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Report No.256

Eliminating Discrimination Against Persons Affected by Leprosy

April 2015

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D.O. No.6(3)/273/2015-LC(LS) 7 April, 2015

Dear Mr. Sadananda Gowda ji,

On a reference from the then Minister for Law and Justice, Shri Ravi Shankar Prasad, the Law Commission of India undertook the task of identifying laws which can either be repealed or which need amendments in view of the existing climate of economic liberalization. Through its four Reports, viz., Report Nos. 248-251, the Commission recommended repeal of 288 obsolete laws. In its Report No.249, the Commission recommended the repeal of The Lepers Act, 1898 in consultation with the relevant State(s). However, on a request from the Leprosy Mission Trust of India, the Commission took up the study of amending / repealing laws discriminatory towards people affected by leprosy.

Leprosy is one of the oldest known diseases, but remains misunderstood in all its aspects including its etiology, causation, means of transmission and curability. To this day, it remains among the most dreaded of diseases. In 2014, India had the largest number of new Leprosy cases globally (58%). From 2005 till 2014, the National Leprosy Eradication Programme (NLEP) has recorded a rate of 1.25 to 1.35 lakh new cases every year, a majority being children, who are threatened with isolation and discrimination at a very young age.

Although Leprosy may cause irreversible disabilities, with advances in medicine, it is now a completely curable disease that can be rendered non-infectious early on in treatment itself, through Multi-Drug Therapy, which has cured more than 15 million persons over two decades alone. Government of India has undertaken programmes to provide free-of-cost treatment to Persons affected by Leprosy, even as the search continues for newer and more effective methods of treatment.

However, a major obstacle to uplift the status of Persons affected by Leprosy is the social stigma associated with Leprosy. In many spheres of life, such persons continue to be outcast from society.

Another problem is that of Indian laws, which continue to directly and indirectly discriminate against Persons affected by Leprosy. In 2010, the United Nations General Assembly unanimously adopted a Resolution on the Elimination of Discrimination against Persons affected by Leprosy, accompanied by Principles and Guidelines listing out measures to improve the living conditions of such persons. Further, the United Nations Convention on the Rights of Persons with Disabilities, 2007 ("UNCRPD") promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.

India has signed and ratified the UNCRPD, and is also a member of the UN General Assembly that unanimously passed the Resolution on the Elimination of Leprosy. However, no action has been taken by the Central Government or by State Governments to modify or repeal any of the legislations. Under the Constitution, the Union of India has both the obligation as well as the competence to enact a comprehensive law eliminating discrimination against Persons affected by Leprosy. This is now an urgent need.

To address precisely this concern, after a series of meetings and deliberations, the Law Commission of India has finalized its **Report No.256** titled "**Leprosy Affected Persons and the Laws applicable to them**" and is submitted herewith for consideration by the Government.

With warm regards,

Yours sincerely,

Sd/-

[Ajit Prakash Shah]

Mr. D.V. Sadananda Gowda
Hon'ble Minister for Law and Justice
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Report No.256

Eliminating Discrimination Against Persons Affected by Leprosy

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CHAPTER I

INTRODUCTION AND BACKGROUND TO THE REPORT

1.1 As per the letter dated 24 June 2014 from Shri Ravi Shankar Prasad, the Minister for Law and Justice, Government of India, the 20th Law Commission of India under the Chairmanship of Justice (Retd.) A.P. Shah undertook the task of identifying laws, which can either be repealed or which need change in light of the existing climate of economic liberalization.

1.2 The study titled **"Legal Enactments Simplification and Streamlining"** undertaken by the Law Commission, produced four interim reports on laws, rules, regulations and circulars ("laws") that are in force in India, which warrant immediate repeal or amendment.

1.3 In its Second Interim Report No. 249 on "**Obsolete Laws: Warranting Immediate Repeal**", the 20th Law Commission recommended the repeal of the Lepers Act (Act 3) of 1898, in consultation with the relevant State(s). Section 1(3) of the Lepers Act mandates that it shall not come into force in any territory until the concerned State Government makes a declaration to that effect. Contrary to general conception, the Lepers Act continues to exist on the statute books of India, even though the States of Gujarat, Assam, Nagaland, Meghalaya, West Bengal, Tamil Nadu, Tripura, Punjab, Karnataka, Orissa, Himachal Pradesh, and Maharashtra, and the Union Territories of Delhi, Andaman and Nicobar Islands, Lakshadweep, Dadra and Nagar Haveli and

Chandigarh have repealed its application within their respective jurisdictions. The Act provides for the exclusion, segregation and medical treatment of pauper lepers. It also provides for the establishment of 'leper asylums' and conditions for employment of personnel in these asylums.

1.4 The Law Commission recognised that the Lepers Act is completely out of sync with the modern understanding of Leprosy and its treatment through Multi-Drug Therapy ("MDT").[1] As a result of its observations, the Commission recommended the repeal of the Act for being in violation of Article 14 of the Constitution, owing to the forcible exclusion and segregation of persons affected by Leprosy under the Act.[2]

1.5 The Law Commission also acknowledged in its Second Interim Report No. 249 that India is a member of the UN General Assembly that unanimously passed the Resolution on the Elimination of Discrimination against Persons affected by Leprosy and their Family Members, 2010 (A/RES/65/215) ("UN Resolution on Persons affected by Leprosy and their Family Members").[3] The Lepers Act, as mentioned in the Second Interim Report, goes against the spirit of this Resolution and therefore requires immediate repeal in consultation with States, which continue to apply it within their respective territories.

1.6 After the release of the Second Interim Report, The Leprosy Mission Trust India approached the Law Commission in late 2014, for further action in

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[1] Recommendation 57, Law Commission Report on "Obsolete Laws: Warranting Immediate Repeal", Second Interim Report No. 249, Law Commission of India, Government of India (October, 2014) pg 32-33. ("Law Commission Report No. 249").

[2] *Ibid.*

[3] Law Commission Report No. 249 (n 1).

respect of laws applicable to the persons affected by Leprosy.

1.7 The Leprosy Mission Trust India ("TLMTI"), was founded in 1874 as 'The Mission to Lepers' by Wellesley Bailey.[4] In its 140 years of existence, TLMTI has through a comprehensive, participatory and country-wide consultation involving Persons affected by Leprosy, endeavoured to promote and undertake various efforts for the benefit of Persons affected by Leprosy, which include awareness and advocacy programs, healthcare and sustainable livelihood initiatives, and education, training and research.[5] However, after India's declaration that Leprosy is no longer a public health issue, on the basis of a World Health Organisation ("WHO") standard,[6] the cause of persons affected by Leprosy has taken a backseat in the Indian context, making it harder for TLMTI and other similar organisations working on Leprosy in India, to translate their efforts in a scalable measure to cater to the needs of persons affected by Leprosy. Complete eradication of Leprosy is however different from this standard of elimination as a public health issue.

1.8 The 20th Law Commission took note of the commendable efforts of TLMTI in addressing the concerns of Persons affected by Leprosy through its awareness and advocacy initiatives. The Commission also recognised the need for the modification and repeal of existing laws, regulations, policies, customs

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[4] The "Our History" page on the website of the Leprosy Mission Trust India (TLMTI), available at <http://www.tlmindia.org/index.php/about-us/who-we-are/our-history>, accessed on 24th January, 2014.

[5] The "About Us" page on the website of TLMTI, available at <http://www.tlmindia.org/index.php/about-us/who-we-are>, accessed on 24th January, 2014.

[6] 'Guide to Eliminate Leprosy as a Public Health Problem', WHO (2000), available at <http://www.who.int/lep/resources/Guide_Int_E.pdf?ua=1>, accessed on 24th January, 2014.

and practices that negatively affect Persons affected by Leprosy and promote their exclusion, segregation and discrimination. In light of these observations, the Law Commission has undertaken the present study on "**Eliminating Discrimination against Persons affected by Leprosy**" in order to provide the Government with a detailed insight into the level of discrimination and stigma associated with Leprosy, along with its constructive recommendations for a new model law to eliminate discrimination faced by Persons affected by Leprosy.

1.9 The second chapter of this Report deals with the disease of Leprosy and the current status of Persons affected by Leprosy. The third chapter examines the attempts made thus far in addressing the concerns of Persons affected by Leprosy in India. The fourth chapter provides an insight into the domestic legal framework that facilitates direct and indirect discrimination of Persons affected by Leprosy and their family members, while the fifth chapter focuses on the international efforts in addressing these concerns through the United Nations Convention on the Rights of Persons with Disabilities, UN General Assembly Resolution on Persons affected by Leprosy and their Family Members, and the Principles and Guidelines for the Elimination of Discrimination against Persons affected by Leprosy and their Family Members'. The sixth chapter offers an insight into the past and present practices in other jurisdictions in relation to Persons affected by Leprosy. The seventh chapter lists out the recommendations, including the specific provisions and laws that require repeal, amendment or modification and the proposal for affirmative action that promotes the social inclusion of Persons affected by Leprosy. The final chapter proposes a draft legislation in India that endorses the elimination of discrimination against Persons affected by Leprosy and their family members through deriving its legislative competence from Article 253 of the Constitution.

1.10 In order to undertake the present study on Persons affected by Leprosy and to formulate the draft legislation addressing the abovementioned issues, the Commission formed a sub-committee comprising of the Chairman, Justice S.N. Kapoor, Professor (Dr.) Mool Chand Sharma, Prof. (Dr.) Yogesh Tyagi, Dr. Arghya Sengupta, Ms. Yashaswini Mittal, and Ms. Vrinda Bhandari.

1.11 The Commission would also like to place on record its special appreciation for Mr. Munish Kaushik, Ms. Seema Baquer and Ms. Nikita Sarah, the representatives of The Leprosy Mission Trust India, whose inputs were incisive, vital and require special mention. It appreciates the commendable efforts put in by Mr. Arghya Sengupta and Ms. Yashaswini Mittal of Vidhi Centre for Legal Policy and Ms. Vrinda Bhandari and Ms. Sumathi Chandrashekaran, Consultants to the Commission in finalizing this report. Ms. Ayushi Agarwal Law Student, provided research assistance.

1.12 Thereafter, upon extensive deliberations, discussions and in-depth study, the Commission has given shape to the present Report.

CHAPTER II

LEPROSY AND THE STATUS OF PERSONS AFFECTED BY LEPROSY IN INDIA: THE NEED FOR CHANGE

A. Understanding Leprosy

2.1.1 Leprosy or Hansen's disease is one of the world's oldest diseases. Ancient Hindu scriptures make specific references to Leprosy, while Ayurvedic texts of the 6th Century BC note the symptoms of Leprosy.[7] The ancient Manusmriti also discusses Leprosy while laying down the rules and regulations governing marriage.[8] However, in spite of its ancient history, Leprosy as a disease is largely misunderstood, in all its aspects including its etiology, causation, means of transmission and its curability.[9]

2.1.2 The disease of Leprosy is triggered by the causative agent *Mycobacterium Leprae*, a bacillus which was first discovered by a Norwegian doctor, Gerhard Armauer Hansen in 1873.[10] An untreated person suffering from Leprosy can spread the infection through the passage of air.[11] According to sources, more than 85% of Persons affected by Leprosy are non-infectious and do not spread Leprosy, while over 99% of the world population has a natural immunity or

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[7] Navin Chawla, "Vocational Rehabilitation and Social Reintegration of the Leprosy Affected in India", available at <http://eci.nic.in/ECI_Main/DJ/Vocational%20and%20Rehabilitation%20and%20Social%20Reintegration%20of%20the%20Leprosy%20Affected%20in%20India%20(Page1-Page114).pdf>, accessed on 24th January, 2014.

