

Bill No. XXII of 2021

THE RIGHTS OF PERSONS AFFECTED BY LEPROSY AND MEMBERS OF THEIR
FAMILY (PROTECTION AGAINST DISCRIMINATION AND
GUARANTEE OF SOCIAL WELFARE)
BILL, 2021

ARRANGEMENT OF CLAUSES

CLAUSES

CHAPTER I
PRELIMINARY

1. Short Title, extent and commencement.
2. Definitions.
3. Guiding Principles.

CHAPTER II
RIGHTS AND ENTITLEMENTS

4. Right to Equality and Non-Discrimination.
5. Prohibition of Discrimination.
6. Right to life and personal liberty.
7. Right to own property.
8. Right to form a family.
9. Right to participation.
10. Access to medical treatment.
11. Access to welfare measures by the Central and State Government.
12. Protection from torture or cruel, inhuman or degrading treatment or punishment.
13. Protection from abuse, violence and exploitation.

CHAPTER III
EDUCATION

14. Duty of educational institutions to provide education.
15. Reservations in primary, secondary and higher educational institutions.

CHAPTER IV
SKILL DEVELOPMENT AND EMPLOYMENT

16. Vocational and self-employment.
17. Reservations of Posts.
18. Incentives to employers in the private sector.
19. Reasonable Accommodation in employment.
20. Special Employment Exchange.

CLAUSES

CHAPTER V

SOCIAL INCLUSION, HEALTHCARE AND REHABILITATION

21. Social Security.
22. Healthcare facilities.
23. Rehabilitation.
24. Promotion of training and awareness programs on leprosy.

CHAPTER VI

MULTI-DRUG THERAPY FOR PEOPLE LIVING WITH LEPROSY

25. Central Government and State Government to take measures.
26. Multi-Drug Therapy by Central and State Government.

CHAPTER VII

DISCLOSURE OF MEDICAL RECORDS

27. Disclosure of medical records.

CHAPTER VIII

APPOINTMENT OF OMBUDSPERSONS

28. Appointment of Ombudspersons.
29. Powers of Ombudspersons
30. Procedure of complaint.
31. Orders of Ombudspersons.
32. Authorities to assist Ombudspersons.
33. Report to the State Government.

CHAPTER IX

OFFENCES AND PENALTIES

34. Penalty for contravention.
35. Penalty for certain actions of individuals.
36. Penalty for failure to comply with orders of Ombudspersons.
37. Penalty for breach of confidentiality.
38. Penalty for failure to furnish information.
39. Offences by Establishments.
40. Prohibition of victimisation.
41. Court to try offences.
42. Offences to be cognizable and bailable.

CHAPTER X

REPEAL OF CERTAIN ENACTMENTS

43. Substitution of certain terms.
44. Amendments to certain enactments.
45. Act to have overriding effect.

(iii)

CLAUSES

CHAPTER XI

MISCELLANEOUS

46. Central Government to provide funds.
47. Act to be in addition to and not in derogation of any other law.
48. Action taken in good faith.
49. Power to remove difficulties.
50. Power of appropriate Government to make rules.

SCHEDULE - *Amendments.*

Bill No. XXII of 2021

THE RIGHTS OF PERSONS AFFECTED BY LEPROSY AND MEMBERS
OF THEIR FAMILY (PROTECTION AGAINST DISCRIMINATION AND
GUARANTEE OF SOCIAL WELFARE) BILL, 2021

A

BILL

to protect the human rights of persons affected by leprosy, to eliminate discrimination against them and their families, to promote their social welfare, to take steps for the prevention and control of leprosy and for matters connected therewith or incidental thereto.

WHEREAS the spread of leprosy and discrimination against persons affected by leprosy and their family members is a matter of grave concern to all, and there is an urgent need for the protection of the human rights of such persons, by repealing and amending existing laws the discriminate against them;

AND WHEREAS there is a necessity for effective care, support, treatment and social inclusion and integration of persons affected by leprosy and their families;

49 of 2016.

