment, potential side effects, and the fact that treatment must be continued even after the symptoms subside.[187] Such knowledge

182. WORLD HEALTH ORG., TUBERCULOSIS, ETHICS, AND HUMAN RIGHTS 14 (2013), http://www.euro.who.int/__data/assets/pdf_file/0004/242941/Tuberculosis,-ethics-and-human-rights.pdf.

183. WORLD HEALTH ORG., U.N. HUMAN RIGHTS, A HUMAN RIGHTS-BASED APPROACH TO HEALTH 2 (n.d.), http://www.ohchr.org/Documents/Issues/ESCR/Health/HRBA_HealthInformationSheet.pdf [hereinafter APPROACH TO HEALTH].

184. *See* G.A. Res. 217 (III) A, Universal Declaration of Human Rights, art. 1 (Dec. 10, 1948); G.A. Res. 2200A (XXI), *supra* note 12, art. 1; Highest Attainable Standard, *supra* note 14, ¶ 3.

185. *Factsheet*, *supra* note 10.

186. APPROACH TO HEALTH, *supra* note 183, at 3.

187. *See* Radha Aras et al., *Knowledge About Treatment Aspects Of Pulmonary Tuberculosis Patients Registered Under Revised National Tuberculosis Control Programme (RNTCP)*, 5 INDIAN J. APPLIED RES. 609, 609 (2015), https://www.worldwidejournals.com/indian-journal-of-applied-research-%28IJAR%29/file.php?val=April_2015_1427897254__188.pdf; R. Bansal et al., *Knowledge And Misconceptions Of Pulmonary Tuberculosis Patients At DOTS Centre*, *Urban Meerut*, 25 INT'L J. COMMUNITY HEALTH 119, 120 (2013), http://www.iapsmupuk.org/journal/index.php/IJCH/article/view/357/194; Rahul Ramesh Bogam, *Knowledge Of Tuberculosis: A Survey Among Tuberculosis Patients At Tertiary Health Care Center In Pune City*, 2 GLOBAL RES. ANALYSIS 128, 129 (2013), https://www.worldwidejournals.com/global-journal-for-research-analysis-GJRA/recent_issues_pdf/2013/March/March_2013_1363599514_05d91_50.pdf; Rituparna Das & S. Baidya, *A Study on Knowledge of Pulmonary Tuberculosis and DOTS among Pulmonary Tuberculosis Patients in West Tripura District, India*, 12 SAARC J. TUBERCULOSIS, LUNG DISEASES & HIV/AIDS 3, 3 (2015); Malini Kar & M. Logaraj, *Awareness, Attitude and Treatment Seeking Behavior Regarding Tuberculosis in a Rural Area of Tamil Nadu*, 57 INDIAN J. TUBERCULOSIS 226, 227 (2010), http://medind.nic.in/ibr/t10/i4/ibrt10i4p226.pdf; Kulkarni et al., *supra* note 105; Hetvi D. Mahida et al., *Are Urban Slum Dwellers Aware About Tuberculosis—A Cross Sectional Study in Surat City*, 5 NAT'L J. COMMUNITY MED. 346, 348 (2014), http://njcmindia.org/uploads/5-3_346-348.pdf; Lancelot M. Pinto & Zarir F. Udwadia, *Private Patient*

gaps have serious implications for informed consent, contribute to interrupted treatment,[188] and relegate patients to a passive role in their healthcare. Moreover, a participatory approach would build patient trust and strengthen cooperation, both of which are essential for health programs to succeed.[189]

A participatory approach should also involve the patients in the design, implementation, and monitoring of TB programs.[190] The National Rural Health Mission's Village Health, Sanitation and Nutrition Committees (VHSNCs) are well placed to facilitate this. These Committees are explicitly intended to "provide an institutional mechanism for the community to voice health needs, experiences and issues with access to health services"[191] and to "ensure community participation at all levels."[192] They are formed at the village level and should include local politicians, health workers, and community members, including women, health system beneficiaries, and those from disadvantaged groups.[193] The VHSNCs are supposed to provide health system beneficiaries a role in monitoring and accountability by maintaining a public services register noting gaps in services and corrective actions to be taken (and by whom), visiting public health facilities to assess the availability and quality of services, and serving as a grievance redressal mechanism.[194] Where the Committee itself cannot resolve a complaint, it must forward the complaint to the district grievance redressal committee.[195] The VHSNCs are specifically involved with the RNTCP because their oversight includes confirming

Perceptions About A Public Programme; What Do Private Indian Tuberculosis Patients Really Feel About Directly Observed Treatment, 10 BMC PUB. HEALTH 357, 357 (2010), https://bmcpublichealth.biomedcentral.com/track/pdf/10.1186/1471-2458-10-357?site=bmcpublichealth.biomedcentral.com.

188. Vijay et al., *supra* note 62, at 7.

189. *See* Right of Everyone, *supra* note 150, ¶ 14; COLEMAN ET AL., *supra* note 163, at 13.