[8] *Ibid.*

[9] Leprosy: The Facts, Myth and Treatment of Disease, Ministry of Health and Family Welfare, available at <http://mohfw.nic.in/WriteReadData/l892s/9823984802http.pdf>, accessed on 24th January, 2014.

[10] Shigeki Sakamoto, "Requests Addressed To The Advisory Committee Stemming From Human Rights Council Resolutions: Elimination Of Discrimination Against Persons Affected By Leprosy And Their Family Members", UN Human Rights Council, Doc. No. A/HRC/AC/3/CRP.2 (31 July, 2009).

[11] Leprosy: The Facts, Myth and Treatment of Disease (n 9).

resistance to Leprosy.[12] Persons affected by Leprosy exhibit symptoms of pale and reddish skin, numbness of hands or feet or loss of feeling in a patch of skin.[13] The incubation period of Leprosy ranges from five years to as long as twenty years.[14]

2.1.3 Leprosy has been largely known to be a human disease, in that the human body is the principal reservoir of *Mycobacterium Leprae*.[15] If not treated early, Leprosy can lead to Grade I (i.e. sensory impairment, or muscle weakness without contractures) or Grade II (i.e. visible impairment, muscle atrophy, or bone absorption of shortening or contractures) deformities.[16] One of the important factors leading to disabilities in Persons affected by Leprosy is the early neglect in getting a diagnosis, and proper treatment for those who exhibit signs of absence of pain, itching and other such symptoms.[17] Neglect over prolonged periods usually leads to the infection getting severe, causing deformity and secondary pyogenic infection causing permanent damage to hands and feet, loss of eyebrows and depressed noses.[18] Manifestations of the disease appear to vary according to geographical variations and host responses.[19]

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[12] *Ibid*; *See* also "Leprosy in Our Time", A Report by the Nippon Foundation and Sasakawa Memorial Health Foundation (2013), available at <http://www.nippon-foundation.or.jp/en/what/projects/leprosy/Leprosy_in_Our_Time2013.pdf>, accessed on 24th January, 2014.

[13] Shigeki Sakamoto (n 10).

[14] Navin Chawla (n 7); Leprosy: The Facts, Myth and Treatment of Disease (n 9).

[15] Leprosy: The Facts, Myth and Treatment of Disease (n 9).

[16] Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy, Updated Operational Guidelines, WHO (2011-2015), available at <http://www.searo.who.int/entity/global_leprosy_programme/documents/enhanced_global_strategy_2011_2015_operational_guidelines.pdf>, accessed on 24th January, 2014; *See* also Leprosy: The Facts, Myth and Treatment of Disease (n 9).

[17] Leprosy: The Facts, Myth and Treatment of Disease (n 9).

[18] Leprosy: The Facts, Myth and Treatment of Disease (n 9).

[19] Leprosy: The Facts, Myth and Treatment of Disease (n 9).

2.1.4 The disease of Leprosy has two main varieties - lepromatous and non-lepromatous.[20] The persons falling under the lepromatous variety, comprise about 15-20% of Persons affected by Leprosy.[21] The lepromatous variety is a severe form of Leprosy that causes the easy spread of infection when left untreated or inadequately treated.[22] Up to 80-85% of all cases of Leprosy are of the non-lepromatous or non-severe variety, where the infection is feeble, and does not spread easily to others.[23] In India the vast majority of Persons affected by Leprosy, are of the non-lepromatous variety.[24] A majority of Leprosy-affected beggars also fall within this category.[25]

B. Facts and Myths surrounding Leprosy

2.2.1 There are several myths and distortions surrounding Leprosy that are sought to be clarified in this Chapter. Such myths consider Leprosy as a hereditary and infectious disease that is caused due to impure blood and poverty.[26] Many also believe that the infection of Leprosy spreads through food and water and is difficult to detect.[27] However, all such beliefs are not based on evidence and therefore without merit.[28]

2.2.2 Leprosy is not a hereditary disease and is not caused due to impure blood or poverty, but due to the causative agent *Mycobacterium Leprae* as mentioned above. Further, even though Leprosy is a chronic infectious disease, it is neither difficult to

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[20] Navin Chawla (n 7).
[21] Navin Chawla (n 7).
[22] Navin Chawla (n 7).
[23] Navin Chawla (n 7).
[24] Navin Chawla (n 7).
[25] Navin Chawla (n 7).
[26] Leprosy: The Facts, Myth and Treatment of Disease (n 9).
[27] Leprosy: The Facts, Myth and Treatment of Disease (n 9).
[28] Leprosy: The Facts, Myth and Treatment of Disease (n 9).

diagnose nor hard to treat. The main consideration for an effective Leprosy treatment is early detection and regularity in treatment.

2.2.3 All persons are not susceptible to Leprosy, although insanitary conditions, malnutrition and lack of personal hygiene may increase the chances of getting infected by the Leprosy bacillus or a host of other diseases and infections caused on account of such conditions.[29] Further, Leprosy is not a fatal disease, even though on account of the stigma and discrimination, it may cause permanent psychological and social damage to the victims.[30]

C. The Prevalence of Leprosy

2.3.1 To this day, Leprosy continues to be the most dreaded of all diseases (with the possible and recent exception of AIDS).[31] As of 2014, India accounts for 58% of the new Leprosy cases in the world, leading the list of countries that have reported high figures of Leprosy infection globally.[32] As per the 1985 records of the WHO, India had estimated 7,30,540 of its citizens to be affected by Leprosy. However after the introduction of MDT in the same year, the government was able to reduce the overall rate of Leprosy to 1 new case per 10,000 population by December 2005, by means of door to door surveys and other drives initiated for the purpose of administering MDT. This reduction in the overall rate marked the elimination of Leprosy as a public health issue in India.

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[29] Navin Chawla (n 7).

[30] Navin Chawla (n 7).

[31] Navin Chawla (n 7).

[32] Annual Report of the International Federation of Anti-Leprosy Associations (2012 – 2013), available at <http://www.ilep.org.uk/fileadmin/uploads/Documents/Annual_Reports/annrep13.pdf>, accessed on 24th January, 2014.

2.3.2 However, once the declaration of the elimination of Leprosy as a public health issue was made, the vertical health programme of Leprosy was merged into the general healthcare system of the country. This transition did not happen as smoothly and in as well-planned a manner as it should have, leading to gaps in service delivery including the detection of Leprosy, which continue to exist till today. In addition, from 2005 onwards there was an increase in the incidence of Leprosy in India, on account of the shift in public health priorities from Leprosy to AIDS and cancer. Thus, from 2005 till 2014, the National Leprosy Eradication Programme (NLEP) of the Government of India has been recording a rate of 1.25 to 1.35 lakh new cases every year.[33]During 2013-2014 alone, 1.27 lakh new cases of Leprosy were detected in India.[34] A major portion of these new cases of Leprosy in India are of children, who face the threat of isolation and discrimination at a very young age. An estimated number of 850 Leprosy colonies are currently operating in India and housing Persons affected by Leprosy that have been otherwise segregated from the public.[35]

2.3.3 Therefore, after a sharp decline till 2005, the detection or incidence of Leprosy has not shown much improvement. It is however pertinent to mention that the recent draft of the National Health Policy, 2015 endeavours to carry on the efforts of the Government to fully eliminate Leprosy in India through an integrated approach towards "communicable diseases". This however does not extend to repealing

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[33] NLEP – Progress Report for the year 2013-14, Central Leprosy Division, Directorate General of Health Services, available at <http://nlep.nic.in/pdf/Progress%20report%2031st%20March%202013-14.pdf>, accessed on 24th January, 2014.

[34] *Ibid.*

[35] NLEP – Progress Report (n 33).

discriminatory legislation and introducing new protective legislation which is the subject matter of this Report.

D. Preventive and Curative Treatments

2.4.1 Prior to its earliest known cure, there was no scientifically established treatment for Leprosy. On account of the lack of a cure, isolation of the patient into asylums and Leprosy colonies was considered to be the only measure for the containment of the disease from spreading onto the healthy population.[36] Later on, with the introduction of Dapsone as the earliest known cure, Leprosy control programs took the form of Survey, Education and Treatment ("SET") strategy model, comprising house-to-house surveys for case detection, treatment in out-patient clinics, and health education.[37] However, on account of the reluctance of people to cooperate with household surveys, and their hesitation to attend Leprosy clinics due to the prevailing ostracism against the disease, it became difficult for Persons affected by Leprosy to get treated with Dapsone in the initial years.[38] In addition, Persons affected by Leprosy who did get treated with Dapsone, in some instances, developed resistance to the drug and therefore could not benefit from the treatment.[39]

2.4.2 Although Leprosy is the cause of irreversible disabilities,[40]with advances in science and technology in the field of Leprosy treatment during the last three

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[36] Leprosy: The Facts, Myth and Treatment of Disease (n 9).

[37] Report of the Working Group on Disease Burden for the 12th Five Year Plan, Planning Commission, Government of India (2011), available at <http://planningcommission.gov.in/aboutus/committee/wrkgrp12/health/WG_3_1communicable.pdf>, accessed on 24th January, 2014.

[38] Navin Chawla (n 7).

[39] Navin Chawla (n 7).

[40] Navin Chawla (n 7).

decades, it is now a completely curable disease that can be rendered non-infectious in the initial stages of the treatment itself. The treatment that has made it possible to cure Leprosy is the process of Multi-Drug Therapy (“MDT”), which was first recommended by the WHO in early 1980s after over 40 years of research and testing.[41] Under MDT, powerful drugs such as Rifamipicin, Clofazimine and others in combination with Dapsone, are administered to the affected person to effectively fight the Leprosy bacillus. Over the past two decades, more than 15 million Persons affected by Leprosy are said to have been cured under MDT.[42]

2.4.3 The MDT regimen requires regularity, supervision and continuity to be effective. The regimens are worked out on the basis of whether a particular case involves paucibacillary (very few number of bacilli), which requires a prescribed regimen for about six months, or multibacillary (very large number of bacilli), which requires a prescribed regimen of about one year on an average. After its first dose itself, MDT kills 99.9% of the Leprosy bacteria that cause the disease, thereby rendering Persons affected by Leprosy non-contagious and eliminating the need for the segregation of such persons along with their family members.[43] MDT has been used to treat patients in India for the past two decades, and has been instrumental in substantially reducing the incidence of Leprosy among Indians, especially during

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[41] Shigeki Sakamoto (n 10).

[42] Report by the Nippon Foundation and Sasakawa MemorialHealth Foundation (n 12).

[43] Shigeki Sakamoto (n 10); *See* also Eighth Report of the WHO Expert Committee on Leprosy, WHO Technical Report Series (2012), available at <http://www.searo.who.int/entity/global_leprosy_programme/publications/8th_expert_comm_2012.pdf>, accessed on 24th January, 2014; Report of the tenth meeting of the WHO Technical Advisory Group on Leprosy Control, WHO Regional Office for South-East Asia (2009), available at <http://www.searo.who.int/entity/global_leprosy_programme/publications/10th_tag_meeting_2009.pdf>, accessed on 24th January, 2014.

the 1985-2005 period.[44] An early detection of the disease along with its immediate treatment via MDT can save infected persons from irreversible deformities.[45] After completing a full course of treatment through MDT, a relapse of the disease in previously affected persons is very rare.[46]

2.4.4 In addition to treatment under MDT, reconstruction surgery ("RCS") is also performed on the Persons affected by Leprosy for the correction of disability of hands, feet and eyes caused on account of the disease.[47] The Government of India has undertaken programmes to provide free-of-cost treatment to Persons affected by Leprosy through MDT and has also introduced subsidies and compensation schemes for RCS for such persons.[48]Meanwhile, the search is on for newer and more effective methods of treatment of Leprosy through vaccination and prophylaxis.