AND WHEREAS the Rights of Persons with Disabilities Act, 2016 does not cover persons affected by leprosy that are still to be diagnosed or those undergoing treatment and also does not recognise the discrimination and stigma faced by the family members of persons affected and cured of leprosy;

AND WHEREAS the General Assembly of the United Nations, of which India is a member, recalling and reaffirming its previous commitments on leprosy, has unanimously adopted a Resolution on the Elimination of Discrimination against Persons affected by Leprosy and their Family Members in 2010, accompanied by Principals and Guidelines listing out measures to improve the living conditions and social inclusion of such persons;

AND WHEREAS the United Nations Convention on the Rights of Persons with Disabilities 2006 (“UNCRPD”) to which India is a party, promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities;

AND WHEREAS the Republic of India, having signed the Resolution of the General Assembly of the United Nations on leprosy and having signed and ratified the UNCRPD, 2006 has to make provision to give effect to the said Resolution and Convention;

Be it enacted by Parliament in the Seventy-second Year of the Republic of India as follows:—

CHAPTER I

PRELIMINARY

Short title,
extent and
commencement.

1. (1) This Act may be called the Rights of Persons Affected by Leprosy and Members of their Family (Protection against Discrimination and Guarantee of Social Welfare) Act, 2021. 5

(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,— 10

(a) ‘abuse’ means any unwelcome verbal or non-verbal act or behaviour towards a person affected by leprosy or a member of the family of a person affected by leprosy which causes:—

(i) bodily pain or harm to a person affected by leprosy or a member of the family of a person affected by leprosy; 15

(ii) humiliation or embarrassment to a person affected by leprosy or a member of the family of a person affected by leprosy; or

(iii) deprivation of economic and financial resources, foods and fluids or any other form of support, to which a person affected by leprosy or a member of the family of a person affected by leprosy is entitled: 20

Provided that the word ‘leper’ shall be included with in the meaning of ‘abuse’ when any person affected by leprosy is referred to by such word;

(b) ‘appropriate Government’ means;

(i) in relation to an establishment of the Central Government, or any establishment, wholly or substantially owned or financed by that Government or a Cantonment Board constituted under the Cantonments Act, or a Union Territory without legislature, or the provider of a service which pertains to List I in the Seventh Schedule to the Constitution, the Central Government; 25
41 of 2006.

(ii) in all other cases, the State Government or, as the case may be, the Government of a Union Territory with legislature. 30

(c) ‘barrier’ means any factor including attitudinal, cultural, economic, institutional, political, religious, social or structural factors which hampers the full and effective participation, of a person affected by leprosy or a member of the family of a person affected by leprosy in society;

(d) '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 or her extent of disability has been specified in measurable terms;

5 *Explanation—*

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

(ii) Grade 2 disability means 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.

(e) 'discrimination' means any act or mission which directly or indirectly, expressly or by effect, immediately or over a period of time—

(i) imposes any burden, obligation, liability, disability or disadvantage on any person or category of persons, who are either effected by leprosy or associated with persons affected by leprosy; or

(ii) denies, restricts or withholds any benefit, opportunity or advantage from any person or category of persons, who are either affected by leprosy or associated with persons affected by leprosy, including denial of employment, movement in public spaces and reasonable accommodation;

20 and the expression "discriminate" is to be construed accordingly.