190. OFFICE OF THE U.N. HIGH COMM'R FOR HUMAN RIGHTS, PRINCIPLES AND GUIDELINES FOR A HUMAN RIGHTS APPROACH TO POVERTY REDUCTION STRATEGIES 14-15 (n.d.), http://www.ohchr.org/Documents/Publications/PovertyStrategiesen.pdf; *see* APPROACH TO HEALTH, *supra* note 183, at 2-3.

191. NAT'L RURAL HEALTH MISSION, *supra* note 148, at 37.

192. NAT'L RURAL HEALTH MISSION, HANDBOOK FOR MEMBERS OF VILLAGE HEALTH SANITATION AND NUTRITION COMMITTEE 1 (n.d.), http://www.nhm.gov.in/images/pdf/communitisation/vhsnc/Resources/Handbook_for_Members_of_VHSNC-English.pdf.

193. NAT'L HEALTH MISSION, VILLAGE HEALTH SANITATION & NUTRITION COMMITTEE, INTRODUCTION 1 (n.d.), http://www.nhm.gov.in/communitisation/village-health-sanitation-nutrition-committee.html.

194. *See* NAT'L RURAL HEALTH MISSION, *supra* note 148, at 41, 45.

195. *Id.* at 45.

that TB drugs and diagnostics are available in local public health centres.[196]

However, in practice, many of the VHSNCs are not effective. Recent studies have found that the VHSNCs studies performed few of their specified functions, failed to monitor health centres, had little (or no) training, did not hold regular meetings, failed to follow up on action items from prior meetings, and even failed to understand their roles in the community.[197] The government's own Common Review Mission concluded in 2014 that NHM grievance redressal mechanisms are "weak across states"—many states do not have complaint/suggestion boxes for patient feedback, and even where they exist, there is no mechanism to analyse and address the issues highlighted.[198]

India should strengthen the VHSNCs. VHSNC members need to be properly trained on their roles and responsibilities and a strong oversight mechanism (perhaps at the district level) needs to be implemented. The government should consider replicating successful state-level practices, such as identifying specific authorities for grievance redressal at various levels (such as the Principal Secretary and Health Commissioner at the state level and the Chief Medical and Health Officer at district level), forming committees in district hospitals and community health centres for reviewing complaints, and creating a state-level centralized call centre with a toll-free number.[199] The RNTCP should also support formation of TB patient groups in every district so that cured patients can serve as adherence advocates for TB patients undergoing treatment.[200]

196. *Id.* at 58-59.

197. Pramod Kumar Sah et al., *Performance of Village Health, Nutrition and Sanitation Committee: A Qualitative Study from Rural Wardha, Maharashtra*, 1 HEALTH AGENDA 112, 115 (2013), http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.707.1401&rep=rep1&type=pdf; V. Semwal et al., *Assessment of Village Health Sanitation and Nutrition Committee under NRHM in Nainital District of Uttarakhand*, 25 INDIAN J. COMMUNITY HEALTH 472, 475, 476 (2013), http://www.iapsmupuk.org/journal/index.php/IJCH/article/view/558/275; Aradhana Srivastava et al., *Are Village Health Sanitation and Nutrition Committees Fulfilling Their Roles for Decentralised Health Planning and Action? A Mixed Methods Study from Rural Eastern India*, 16 BMC PUB. HEALTH 1, 5 (2016), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4722712/pdf/12889_2016_Article_2699.pdf.

198. NAT'L HEALTH MISSION, TUBERCULOSIS, 8TH COMMON REVIEW REPORT 15, 126, 157 (2013), http://nhm.gov.in/images/pdf/monitoring/crm/8th-crm/Report/8th_CRM_Main_Report.pdf.

199. *Id.* at 126.

200. FIFTH JOINT MONITORING MISSION, *supra* note 27, at 41.

V. Conclusion

A human rights approach to TB in India would both uphold patients' dignity and improve the RNTCP's success. India has a strong right-to-health jurisprudence, which could be applied in the context of TB to address, e.g., the socio-economic determinants of TB, inadequate funding, and lack of access to drugs for drug-resistant TB.

The limitations of court involvement must be acknowledged. In the "right to food" case, for example, the Supreme Court's interim orders are "far from being fully implemented," and some state governments have not even bothered to reply to letters from the right-to-food commissioners appointed by Supreme Court despite the Court's direct order to "respond promptly" to them.[201] Other orders in that case have been implemented, but only after a "long and arduous process."[202] Similarly, in *Sankalp Rehabilitation Trust v. Union of India*, the government pledged to provide free ARV medication to HIV patients, but due to inadequate implementation, the petitioners had to request the intervention of the court.[203]

There are also limitations in the case law itself. Indian courts have not followed a human rights approach in cases involving forced isolation, and the case law relating to regulation of the private health sector provides mostly general principles but little direct guidance.

It is our hope that India will implement a human rights approach to TB. Healthcare providers need to engage with patients, not as data points or potential disease transmitters, but rather both as individuals worthy of respect and as partners in creating a healthier society. This will do more than just promote respect for human rights and health justice—it will lead to more effective public health interventions as well.

201. *See* Right to Food Campaign, *supra* note 155, at 13.
202. *Id.* at 29.
203. Jain & Stevens, *supra* note 141, at 44.