2.4.5 As per several surveys and studies conducted on Persons affected by Leprosy, it has been noted that a major obstacle to the uplift of the status of Persons affected by Leprosy is the social stigma associated with Leprosy.[49] Persons suffering from the early stages of the disease are dissuaded from approaching a doctor, on account of fear of ostracisation and isolation.[50]The main reason for the stigma and discrimination against Persons affected by

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[44] Report of the Working Group on Disease Burden (n 37)

[45] Hundred and Thirty-First Report on the 'Petition Praying for the Integration and Empowerment of People Affected by Leprosy', Rajya Sabha Committee on Petitions (2008) ("131st Report on Leprosy").

[46] Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy (n 16).

[47] 131st Report on Leprosy (n 45).

[48] 131st Report on Leprosy (n 45).

[49] Hundred and Thirty-Eight Report on the 'Action Taken by Government on the Observations/Recommendations contained in its Hundred and Thirty-First Report on Petition Praying for the Integration and Empowerment of People Affected by Leprosy', Rajya Sabha Committee on Petitions (2010) ("138th Report on Leprosy").

[50] *Ibid.*

Leprosy has been the disabling and disfiguring nature of Leprosy that goes against the aesthetic notion of physical beauty that prevails in society.[51] The deformities of Persons affected by Leprosy have also been traditionally considered to cause repugnance.[52] Further, in the absence of any understanding about the cause and cure of Leprosy for many decades, the Persons affected by Leprosy were viewed, in a number of societies, as objects of divine punishment where the disease was considered as a visitation of past sins, requiring the out casting of such persons.[53] In many spheres of life the world over including in India, the process of out-casting of Persons affected by Leprosy continues to take place, although the scale of such process has considerably diminished in light of the growing awareness regarding the disease.

2.4.5 In light of the large number of fresh cases in India, especially post-2005, an early detection of Leprosy is the need of the hour to prevent Persons affected by Leprosy from exhibiting physical deformities. To address this issue, the law and policy in India needs to adapt to the growing needs of the Persons affected by Leprosy and remove provisions within its framework that discriminate and isolate such persons. In this context, several attempts have already been made to address the cause of Persons affected by Leprosy that shall be discussed in the next chapter.

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[51] Navin Chawla (n 7).
[52] Navin Chawla (n 7).
[53] Navin Chawla (n 7).

CHAPTER III

ATTEMPTS MADE THUS FAR IN ADDRESSING THE CONCERNS OF PERSONS AFFECTED BY LEPROSY

3.1 Several attempts have been made in India thus far to uplift the status of Persons affected by Leprosy and their family members through concerted action. One such attempt was made by Dr. Shivajirao Patwardhan, a Homeopathic doctor who founded the "Jagdamba Leprosy Mission" or Tapovan in the Amravati district of Maharashtra in 1950, and devoted his whole life for Leprosy patients.[54] Tapovan is considered to be one of the finest and most comprehensive treatment and rehabilitation complexes for Leprosy patients.[55] Dr. Patwardhan undertook great struggles in dispelling the canards associated with the disease of Leprosy and was successful in improving the living conditions of several Persons affected by Leprosy.[56]

3.2 Another sterling endeavour for the uplift of Persons affected by Leprosy was undertaken by Baba Amte (Murlidhar Devidas Amte) in Warora, Maharashtra. Baba Amte started working for those struck by Leprosy outside Warora, immediately after his marriage.[57] He set up 11 weekly clinics around Warora and later started "Anandwan", a self-contained ashram for Persons affected by Leprosy and their family members.[58] Baba Amte's Anandwan was

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[54] Padmashri Dr. Shivajirao Patwardhan, Note on Amravati District, available at <http://court.mah.nic.in/courtweb/static_pages/courts/amravati.pdf>, accessed on 25th January, 2014.

[55] *Ibid.*

[56] Note on Amravati District (n 54).

[57] Maharashtra Bhushan – Baba Amte, Website of the Maharashtra Collector, available at <http://chanda.nic.in/htmldocs/anandwan.html>, accessed on 25th January, 2014.

[58] *Ibid.*

registered in 1951, and has since grown considerably in light of grants and land given by the government.[59] Anandwan today consists of two hospitals, a university, an orphanage, a school for the blind and technical wings.[60] It is now a self-sufficient unit, where more than 5,000 people are dependent on it for their livelihood.[61]

3.3 In addition to the aforementioned efforts by individuals, several efforts have also been undertaken by the government to tackle the concerns of Persons affected by Leprosy. In this regard, an appeal for the integration and empowerment of Persons affected by Leprosy had been made to governments at the Central and State level by the Rajya Sabha Committee on Petitions in their Hundred and Thirty First-Report.[62] The Committee, in its report, looked into eleven points for consideration that included the formulation of a national policy for the empowerment of Persons affected by Leprosy, amendment to all the relevant legislations that harmed the interest of Persons affected by Leprosy, access to medical facilities and civic amenities and other such assistance measures that are for the general benefit of such persons.[63] Through the Report, the Committee made several pertinent recommendations that sought to do away with the marginalisation and stigmatisation of Persons affected by Leprosy and that strived to make the legal framework in India more responsive to their needs.[64]

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[59] Maharashtra Bhushan – Baba Amte (n 57); *See* also Baba Amte, Website of Anandwan, available at <http://www.anandwan.in/about-anandwan/baba-amte.html>, accessed on 25th January, 2014.

[60] *Ibid.*

[61] Maharashtra Bhushan – Baba Amte (n 57) and Baba Amte (n 59).

[62] 131st Report on Leprosy (n 45).

[63] 131st Report on Leprosy (n 45).

[64] 131st Report on Leprosy (n 45).

3.4 Subsequently, the Hundred and Thirty-Eighth Report of the same Committee analysed the actions taken by the Central and State governments on the recommendations/observations contained in the Hundred and Thirty-First Report.[65] In this Report, the Committee took note of the actions taken by the government on the relevant recommendations made previously and analysed the progress made thereafter on those actions.[66] In this regard, with respect to legislative amendments, the Committee noted the explanations offered by the relevant Ministries and made additional recommendations, in instances where necessary.[67]

3.5 However even though the efforts made thus far have been noteworthy and have considerably improved the lives of many Persons affected by Leprosy and their family members, the long-standing stigma associated with Leprosy and the archaic laws applicable to them continue to exist. This is most evident if we consider the domestic legal framework, described in detail in the next chapter.

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[65] 138th Report on Leprosy (n 49).
[66] 138th Report on Leprosy (n 49).
[67] 138th Report on Leprosy (n 49).

CHAPTER IV

THE DOMESTIC LEGAL FRAMEWORK: FACILITATING DIRECT AND INDIRECT DISCRIMINATION AGAINST PERSONS AFFECTED BY LEPROSY IN INDIA

4.1 Several Indian laws are both directly as well as indirectly discriminatory against Persons affected by Leprosy. The issues surrounding such discrimination were taken up for consideration by the Rajya Sabha Committee on Petitions in 2008 and have also been deliberated upon by the same Committee in its Action Taken Report (Hundred and Thirty-Eight Report) of 2010.[68] However, no affirmative action has been taken by the Central Government or by some of the State Governments, to modify or repeal any of the legislations that are applicable to Persons affected by Leprosy.

4.2 Certain provisions under the Hindu Marriage Act, 1955, the Dissolution of Muslim Marriage Act, 1939, the Indian Divorce Act, 1869, the Indian Christian Marriage Act, 1872, the Special Marriage Act, 1954 and the Hindu Adoption and Maintenance Act, 1956, are directly discriminatory against Persons affected by Leprosy and consider Leprosy to be an 'incurable and virulent' disease. An infection from Leprosy for not less than two years, under these legislations, serves as a legitimate ground for divorce or separation between spouses.

4.3 Under the State Beggary Acts, Persons affected by Leprosy are earmarked in the same category as persons suffering from lunacy. Further,

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[68] *See* 131st Report on Leprosy (n 45) and 138th Report on Leprosy (n 49).

medical examination and arrest and detention of Persons affected by Leprosy for an unspecified duration are also provided for under these Acts, in line with past notions wherein Leprosy was considered to be incurable. Children, who are wholly dependent on begging until the age of five and who have a parent suffering from Leprosy, are also liable to be detained under such Acts. The Life Insurance Corporation Act, 1956 contains a discriminatory provision, wherein higher premium rates are to be charged from Persons affected by Leprosy on account of the higher risk to their lives as understood through past notions. Several State Municipal and Panchayati Raj Acts, which are listed out in Chapter VII, also contain specific provisions that bar Persons affected by Leprosy from holding or contesting for civic posts.

4.4 In respect of indirect discrimination, relevant provisions under the Railways Act, 1989, the Motor Vehicles Act, 1988, the Industrial Disputes Act, 1947 and State Acts such as the Bombay Municipal Corporation Act, 1888, permit the denial of certain rights, privileges and concessions to persons who suffer from an infectious or contagious disease or disability. Leprosy, in light of its traditional understanding, continues to be included within the range of such contagious diseases and disabilities. On the other hand, the Rehabilitation Council of India Act, 1992 and the Persons with Disabilities Act, 1995, do not include all categories of Persons affected by Leprosy within their purview, which results in the denial of access to special privileges for many of such persons.

4.5 In addition to the aforementioned legislations, the decision of the Supreme Court in

Dhirendra Pandua v. State of Orissa[69] also adds to the long-standing notion of Leprosy being an incurable and infectious disease requiring segregation and special treatment. In the aforementioned case the criteria for selection of persons to civic offices under Sections 16(1)(iv) and 17(1)(b) of the Orissa Municipal Act, 1950 was discussed. The two sections disqualified Persons affected by Leprosy from occupying civic offices under the said Act. The Supreme Court noted that although scientific developments now have a cure for Leprosy, few studies demonstrated that nearly 10% of the patients continue to harbour viable persisters of the disease, despite two years of regular therapy.[70] The Court further noted that in light of available sources, it was evident that despite various measures, at the relevant time, reactivation of Leprosy could not be completely ruled out and was dependent on a multiplicity of factors.[71] In light of its findings, the Court upheld the disqualification of the petitioner by observing that the legislature in its wisdom has rightfully retained the provisions in the statute that bar Persons affected by Leprosy from occupying civic offices, as there is a reasonable concern of the disease being contagious.[72]

4.6 It is pertinent to mention here however, that the Supreme Court observed in its discussion in the aforementioned case, that the notion about Leprosy was changing, given that in light of the recommendation of the Working Group on Eradication of Leprosy, appointed by the Government of India, several State Governments and Union Territories had repealed the antiquated Lepers Act, 1898 and similar

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[69] AIR 2009 SC 163.

[70] *Ibid* at Para 19-21.

[71] *Ibid.*

[72] *Ibid* atPara 27-29.

State Acts that provided for the segregation and medical treatment of Persons affected by Leprosy.[73] The Court stated that, keeping in view the research conducted on Leprosy along with professional inputs, the legislature may perhaps seriously reconsider its stance of retaining provisions in statutes that discriminated against such persons.[74]

4.7 The need for better treatment of Persons affected by Leprosy has also been recognised by Courts, in instances where Persons affected by Leprosy have been segregated or discriminated against. For example, in a recent order in the case *of Pankaj Sinha v. Union of India,*[75] the Supreme Court again noted that even though Leprosy, as of today, is curable, on account of the lack of empathy shown by the concerned authorities, it still remains a stigmatic disease in the society. The Court also held that such stigmatisation affects human dignity and the basic concept of humanness.[76]

4.8 In the case of *Maharashtra State Road Transport Corporation v. Uttam Shatrughan Raserao*,[77] the employment of the complainant was terminated as he was considered unfit to work. The complainant suffered from Leprosy and was considered to be in a poor condition to work in any post offered by the establishment authorities. However, the Bombay High Court dismissed the arguments advanced by the establishment authorities, and held that since Leprosy is now curable, persons suffering from the disease need to be treated and rehabilitated instead of being

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[73] *Ibid* atPara 30-31.

[74] *Ibid.*

[75] Supreme Court Order dated 28 November, 2014, Manupatra citation: MANU/SCOR/51230/2014.

[76] *Ibid.*

[77] 2002 (4) BomCR 68.

shunned.[78] The Court finally extended the grant of benefits in favour of the complainant in light of the clarifications issued by the establishment, wherein employees whose services were terminated on account of their permanent disability were entitled to a supplementary gratuity.[79] In the case of *Dhirendra Pandua* as well, the Court took cognizance of the changing notions regarding Leprosy and called upon the legislature to consider changing the legislations applicable to Persons affected by Leprosy in light of scientific developments that had found a cure to the disease.[80]

4.9 Considering these legislative and judicial patterns and as noted in *Dhirendra Pandua*, the law applicable to Persons affected by Leprosy in India is obsolete as it adheres to specific standards of treatment and segregation that are no longer applicable to such persons, especially in light of the recent compelling developments in science and the discovery of MDT, which has emerged as a reliable and suitable cure for Leprosy.

4.10 Thus, a strong case can be made out for the need for legislative intervention in amending, modifying and/or repealing relevant provisions under various legislations that discriminate against Persons affected by Leprosy and seek to segregate them from the general public.

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[78] *Ibid* at Para 4.
[79] *Ibid.*
[80] Dhirendra Pandua v. State of Orissa (n 69) atPara 30-31.

CHAPTER V

INTERNATIONAL EFFORTS IN ADDRESSING THE CONCERNS OF PERSONS AFFECTED BY LEPROSY AND THEIR FAMILIES

5.1 The United Nations General Assembly unanimously adopted a Resolution on the Elimination of Discrimination against Persons affected by Leprosy [81] ("UN Resolution on Leprosy") on 21st December 2010. This Resolution recognised and strongly urged nations to abide by the Principles and Guidelines for the Elimination of Discrimination against Persons affected by Leprosy and their Family Members' [82] ("Principles and Guidelines on Leprosy") adopted by the UN Human Rights Council in 2010.

5.2 The Resolution and the Principles and Guidelines substantiate the need for amending and repealing laws applicable to Persons affected by Leprosy and call on governments to pursue measures to end the discrimination of such persons. [83] Specifically, they call on governments to modify, repeal or abolish existing laws, regulations, policies, customs and practices that discriminate directly or indirectly against Persons affected by Leprosy and their family members. [84] Family members of such persons are included within the ambit of the Resolution and the Principles and Guidelines on Leprosy, in order to promote the understanding that Leprosy is no longer an easily communicable disease and is in fact curable through the MDT. The family members of Persons affected by Leprosy are exposed to discrimination and

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[81] UNGA res. 68/215, Sixty-Fifth Session, UN Doc. A/RES/65/215 (2010).

[82] UNHRC res. A/HRC/15/30 (30 September, 2010).

[83] *Ibid.*

[84] *Ibid.*

exclusion on account of their association with the Person affected by Leprosy.[85]

5.3 The Principles and Guidelines on Leprosy list out several measures for improving the living conditions of Persons affected by Leprosy. These measures include treatment of Persons affected by Leprosy and their family members with dignity, and on an equal basis with other members of society as provided for under international human rights instruments including the Universal Declaration of Human Rights ("UDHR"), International Covenant on Economic, Social and Cultural Rights ("ICESCR"), International Covenant on Civil and Political Rights ("ICCPR") and the Convention on Rights of Persons with Disabilities. As per the Principles and Guidelines, Persons affected by Leprosy and their family members cannot be denied the right to marry, the right to have children and the right to adopt. Persons affected by Leprosy and their family members are required to be given the same rights as everyone else with respect to (1) citizenship and identity documents; (2) recruitment policies; and (3) education and training in any field.

5.4 The Principles and Guidelines also calls upon States to uphold the dignity of Persons affected by Leprosy and their family members, through the repeal, amendment and modification of legislations to suit the needs of such persons and to ensure equality and non-discrimination of such persons through prohibitions and specific measures. The States are also asked to pay special attention to women, children and other vulnerable groups affected by Leprosy, while implementing its programs for the benefit of Persons affected by Leprosy. Access to healthcare, promotion in

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[85] Strategic Framework for Reduction of Stigma & Discrimination, NLEP, available at <http://nlep.nic.in/pdf/Stigma.pdf>, accessed on 25th January, 2014.

standard of living, participation in political, cultural and recreational activities and reunification with family along with community living are also guaranteed under the Principles and Guidelines for the benefit of Persons affected by Leprosy and their family members. The key measures for the enforcement of the Principles and Guidelines include legislative interventions and awareness building initiatives that promote the inclusion of Persons affected by Leprosy and their family members into mainstream society.

5.5 The United Nations Convention on the Rights of Persons with Disabilities, 2007 ("UNCRPD") also promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.[86] The UNCRPD does not specifically deal with Persons affected by Leprosy or their family members, but provides the framework for tackling their concerns through equal opportunity measures, awareness programs and prohibitions against segregation and discrimination on the basis of their disability.[87]

5.6 India has signed and ratified the UNCRPD, and is also a member of the UN General Assembly that unanimously passed the Resolution on the Elimination of Leprosy.[88] Being part of the UN General Assembly, India has the obligation to suitably change or repeal its laws in order to make them more amenable to the present-day needs of the Persons affected by Leprosy in light of the UN Resolution that specifically calls on nations to abide by the Principles and Guidelines on Leprosy adopted by the UN Human Rights Council. In

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[86] UN Doc. A/61/611 (2006).

[87] *Ibid.*

[88] Data provided to the Law Commission of India by The Leprosy Mission Trust India (TLMTI) (on file with the Law Commission).

this regard, Article 51 and Article 253 of the Constitution of India[89] play an important role in entrusting the Parliament of India with the requisite power to operationalise this change or repeal the discriminatory laws discussed above, as necessary. Article 51 deals with India's obligation to promote international peace and endeavour to uphold its international obligations and commitments. Since the eradication of leprosy is a clear international commitment, the State is obliged to take all measures to ensure its fulfilment. In this effort, it is aided by Article 253 which vests the legislative competence in Parliament to make laws in furtherance of India's international commitments, irrespective of whether the subject-matter in question falls in List II of the Seventh Schedule of the Constitution, i.e. within the legislative competence of the States. Thus the Union of India has both the obligation as well as the competence to enact a comprehensive law eliminating discrimination against Persons affected by Leprosy which is a key step in the eradication of the stigma associated with the disease in the country. This is now an urgent need when one considers that it has been five years since the adoption of the UN Resolution on the Elimination of Leprosy and no definitive action has been taken by the Government of India in the interim.

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[89] Article 51 of the Directive Principles on State Policy under Part IV of the Constitution reads as:

The State shall endeavour to— (a) promote international peace and security; (b) maintain just and honourable relations between nations; (c) foster respect for international law and treaty obligations in the dealings of organized peoples with one another; and (d) encourage settlement of international disputes by arbitration;

Article 253 of the Chapter on Relations between the Union and the States under Part XI of the Constitution reads as:

Notwithstanding anything in the foregoing provisions of this Chapter, Parliament has power to make any law for the whole or any part of the territory of India for implementing any treaty, agreement or convention with any other country or countries or any decision made at any international conference, association or other body.

CHAPTER VI

PRACTICES IN OTHER JURISDICTIONS IN RELATION TO PERSONS AFFECTED BY LEPROSY

6.1 Till a little more than a decade ago, several jurisdictions across the world sanctioned the compulsory segregation and isolation of Persons affected by Leprosy through legislation. For instance, South Africa, Australia and Pakistan implemented legislations that were similar to the Lepers Act, 1898 in India, to enforce compulsory segregation of Leprosy patients.[90] Japan set up leprosaria under the Leprosy Prevention Law of 1907, to segregate all Leprosy patients and place them separately in such leprosaria.[91] In 1907, Philippines also imposed a legal responsibility on the Director of Health to compulsorily segregate such persons.[92] The laws of Malaysia, Bahamas, Republic of Korea, Egypt, Singapore and Myanmar also sanctioned the isolation of such persons for quite some time.[93]

6.2 In the addition to the practice of segregation, Singapore prohibited Persons affected by Leprosy from travelling by public transport under its Railways Act of 1906, while Thailand required aliens to submit along with their application, a recent medical certificate from a physician attesting to the fact that the alien was not of unsound mind and not suffering from leprosy under its Alien Occupation Law.[94] Persons affected by Leprosy were further denied national identity cards in the State of Angola, while the children of such persons were denied from attending

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[90] Shigeki Sakamoto (n 10).

[91] Shigeki Sakamoto (n 10).

[92] Shigeki Sakamoto (n 10).

[93] Shigeki Sakamoto (n 10).

[94] Shigeki Sakamoto (n 10).

public schools in the villages of China for many years.[95]

6.3 However, the stigmatisation and ostracisation of Persons affected by Leprosy through such laws and practices started to diminish after the late 1990s, when the world community took note of the discriminatory spirit of such laws and decided to curtail their implementation in their individual jurisdictions.[96] To this end, several countries redrafted their legislations and policies to make them more amenable to the needs of Persons affected by Leprosy and to ensure that the basic rights of all such persons were statutorily guaranteed to them. A few of such legislations and policies that are significant have been laid down below.

(i) Azerbaijan

6.3.1 The State of Azerbaijan has been committed to providing political and financial support for the elimination of discrimination against registered Leprosy patients and their family members.[97] To this end, the government of Azerbaijan has (1) started public awareness campaigns through the media and through publications to dispel the misconceptions surrounding Leprosy; and (2) established patient care institutions for the benefit of Persons affected by Leprosy.[98] In recent years, the government has also recognised the right of those affected by Leprosy to access free-of-cost treatment, education and work

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[95] Shigeki Sakamoto (n 10).

[96] Shigeki Sakamoto (n 10).

[97] Annual Report of The United Nations High Commissioner For Human Rights And Reports Of The Office Of The High Commissioner And The Secretary-General on the Elimination of Discrimination against Persons affected by Leprosy and their Family Members, UN Doc. No. A/HRC/10/62 (23 February, 2009), available at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G09/115/36/PDF/G0911536.pdf?OpenElement>, accessed on 25th January, 2015 (“Annual Report of the OHCHR”).

[98] Annual Report of the OHCHR (n 97).

opportunities and to receive State compensation.[99] Persons affected who have undergone treatment and have been cured of Leprosy are also provided with a one-time financial package, as well as with a job and private dwelling by the local executive power to assist them in reintegrating themselves into society.[100]

(ii) Costa Rica

6.3.2 In 1974, Costa Rica introduced an ambulatory treatment without confinement for Persons affected by Leprosy along with an education campaign to combat discrimination against Persons affected by Leprosy.[101] In 2002, the commitments to eliminating the disease by 2005 were further strengthened by the government of Costa Rica through several protocols and public health measures, such as the re-instauration of epidemiological vigilance and the strengthening of capacities for health professionals.[102]

(iii) Ecuador

6.3.3 Under Articles 32 and 50 of the Constitution of Ecuador, all persons who suffer from catastrophic diseases and are in need of preferential and specialised treatment, are guaranteed the right to free-of-cost health services.[103] In this regard, the treatment through MDT is made available free-of-cost, to all Persons affected by Leprosy, through the generous donations of the WHO and the Pan-American Health Organization.[104]

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[99] Annual Report of the OHCHR (n 97).
[100] Annual Report of the OHCHR (n 97).
[101] Annual Report of the OHCHR (n 97).
[102] Annual Report of the OHCHR (n 97).
[103] Annual Report of the OHCHR (n 97).
[104] Annual Report of the OHCHR (n 97).

6.3.4 Based on statistical information and disease control, the government of Ecuador has undertaken specific steps (1) to train its health personnel; (2) to coordinate with national and international civil society organizations in order to implement education campaigns to fight discrimination against the disease; (3) to provide specialised medical attention to persons with disabilities as a result of Leprosy; and (4) to systematically control and monitor the main provinces where Leprosy is prevalent.[105]

(iv) Egypt

6.3.5 In Egypt, Persons affected by Leprosy are entitled to full medical treatment for Leprosy free-of-cost and at any medical establishment, until such persons have been cured and have fully recovered.[106] In cases where Leprosy has led to disabilities, the Persons affected by Leprosy can also undergo medical and social rehabilitation in order to reintegrate themselves as well as their family members, back into mainstream society.[107] Law No. 131 of 1946, which provides for the segregation of Persons affected by Leprosy has not been enforced in Egypt since 1984, after the introduction of MDT as recommended by the WHO.[108]

(v) Finland

6.3.6 Under Section 6 of the Constitution of Finland, the general standards on non-discrimination ensure that every person, including Persons affected by Leprosy and their family members, are treated

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[105] Annual Report of the OHCHR (n 97).
[106] Annual Report of the OHCHR (n 97).
[107] Annual Report of the OHCHR (n 97).
[108] Annual Report of the OHCHR (n 97).

equally before the law.[109] In addition, the Finnish Non-Discrimination Act provides for a general framework for equal treatment of all such persons in all aspects of employment, occupation and education.[110] The said Act defines discrimination in an extensive way, attempting to cover both direct and indirect discrimination.[111] Provisions to prevent discrimination against all persons on any ground are also included within the Penal Code, the Employment Contracts Act and the Act on the Status and Rights of Patients.[112]

(vi) Greece

6.3.7 The Greek Law No. 1137/1981 specifically provides for the treatment and social protection of persons suffering from Hansen's disease that includes the provision for monthly income support to Persons affected by Leprosy who are either undergoing treatment, or have been treated and cured of the disease.[113] The income support is also provided to the family members of Persons affected by Leprosy including their children.[114] In addition to support and treatment, the Law No. 1137 imposes a mandatory duty upon doctors and hospital staff to ensure confidentiality.[115] Terms such as "leprosy" or "leper" have been eliminated from all public documents in Greece in light of the said law.[116]

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[109] Annual Report of the OHCHR (n 97).
[110] Annual Report of the OHCHR (n 97).
[111] Annual Report of the OHCHR (n 97).
[112] Annual Report of the OHCHR (n 97).
[113] Annual Report of the OHCHR (n 97).
[114] Annual Report of the OHCHR (n 97).
[115] Annual Report of the OHCHR (n 97).
[116] Annual Report of the OHCHR (n 97).

(vii) Japan

6.3.8 In March 2005, the members of the Verification Committee in association with the Japan Law Foundation presented a report entitled "Verification Committee Concerning Hansen's Disease Problem".[117] The Committee was set up by the Ministry of Health, Labour and Welfare to assess the scientific and historical significance of the segregation policy in relation to Persons affected by Leprosy and to provide guidance on the formulation of government policies in relation to such persons.[118]

6.3.9 Subsequently in 2001, an Act on Payment of Compensation to Inmates of Hansen's' Disease Sanatoria was passed in Japan to provide financial assistance to Persons affected by Leprosy.[119] Another law aimed at extending social welfare services to such persons was enacted in 2008.[120] In the same year, the Ministry of Justice also placed the elimination of prejudice against persons living with HIV and Persons affected by Leprosy as a priority for its human rights week that year.[121]

(viii) Korea

6.3.10 The National Assembly in the Republic of Korea passed a legislative bill for People affected by Leprosy on 20 September, 2007.[122] The Government also publicly apologised and offered compensation to

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[117] Verification Committee Concerning Hansen'sDisease Problem, Final Report (Japan Law Foundation, 2005), available at <http://www.mhlw.go.jp/english/policy/health/01/pdf/01.pdf>, accessed on 25th January, 2015; *See* also Annual Report of the OHCHR and the Secretary General (n 97).

[118] *Ibid.*

[119] Annual Report of the OHCHR (n 97).

[120] Annual Report of the OHCHR (n 97).

[121] Annual Report of the OHCHR (n 97).

[122] Annual Report of the OHCHR (n 97).

Persons affected by Leprosy on account of the systematic wrongdoings against such persons that had continued for several decades.[123]

(ix) Oman

6.3.11 The Royal Decree No. 101/96 in Oman ensures material and medical assistance to Omani citizens and their families in case of sickness, incapacity or old age.[124] Under the Islamic Sharia law, the values of cooperation, dignity and equality prevail irrespective of social status, health and any other consideration.[125] The Omani Ministry of Social Development is vested with the responsibility of addressing issues surrounding Leprosy.[126] A government house set-up for Persons affected by Leprosy can accommodate up to ten Leprosy patients at a time, who then enjoy the best social, psychological and healthcare services available.[127] The families of such persons also receive housing assistance and monthly social security grants during the treatment of such persons and after the completion of treatment.[128] After the completion of treatment, the Omani Ministry also endeavours to make an effort to support the re-integration of the discharged persons into society.[129]

(x) Ukraine

6.3.12 Under Article 27 of the Ukrainian Law No. 1645-III dated 6 April 2000, all Persons affected by Leprosy receive medical assistance and treatment.[130]In

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[123] Annual Report of the OHCHR (n 97).
[124] Annual Report of the OHCHR (n 97).
[125] Annual Report of the OHCHR (n 97).
[126] Annual Report of the OHCHR (n 97).
[127] Annual Report of the OHCHR (n 97).
[128] Annual Report of the OHCHR (n 97).
[129] Annual Report of the OHCHR (n 97).
[130] Annual Report of the OHCHR (n 97).

addition, Law No. 1645-III also provides for the setting-up of specialised medical facilities for the Leprosy patients.[131] While living in these facilities, Leprosy patients enjoy the freedom of movement, regular communication and the right to vote.[132] Persons affected by Leprosy are also given land for agricultural work, and are allowed to be adequately represented in local state organizations and municipalities.[133]

6.3.13 The above-mentioned legislations and policies are significant in that they demonstrate the attempts made by the international community to eliminate discrimination against Persons affected by Leprosy through affirmative action and anti-discrimination policies. The Law Commission has taken note of these laws and policies in other jurisdictions and has endeavoured to incorporate some of the best practices in these laws and policies into its proposed Bill annexed to this Report.

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[131] Annual Report of the OHCHR (n 97).
[132] Annual Report of the OHCHR (n 97).
[133] Annual Report of the OHCHR (n 97).

CHAPTER VII
RECOMMENDATIONS

A. Repeal or Amendment of the Laws

7.1 In this Chapter, the Law Commission examines the specific provisions that directly or indirectly discriminate against Persons affected by Leprosy and therefore require immediate repeal, amendment or modification in order to make their application more amenable to the present-day developments in the treatment of Leprosy.

(i) Personal Laws

7.2 Under Section 13(1)(iv) of the Hindu Marriage Act, 1955, Section 2(vi) of the Dissolution of Muslim Marriage Act, 1939, Section 10(1)(iv) of the amended Indian Divorce Act, 1869, Section 27(g) of the Special Marriage Act, 1954 and Section 18(2)(c) of the Hindu Adoption and Maintenance Act, 1956, Leprosy affecting either spouse constitutes a ground for divorce, annulment of marriage or separation without forfeiture of maintenance. One of the main objectives behind the inclusion of these provisions under the relevant legislations has been to restrain the spread of the infection of Leprosy (given that it is a communicable disease) to the unaffected spouse. However as noted above in this Report, Leprosy is no longer an incurable disease and can be treated by MDT, which in its first dose itself kills 99.9% of the Leprosy bacillus and renders the infection non-contagious and non-virulent. On account of this, the Law Commission recommends that an infection of Leprosy affecting either spouse should not *by itself* constitute a ground for divorce, annulment of marriage or separation. The need for repeal of these provisions has been recognised by the Rajya Sabha Committee on Petitions in its Hundred and Thirty-First Report and in its Hundred and Thirty-Eighth Report.

(ii) Beggary Laws - including Andhra Pradesh Prevention of Begging Act, 1977, Bombay Prevention of Begging Act, 1959, Gujarat Prevention of Begging Act, 1959 and several other analogous legislations

7.3 Under all the State-level beggary prevention laws, the term *leper* has been used to refer to Persons affected by Leprosy. These laws also allow for beggars and their dependents who suffer from Leprosy to be detained or confined to Leprosy asylums indefinitely. The purpose behind such detention and confinement relates to the notion that Leprosy is an incurable and contagious disease. However, as noted in this Report, this notion is incorrect since Leprosy is now curable by MDT. Hence, Persons affected by Leprosy should not be detained or confined to Leprosy asylums indefinitely only on account of their infection of the disease. Additionally, the use of the term *leper* is derogatory and contributes to the stigma associated with the disease. Therefore, the Law Commission recommends that such a term should be removed from the statute book and all government records to curtail the perpetuation of the stigma associated with the disease. The need for the removal of the term *leper* under State beggary prevention laws has been recognised by the Rajya Sabha Committee on Petitions in its Hundred and Thirty-First Report and its Hundred and Thirty-Eighth Report.

(iii) The Persons with Disabilities Act, 1995 and Rights of Persons with Disabilities Bill, 2014

7.4 Under Section 2(I)(iii) of the Persons with Disabilities Act, 1995 *disability* means *inter-alia* a Leprosy-cured person. The term Leprosy-cured has been defined under Section 2(n) of the Act and Section 9 of the Rights of Persons with Disabilities Bill, 2014, to mean any person who has been cured of Leprosy but is suffering from (i) loss of sensation in hands or feet as well as loss of sensation and paresis in the eye and eye-lid but with no manifest deformity; (ii) manifest deformity and paresis; but having sufficient mobility in their hands and feet to enable them to engage in normal economic activity; (iii) extreme physical deformity as well as advanced age which prevents him from undertaking any gainful occupation. Under Section 2(t) of the Act, persons with disability are individuals who are suffering from not less than 40% of any disability as certified by a medical authority. Section 2(1)(c) of the Rehabilitation Council of India Act, 1992 uses the same definition of *disability* with all its sub-categories, as mentioned under Section 2(I) the Persons with Disabilities Act. As per TLMTI, the term Leprosy-cured does not appear to include Persons affected by Leprosy who are undetected or undergoing treatment and yet exhibit all or any of the three conditions described in the schedule. This term should therefore be amended to have a wider scope that covers larger number of persons who are affected by Leprosy, such as undetected Persons affected by Leprosy or Persons affected by Leprosy undergoing treatment.

7.5 Further, TLMTI has provided data that indicates that the 40% and above disability criteria under the Persons with Disabilities Act fails to cover persons cured of Leprosy with only Grade I disability, since the loss of sensation constitutes only 6-9% disability as per calculation process. On account of these observations, the Law Commission recommends that the term *Leprosy cured* needs to either be removed or broadened to cover all categories of Persons affected by Leprosy.

(iv) State Municipal and Panchayati Raj Acts – including the Orissa Municipal Act, 1950, Andhra Pradesh Municipalities Act, 1965, Orissa Gram Panchayats Act, 1964, Andhra Pradesh Panchayati Raj Act, 1994, Chhattisgarh and Madhya Pradesh Panchayati Raj Act, 1993, the Rajasthan Panchayati Act, 1994 and the Rajasthan Municipality Act, 1959 and several other analogous legislations.

7.6 The provisions on eligibility in the various State Municipality and Panchayat Raj legislations listed above, state that Persons affected by Leprosy are liable to be disqualified from holding a civic post on the ground of their infection of Leprosy. The validity of these provisions has been upheld by the Supreme Court in its judgement in the case of *Dhirendra Pandua.* However, subsequent to this judgement, several nations including India, have taken note of the rampant discrimination against Persons affected by Leprosy and have pledged through the UN Resolution on the Elimination of Leprosy to end all forms of discrimination and segregation against such persons. Under Principle 5 of the Principles and Guidelines on Leprosy adopted by the Resolution, all States including India, have been vested with the duty to provide Persons affected by Leprosy and their family members, with the right to stand for elections and to hold office at all or any level in the government on an equal basis as others. In light of this Principle, the Law Commission observes that there is a strong basis to do away with the restrictions on eligibility of Persons affected by Leprosy to stand for civic posts.

B. Call for Affirmative Action

7.7 In addition to the modification and repeal of specific provisions as discussed above, the Law Commission also recommends the enactment of a legislation that promotes the social inclusion of Persons affected by Leprosy and their family members through affirmative action. India's commitment to uphold the UNCRPD and UN Resolution on the Elimination of Leprosy as discussed previously, provides the required basis for the enactment of such a legislation under Article 253 of the Constitution of India.

7.8 In this regard, the *non-obstante* clause under Article 253 read along with Entry 14 of List I of Schedule VII of the Indian Constitution (Union List), provides the Parliament of India with the requisite power to make any law for the whole or any part of the Indian territory for implementing any treaty, agreement or convention with any other country or countries or any decision made at any international conference, association or other body. The power under Article 253 has been exercised to give effect to various treaties and agreements that include the UNCRPD, the signing of the Uruguay Round final Act on GATT 1994 and the decisions taken at the United Nations Conference on the Human Environment held in Stockholm, 1972.

7.9 The relevant legislation promoting affirmative action towards Persons affected by Leprosy and their family members needs to take note of the contemporary needs of such persons and address all aspects of their well-being in order to promote their holistic development and inclusion into society.

7.10 The key aspects that require attention in the context of such a legislation include the following:

(i) Measures against discrimination

7.10.1 It has been noted at various instances in this Report that Persons affected by Leprosy along with their family members are discriminated against in every institution, be it political, social, economic or educational. [134] Such discrimination against both Persons affected by Leprosy and their family members ranges from non-admission, to segregation, to discouragement to participate.[135] Children of Persons affected by Leprosy, who are not infected with the disease, are also treated in a similar fashion by society.[136]

7.10.2 The Law Commission recommends that to tackle these issues of discrimination, the proposed legislation on Persons affected by Leprosy and their family members, should (a) prohibit discrimination against Persons affected by Leprosy and their family members in all institutions; (b) implement affirmative measures for the social inclusion of such persons into mainstream society; (c) guarantee to all such persons, the right to access healthcare, adequate housing, education, employment and other such basic amenities.

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[134] Data provided by TLMTI (n 88).

[135] Data provided by TLMTI (n 88).

[136] Data provided by TLMTI (n 88).

(ii) Land Rights

7.10.3 As has been noted previously, the long-standing practice of moving Persons affected by Leprosy and their family members from mainstream society into clusters near hospitals needs to be curbed. These clusters have come to be known as Leprosy colonies, and are usually established outside the city limits. This practice reinforces segregation and deprives the Persons affected by Leprosy and their family members from owning or possessing property. These colonies are either established on government land including forest and railway lands or private land given for the purpose of establishing such colonies by private individuals or institutions.[137]

7.10.4 As noted previously, there are at present about 850 colonies in India.[138] It has also been estimated that no new Leprosy colonies have come up in the last 14 years, although people diagnosed with the disease continue to migrate to existing colonies.[139] Further, people who have been living in the colonies for years together wish to continue residing there with their families including children. However, in spite of their continued residence in these colonies, many Persons affected by Leprosy and their family members still do not have any land rights and live under the constant threat of eviction.[140] The lack of ownership and title to land also discourages Persons affected by Leprosy and their family members from developing the colony.

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[137] Data provided by TLMTI (n 88).
[138] Data provided by TLMTI (n 88).
[139] Data provided by TLMTI (n 88)..
[140] Data provided by TLMTI (n 88).

7.10.5 The Law Commission recommends that to tackle these issues of land rights, the proposed legislation should (a) take measures to legalise title and ownership of property in Leprosy colonies; and (b) in case, land rights cannot be given, explore alternative settlement options with the consent of the Persons affected by Leprosy and their family members.

(iii) Right to Employment

7.10.6 The economic empowerment of Persons affected by Leprosy and their family members is a crucial need, which must be actively supported and facilitated by the State. However, many employers misuse the existing employment legislations to terminate the employment of persons once they are diagnosed with Leprosy.[141]

7.10.7 *Section 2(o)(oo)(c) of the Industrial Disputes Act, 1947* is relevant in this regard, since it states that the termination of the service of an employee or a workman on the ground of continued ill-health does not constitute retrenchment. This section does not mention Leprosy as a ground for termination as such, but may be indirectly resorted to terminate the employment of an affected person or his/her family member due to the social stigma attached to the condition.

7.10.8 The Law Commission recommends that to tackle these issues of employment, the proposed legislation should include measures that prohibit termination of employment of Persons affected by Leprosy and their family members solely on the basis of the infection of the disease and the associated

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[141] Data provided by TLMTI (n 88).

stigma. The government can also consider providing quotas in institutions for Persons affected by Leprosy and their families or alternative employment opportunities, where they are physically capable of being employed, in order to encourage such persons to become financially independent.

(iv) Educational and training opportunities

7.10.9 Persons affected by Leprosy and, in some instances, their family members are denied admission to educational and training institutions on account of Leprosy. On account of this denial, such persons and their family members cannot obtain the requisite professional training or educational qualifications to access employment opportunities. In some cases, the family members of Persons affected by Leprosy forge addresses or lie about their identity in order to go to a school, college or a vocational training institute.[142]

7.10.10 The Law Commission recommends that to tackle these issues, the proposed legislation should endeavour to ensure the admission of Persons affected by Leprosy and their family members in schools, colleges and training institutions for their benefit.

(v) Appropriate use of Language

7.10.11 Language is a significant medium of perpetuating existing stigmas. Bearing this in mind, an effort needs to be made to discourage the use of the term 'leper' and other such synonymous terms, as it carries negative connotations with reference to Persons affected by Leprosy. The term also hampers the efforts for the inclusion of Persons affected by Leprosy into

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[142] Data provided by TLMTI (n 88).

mainstream society and affects their sense of dignity as human beings.

7.10.12 The Law Commission recommends that to tackle this issue of language, the proposed legislation should endeavour to replace the term 'leper' and other such synonymous terms in national, regional or local languages in all government and private documents, to 'persons affected by Leprosy' or a similar term to that effect in the relevant national, regional or local language.

(vi) Right to Freedom of Movement

7.10.13 People affected by Leprosy are not permitted to travel in public transport with the same freedom as others. *Section 56 of the Railways Act, 1989* and *Section 8(4) of the Motor Vehicles Act, 1988* are resorted to, in order to deny Persons affected by Leprosy the right to travel in railways or the right to obtain a driving license, as applicable. The Law Commission recommends that to tackle this issue of movement, the proposed legislation should provide measures that endeavour to ensure that the Persons affected by Leprosy are guaranteed the right of travel in public transport and the right to obtain a license in light of the their treatment and condition. The legislation should also ensure non-discrimination of Persons affected by Leprosy in public transports such as railways.

(vii) Concessions during treatment

7.10.14 Poverty and distance from big cities are a living reality for most of the Persons affected by Leprosy living in the 850 Leprosy colonies of India. Such persons have to travel long distances for education, skills training, livelihood options and accessing healthcare benefits.[143] Many of the Persons affected by Leprosy rely on local public transport for their daily movement, although, as noted before, the access to public transport is highly curtailed for such persons.[144] In such a scenario, monetary help for travel, lodging and medicines can go a long way in assisting such persons in continuing treatment for as long as required. In this regard, the Maharashtra State Road Transport Corporation, for example, has been providing persons cured of Leprosy with 75% concession on their buses.

7.10.15 Following this lead, the Law Commission recommends that the proposed legislation should provide relevant concessions and monetary benefits to Persons affected by Leprosy, who are undergoing treatment, for their travel, lodging during treatment (if required) and their medicines.

(viii) Social Awareness

7.10.16 Creating awareness regarding the cure and transmission of Leprosy is the principal way through which, the discrimination and stigma against Persons affected by Leprosy and their family members can be systematically curbed. The dire lack of awareness regarding the disease leads to segregation of Persons affected by Leprosy and their family members. Additionally, due to lack of awareness regarding the curability and treatment of the disease, many persons are afraid to seek medical assistance on account of the associated stigma.[145]

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[143] Data provided by TLMTI (n 88).

[144] Data provided by TLMTI (n 88).

[145] Data provided by TLMTI (n 88).

7.10.17 The Law Commission recommends that to tackle these issues, the proposed legislation should suggest measures for creating awareness regarding the disease, its treatment and its curability through campaigns and programs in schools, hospitals, government institutions and private establishments.

(ix) Welfare Measures

7.10.18 As has been noted in various parts of the Report, Persons affected by Leprosy and members of their family live under several financial and social constraints that make it impossible, in some instances, to continue treatment and to participate in social and cultural activities in society. However, through the implementation of a variety of welfare measures these issues can be addressed. Such welfare measures include the provision for unemployment benefits, parental leave, health insurance or other such social insurance on account of Leprosy or otherwise. Financial assistance to Persons affected by Leprosy and their family members, while such persons are undergoing treatment or have completed treatment, will also go a long way in addressing their financial concerns. In addition, supplementary measures relating to counselling during treatment, community participation and other such initiatives can also serve as an effective mechanism for the holistic development of Persons affected by Leprosy and members of their family.

7.10.19 The Law Commission recommends that to implement such welfare measures, the proposed legislation should impose specific duties upon public and private establishments to execute such measures in order to foster an environment for financial and social growth of all Persons affected by Leprosy and members of their family. This includes the establishment of Central and State Commissions in order to ensure that such measures are enforced strictly and both private and public establishments are accountable in case of non-enforcement.

C. Summary

7.11 In light of the above stated observations in this Report, the 20th Law Commission recommends that

(i) The following Laws and provisions be repealed:

The Lepers Act, 1898 in its entirety;
Sub-section (g) of Section 27 of the Special Marriage Act, 1954;
Sub-section (vi) of Section 2 of the Dissolution of Muslim Marriage Act, 1939;
Clause (iv) of sub-section (1) of Section 13 of the Hindu Marriage Act, 1955;
Clause (iv) of sub-section (1) of Section 10 of the Indian Divorce Act, 1869;
Clause (c) of sub-section (2) of Section 18 of the Hindu Adoption and Maintenance Act, 1956.

(ii) The following Laws be modified or amended:

The Legal Services Act, 1987

After sub-clause (d) of section 12, the following sub-clause shall be inserted, namely

(dd) a person who suffers from, or has previously suffered or has been cured of Leprosy; or

<u>The Motor Vehicles Act, 1988</u>

After the first proviso to sub-section (4) under Section 8 of the Act, the following proviso shall be inserted, namely:

> *Provided further that the licensing authority shall not refuse to issue a learner's licence to a person affected by Leprosy, who has been certified by a registered medical practitioner, as having either been cured of Leprosy, or as having been administered with the first dose under Multi-Drug Therapy, with continuing treatment for Leprosy being provided.*

(iii) <u>Provisions enabling the government to undertake affirmative action in the following areas be introduced:</u>

Health
Ownership of property
Social Welfare
Education
Employment
Awareness and training
Participation of Persons affected by Leprosy in the formulation of policies
Setting-up of a Central and State Commission on Leprosy, to monitor the compliance of the provisions of the Act in respect of public and private establishments and to make recommendations to the Central or State Government, as applicable, for the proper implementation of this Act.

7.12 Although amendments can be made in each and every law specified above, the Commission recommends that a single statute should deal with all aspects of rights of Persons affected by Leprosy and their family members. This will ensure coherence and send out a strong signal of the resolve of the Government of India to tackle discrimination faced by Persons affected by Leprosy.

7.13 This statute should be titled as the "*Elimination of Discrimination against Persons affected by Leprosy Bill, 2015*". This stand-alone law, apart from comprehensively covering the repeal/modification of the specified statutes, shall contain principles of non-discrimination and equal protection before law. These principles shall specify that (1) No person, or public or private establishment shall discriminate against any person affected by Leprosy, or members of his family on any ground in relation to their affliction of Leprosy, or their disability, physical attributes or any other form of their association with Leprosy; and (2) All persons affected by Leprosy and members of their family shall be entitled to the recognition, enjoyment and exercise, on an equal basis, of all human rights including freedoms guaranteed by the Constitution of India. Further, the law shall also contain enabling provisions regarding affirmative action and repeal and amend discriminatory provisions listed above.

7.14 A model Bill is provided in the Annexure for the consideration of the Government of India. The Law Commission of India believes that the fact that India is home to the most number of Persons affected by Leprosy in the world is a matter of deep shame. Further, despite clear scientific evidence and pioneering social efforts, the stigma associated with leprosy still continues unabated. The proposed Bill is an important step in eliminating the social discrimination faced by such persons, a necessary precursor to their reintegration into society. As a humane society that believes in human rights for all, especially its poorest, the Law Commission believes that the Bill should be converted into a law as expeditiously as possible by the Government of India.

Sd/-
[Justice A.P. Shah]
Chairman

Sd/-	Sd/-	Sd/-
[Justice S.N. Kapoor]	**[Prof. (Dr.) Mool Chand Sharma]**	**[Justice Usha Mehra]**
Member	**Member**	**Member**
Sd/-	Sd/-	Sd/-
[Dr. (Mrs.) Pawan Sharma]	**[P.K. Malhotra]**	**[Dr. Sanjay Singh]**
Secretary	**Ex-officio Member**	**Ex-officio Member**

ANNEXURE

ELIMINATING DISCRIMINATION AGAINST PERSONS AFFECTED BY LEPROSY (EDPAL) BILL, 2015

A Bill

to enact a comprehensive protection regime for persons affected by Leprosy and members of their family; to eliminate any discrimination or denial of equal treatment; to repeal and amend existing laws that negatively affect such persons and promote their segregation and discrimination; and to enable the State to discharge its positive obligations through affirmative action

REAFFIRMING that all human beings are born free and equal in dignity and rights, and that everyone is entitled to the enjoyment of human rights without distinction of any kind, such as caste, sex, language, religion, disability or deformity, national or social origin, birth or other status;

REAFFIRMING that persons affected by Leprosy and members of their family are entitled to be treated as individuals with dignity and bearers of human rights, including equality before the law and the equal protection of the law, without any discrimination;

RECALLING India's obligations as a signatory to the United Nations Resolution on the Elimination of Discrimination against persons affected by Leprosy and their Family Members, 2011, the United Nations Principles and Guidelines for the Elimination of Discrimination against persons affected by Leprosy and their Family Members, 2010, and the United Nations Convention on the Rights of Persons with

Disabilities 2006;

ENABLING the government to give due consideration to the principles and guidelines mentioned herein, while repealing certain obsolete and archaic laws and formulating policies and guidelines for the equal and non-discriminatory treatment of persons affected by Leprosy;

Now therefore be it enacted in the Sixty-fifth year of the Republic of India:-

CHAPTER I: PRELIMINARY

SHORT TITLE AND COMMENCEMENT

1. (1) This Act may be called the Elimination of Discrimination against Persons affected by Leprosy Act, 2015.

(2) It extends to the whole of India.

(3) It shall come into force on such date as the Central Government may, by notification in the Official Gazette, appoint.

DEFINITIONS

2. In this Act, unless the context otherwise requires,—

(1) "appropriate government" means,—

(i) in relation to the Central Government or any establishment wholly or substantially financed by that Government, or any body constituted by a law made by Parliament or a Cantonment Board constituted under the Cantonments Act, 2006, the Central Government; or

(ii) in relation to the State Government or any other establishment under sub-section (2) of this section that is not covered under clause (i) of this sub-section, the State Government;

(2) "establishment"– means and includes a company, club, firm or any other body

corporate or association of persons jointly carrying out a systematic activity for consideration or otherwise including but not limited to;

(i) a society registered under the Societies Registration Act, 1860, or a co-operative society under the Co-operative Societies Act, 1912

(ii) a trust under the Indian Trusts Act, 1882 or corresponding state law under which trusts may be established;

(iii) any organisation or institution or authority established by or under a Central Act or State Act or otherwise;

(iv) any industry under Section 2(j) of the Industrial Disputes Act, 1947; or

(v) any shop or establishment governed by a State Act concerning such shops and establishments;

(3) "disability due to Leprosy" – means grade 1 or grade 2 disability in the hand, leg or eye that hinders full and effective participation of a person affected by Leprosy in society equally with others, whether or not his extent of disability has been specified in measurable terms;

Explanation: (i) Grade 1 disability includes sensory impairment, scars with sensory impairment or muscle weakness without contractures.

(ii) Grade 2 disability includes visible impairment, Lagophthalmos, Iridocyclitis, visual acuity of <6/60, burns, deep cracks, wounds (both simple and deep ulcers), muscle atrophy, bone absorption of shortening or contractures.

(4) "Leprosy" – means a disease triggered by *Mycobacterium Leprae* characterised by symptoms of pale and reddish skin, numbness of hands or feet or loss of feeling in a patch of

skin, and which may lead to disability as defined under sub-section (3) of this section;

(5) "leprosy cured person" – includes, notwithstanding anything in the Persons with Disability Act, 1995 or any other law pertaining to persons with disability, any person affected by Leprosy, regardless of the percentage of his disability, who has been certified by a registered medical practitioner, as having been administered with the first dose under Multi-Drug Therapy, which renders his illness non-contagious, and such person continues with or has completed treatment for Leprosy.

(6) "person affected by Leprosy" – means and includes a person who suffers from, or has previously suffered or has been cured of Leprosy, whether or not such person has undergone treatment under Multi-Drug Therapy;

(7) "Multi-Drug Therapy" (MDT) – means the medical treatment wherein a combination of drugs are administered to a person affected by Leprosy in order to render the infection non-contagious through the first dose and kill *Mycobacterium Leprae*;

(8) "members of their family", with reference to persons affected by Leprosy, means —

(i) spouse of the person affected by Leprosy;
(ii) parents of the person affected by Leprosy;
(iii) children of the person affected by leprosy; and
(iv) brothers or sisters of the person affected by Leprosy.

CHAPTER II: EQUALITY AND NON-DISCRIMINATION

EQUALITY AND NON-DISCRIMINATIO

3. (1) No person, establishment or government, shall discriminate against any person affected by Leprosy, or members of his family on any ground in relation

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to their affliction with Leprosy, or their disability, physical attributes or any other form of their association with Leprosy;

(2) All persons affected by Leprosy and members of their family shall be entitled to the recognition, enjoyment and exercise, on an equal basis, of all human rights including freedoms guaranteed by the Constitution of India.

REPEAL OF CERTAIN ENACTMENTS

4. The statutes and provisions enumerated in Schedule I are hereby repealed.

AMENDMENTS TO CERTAIN ENACTMENTS

5. The statutes and provisions enumerated in column I of Schedule II shall stand amended in accordance with respective entries in column II of Schedule II.

CERTAIN LAWS TO BE INVALID

6. Laws that are not enumerated in Schedule I or Schedule II, whether Central or State, which directly, or indirectly discriminate against persons affected by Leprosy shall be invalid insofar as such laws discriminate against persons affected by Leprosy.

Illustration

A, a person affected by Leprosy who is found begging, is arrested and detained under the provisions of a State Prevention of Begging Act, solely on account of his affliction with Leprosy. With the coming into force of this section, any such provision for the arrest and detention of persons affected by Leprosy under the State Prevention of Begging Act shall be invalid. The detention and arrest of A will be invalid.

SUBSTITUTION OF CERTAIN TERMS

7. Notwithstanding any other law for the time being in force, in all laws that are in force, and in all official records of the Government of India, State Governments, and establishments defined under sub-section (2) of Section 2, the term ‘leper’ and other such terms in national, regional and local

languages, shall be substituted by the term 'persons affected by Leprosy' or any other term in the national, regional or local language that is synonymous.

CHAPTER III: RIGHTS OF PERSONS AFFECTED BY LEPROSY

DUTY TO UPHOLD RIGHTS

8. (1) No government, establishment or person, shall deny persons affected by Leprosy and members of their family, any rights guaranteed to them under this Chapter.

(2) All legislative, administrative and other measures necessary to ensure compliance of the provisions of this Chapter shall be undertaken by the appropriate government.

RIGHT TO HEALTH AND TREATMENT

9. (1) No person affected by Leprosy shall be denied the right to treatment for Leprosy under Multi-Drug Therapy.

(2) All persons affected by Leprosy shall have the right to access other healthcare facilities including but not limited to reconstruction surgeries and medicines.

DISCLOSURE OF MEDICAL RECORDS

10. The medical records relating to Leprosy of persons affected by Leprosy and members of their family shall be treated as confidential and shall not be disclosed to any person or establishment unless:

(1) the prior informed consent of the affected person to such disclosure has been obtained; or

(2) such disclosure, without such consent, is authorised by law.

RIGHT TO OWNERSHIP OF PROPERTY

11. No person affected by Leprosy, or members of his family, shall be denied the right to own property or to reside, purchase, rent, use or otherwise occupy, any property, merely for reason of such person being affected by leprosy.

RIGHT TO ACCESS PUBLIC GOODS AND SERVICES

12. No person affected by Leprosy, or any member of his family, shall be denied the right to access, or enjoy or use any goods, accommodation, service, facility, benefit, privilege or opportunity dedicated for

the use of the general public or customarily available to the public, whether or not for a specific fee, including shops, public restaurants, hotels and places of public entertainment or the use of wells, tanks, bathing ghats, roads, burial grounds or funeral ceremonies and places of public resort.

RIGHT TO MOVEMENT

13. No person affected by Leprosy, or any member of his family, shall be denied the right to movement in respect of all or any public transport or for obtaining a driving license for all or any vehicle, on account of being affected with leprosy.

RIGHT TO EDUCATION

14. No person affected by Leprosy, or any member of his family, shall be denied the right to education and training opportunities in any institution, including the right to continue or resume his education or training in any institution, after duly furnishing a certificate by a registered Medical Practitioner that attests that such affected person has been administered with the first dose under Multi-Drug Therapy and continues to undergo or has completed treatment for Leprosy or any such similar treatment as approved by the Government of India or World Health Organisation.

RIGHT TO EMPLOYMENT

15. No person affected by Leprosy, or any member of his family, shall be denied the right to be nominated, selected or elected, or to continue his appointment, as the case may be, to a public office or for private employment, after he has duly furnished a certificate by a registered Medical Practitioner that attests that such person has been administered with the first dose under Multi-Drug Therapy and continues to undergo or has completed treatment for Leprosy.

RIGHT TO FORM FAMILY

16. No person affected by Leprosy, or any member of his family, shall be denied the right to marry, and form a family including through access to adoption or assisted procreation (including donor insemination).

CHAPTER IV: MEASURES FOR AFFIRMATIVE ACTION

DUTY TO UNDERTAKE MEASURES 17. Without prejudice to the generality of the obligations mentioned under Section 8 and in addition to them, the appropriate government shall undertake all measures specified in this Chapter.

HEALTH-RELATED MEASURES 18. The appropriate government shall undertake the following measures relating to healthcare, for all persons affected by Leprosy and members of their family, that shall include but not be limited to:

(1) implementation of awareness programmes for all persons affected by Leprosy that emphasise the importance of an early treatment through Multi-Drug Therapy, to reduce chances of any kind of disability as a result of Leprosy;
(2) formulation of guidelines and protocols for addressing the healthcare needs of all persons affected by Leprosy;
(3) access to healthcare facilities that include reconstruction surgeries, and goods and services for all persons affected by Leprosy, to improve the health status of, and respond to the needs of all persons affected by Leprosy;
(4) humane treatment of all persons affected by Leprosy by health care providers;
(5) adoption of policies, and programmes for education and training of healthcare professionals, to enable them to deliver the highest attainable standard of healthcare to all persons affected by Leprosy and members of their family;
(6) protection of all persons affected by Leprosy and members of their family against unethical or involuntary medical procedures or research, including in relation to vaccines, treatments or microbicides for terminal or such other diseases; and
(7) providing medical and psychological treatment and counselling for all persons affected by Leprosy and members of their family, to assist them in overcoming their trauma suffered on account of their disability, physical attributes or any other form of their association with Leprosy.

MEASURES RELATED TO OWNERSHIP AND TITLE

19 (1). The appropriate government shall make efforts to provide security of tenure, title and ownership of property for all persons affected by Leprosy and members of their family living in leprosy colonies.

(2) No person affected by Leprosy or members of his family shall be removed or evicted from the existing leprosy colonies without prior sanction of Central or State Commission of Leprosy, as the case may be, and without being rehabilitated and adequately compensated.

MEASURES RELATED TO SOCIAL WELFARE

20. The appropriate government shall undertake the following measures relating to social welfare, for all persons affected by Leprosy, and members of their family, that shall include but not be limited to:

(1) formulation of special financial packages that are designed for providing means of livelihood and adequate housing for persons affected by Leprosy and their family members, during and after the treatment;
(2) formation and establishment of a Community-based Rehabilitation forum;
(3) promotion of schemes for neighbourhood support and security;
(4) access to social security and other social protection measures, including employment benefits, parental leave, unemployment benefits, health insurance or other social insurance, family benefits, funeral benefits, pensions and benefits with regard to the loss of support for spouses or partners as the result of illness or death on account of Leprosy, and poverty reduction strategies and programmes; and
(5) enforcement of social programmes, including support programmes, to address factors relating to discrimination of the affected persons, that increase their vulnerability to isolation, homelessness and mental trauma.

MEASURES RELATED TO EDUCATION AND EMPLOYMENT

21. The appropriate government shall undertake the following measures relating to education and employment for persons affected by Leprosy, who have either been cured of Leprosy, or who have been duly certified, by a registered Medical Practitioner, as having been administered with the first dose under Multi-Drug Therapy and is continuing treatment for Leprosy, and members of the family of any person affected by Leprosy, that shall include but not be limited to:

(1) implementation of educational programmes that impart education and training that is directed at the development of personalities, talents, and mental and physical abilities of persons, to their fullest potential, and responds to their needs; and

(2) access to employment and advancement opportunities, in all areas of public service, including all levels of government service and employment in public institutions.

OTHER MEASURES

22. The appropriate government shall undertake the following other measures in the interest of all persons affected by Leprosy and members of their family, that shall include but not be limited to:

(1) enforcement of social awareness programmes to dispel misconceptions surrounding Leprosy and disseminate information in respect of its treatment through Multi-Drug Therapy;

(2) enforcement of special programmes for addressing discrimination, prejudice and other social factors that undermine the health of persons affected by Leprosy because of their disability, physical attributes; and

(3) implementation of training and awareness-raising programmes in all establishments and institutions, including but not limited to schools and hospitals, to raise awareness regarding the needs of those affected by or associated with the disease.

Participation in the Formulation of Policies

23. Persons affected by Leprosyshall be entitled to participate in the formulation of policies affecting their welfare.

Administration

24. (1) The Central Government shall within 12 months of the coming into force of this Act, by notification, constitute a Central Commission on Leprosy, to monitor the compliance of the provisions under Chapter III and Chapter IV of this Act in respect of all establishments for which the Central Government is the appropriate Government, and to make recommendations to the Central Government, for the proper implementation of this Act.

(2) State Governments shall, within 12 months of the coming into force of this Act, by notification, constitute a State Commission on Leprosy, to monitor the compliance of the provisions under Chapter III and Chapter IV of this Act in all establishments for which the State Government is the appropriate Government, and to make recommendations to the State Government, for the proper implementation of this Act within 12 months of the coming into force of this Act.

Chapter V: Enforcement and Remedies

Non-Compliance of Provisions, Rules or Measures under the Act

25. Notwithstanding any other law for the time being in force, any person affected by Leprosy or member of his family or a person acting bona fide on their behalf, aggrieved with the violation or non-compliance of the provisions of Part III of this Act or any rules made thereunder, may institute a petition against the concerned persons or establishments in the District Court in whose jurisdiction the said person ordinarily resides or where the violation or non-compliance is alleged to have taken place and the provisions of the Code of Civil Procedure, 1908, shall apply to such proceedings.

Legal Aid

26(1). Where persons aggrieved under Section 25 of this Act, are unable to, or do not have the sufficient means to, engage a legal practitioner to represent them in any proceeding under this Act, the appropriate Legal Services Authority under the Legal

Services Authorities Act, 1987 shall provide legal aid to such persons.

(2) Persons affected by Leprosy and members of their family filing a petition under Section 25 of this Act shall be deemed to be persons entitled to legal services under Section 12 of the Legal Services Authorities Act, 1987.

Liability for Non-Compliance

27. In any petition under Section 25, where the Court finds that any person or establishment has breached or not complied with the provisions of this Act, it shall award to the person affected by Leprosy or a member of his family, compensation, and damages of not less than twenty five thousand rupees along with all costs incurred in litigation.

CHAPTER VI: MISCELLANEOUS

Power to Issue Directions

28. The appropriate government may, in exercise of its powers and performance of its functions under this Act, issue such directions, as it may deem fit, for the purposes of this Act, to any person or establishment and such person or establishment shall be bound to comply with such directions.

Power to Call for Information

29. The appropriate government may call for such information from any person or establishment as it may deem necessary to carry out the purposes of this Act.

Power to Make Rules

30. (1) The Central Government may, by notification in the Official Gazette, make rules for carrying out the purposes of this Act;

(2) Every rule made under sub-section (1) shall be laid, as soon as may be after it is made, before each House of Parliament, while it is in session, for a total period of thirty days which may be comprised in one session or in two or more successive sessions, and if, before the expiry of the session immediately following the session or the successive session aforesaid, both Houses agree in making any modification in the rule or both Houses agree that the rule should not be made, the rule shall

thereafter have effect only in such modified form or be of no effect, as the case may be; so, however, that any such modification or annulment shall be without prejudice to the validity of anything previously done under that rule.

POWER TO REMOVE DIFFICULTIES

31. If any difficulty arises in giving effect to the provisions of this Act, the Central government may, by order published in the Official Gazette, make such provisions, not inconsistent with the provisions of this Act, as appear to it to be necessary or expedient for removing the difficulty:

Provided that no order shall be made under this section after the expiry of the period of two years from the date of commencement of this Act.

APPLICATION OF CERTAIN LAWS

32. The provisions of this Act shall be in addition to, and not in derogation of the Persons with Disabilities Act, 1995 or any laws pertaining to persons with disability.

ACT TO HAVE OVERRIDING EFFECT

33. The provisions of this Act shall have effect notwithstanding anything inconsistent therewith contained in any enactment or instrument having the force of law.

SCHEDULE I – REPEALED PROVISIONS AND ACTS

1) Repeal of the Lepers Act, 1898 in its entirety;

2) Repeal of e*xplanation (g) of Section 27* of the Special Marriage Act, 1954;

3) Repeal of *sub-section (vi) of Section 2* of the Dissolution of Muslim Marriage Act, 1939;

4) Repeal of *clause (iv) of sub-section (1) of Section 13* of the Hindu Marriage Act, 1955;

5) Repeal of *clause (iv) of sub-section (1) of Section 10* of the Indian Divorce Act, 1869;

6) Repeal of *clause (c) of sub-section (2) of Section 18* of the Hindu Adoption and Maintenance Act, 1956.

SCHEDULE II – AMENDMENTS

Legislation (I)	Amendment (II)
1) Legal Services Act, 1987	After sub-clause (d) of section 12, the following sub-clause shall be inserted, namely: *(dd) aperson who suffers from, or has previously suffered or has been cured of Leprosy; or*
2) Motor Vehicles Act, 1988	After the first proviso to sub-section (4) under Section 8 of the Act, the following proviso shall be inserted, namely: *Provided further that the licensing authority shall not refuse to issue a learner's licence to a person affected by Leprosy, who has been certified by a registered medical practitioner, as having either been cured of Leprosy, or as having been administered with the first dose under Multi-Drug Therapy, with continuing treatment for Leprosy being provided.*