(f) '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:

21 of 1860. (i) a society registered under the Societies Registration Act, 1860, or a
2 of 1912. 25 co-operative society under the Co-operative Societies Act, 1912;

2 of 1882. (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;

14 of 1947. 30 (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;

(g) 'exploitation' means any form of conduct which is intended for a commercial purpose, whether for money or kind, and which results in the misuse or unjust treatment of a person affected by leprosy or the member of the family of a person affected by leprosy;

(h) 'healthcare provider' means and includes,—

(i) any individual whose vocation or profession is directly or indirectly related to the maintenance of the health of another individual and includes any physician, nurse, paramedic, therapist, psychologist, counsellor or other individual providing medical, nursing, psychological or other healthcare, services, including treatment through Multi-Drug Therapy; or

(ii) any public or private clinical establishment as defined under clause (c) of section 2 of the Clinical Establishments (Registration and Regulation) Act, 2010;

23 of 2010. 45

(i) 'informed consent' means consent given by a person affected by leprosy or a representative of such person specific to a proposed intervention without any coercion,

undue influence, fraud, mistake or misrepresentation and after informing such person or his or her representative, as the case may be, such information as prescribed in the rules, relating to risks and benefits of, and alternatives to, the proposed intervention in such language and in such manner as understood by that the person affected by leprosy or his or her representative, as the case may be;

5

(i) 'local authority' means a municipality, a Cantonment Board, a Panchayat or any other authority, established under an Act of Parliament, or a State Legislature to administer the civic affairs of any habitation as defined in or under such Act;

(j) '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 skins, and which may lead to disability as defined under clause (d) of this section;

10

(k) 'leprosy cured person' means, notwithstanding anything in the Rights of Persons with Disabilities Act, 2016 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, (MDT) which renders his illness non-infectious, or has completed treatment for leprosy;

49 of 2016.

15

(l) 'multi-durg therapy' (MDT) means the medical treatment wherein a combination of drugs is administered to a person affected by leprosy to render the infection non-contagious and kill *Mycobacterium Leprae*;

20

(m) 'members of the family of pesons affected by leprosy' means and includes—

(i) spouse;

(ii) parents;

(iii) children; and

25

(iv) brothers or sisters

of the person affected by leprosy.

(n) 'person affected by leprosy' means and includes a person who suffers from, or has previously suffered from or has been cured of leprosy, whether or not such person has undergone treatment under MDT;

30

(o) 'prescribed' means prescribed by rules made by the appropriate Government under this Act;

(p) 'public building' means a building, irrespective of ownership, which is used and accessed by the public at large; and includes its entrance, exit, parking space, footpath and other appurtenant lands;

35

(q) 'reasonable accommodation' means necessary and appropriate modification and adjustments, not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to a person affected by leprosy the enjoyment or exercise of this or her fundamental rights and freedoms on an equal basis with others;

(r) 'services' means any provision, facility, utility or any other assistance provided in any form to a person or persons affected by leprosy, or a member or members of the family of a person affected by leprosy and includes services relating to banking and finance; education; health; insurance; rehabilitation; recreation and hospitality; transport or travel; and telecommunications, and such other services which may be notified by the Central Government;

40

45

(s) 'violence' means any act of commission or omission which causes physical, emotional, psychological harm or injury to a person affected by leprosy or a member of the family of a person affected by leprosy.

3. The appropriate Government and local authorities shall secure for persons affected by leprosy and members of the family of persons affected by leprosy:—

Guiding Principles.

(a) respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

5 (b) non-discrimination;

(c) full and effective participation and inclusion in society; and

(d) equality of opportunity.

CHAPTER II

RIGHTS AND ENTITLEMENTS

10 4. (1) No person, establishment or appropriate Government shall discriminate against any person affected by leprosy solely on the ground of his or her affliction, disability, or physical attributes, or against any member of the family of the person affected by leprosy solely on the ground of his or here association with a person affected by leprosy.

Right to Equality and Non-Discrimination.

15 (2) The appropriate Government shall take all necessary steps to ensure that persons affected by leprosy and members of the family of persons affected by leprosy enjoy the right to equality before the law and equal protection of laws.

20 5. (1) No establishment, of appropriate Government or person, shall subject a person affected by leprosy, where such person duly furnishes a certificate of a registered medical practitioner that attests that such person has been administered with the first dose under MDT or has been cured of leprosy, or a member of the family of a person affected by leprosy to the following, namely:—

Prohibition of Discrimination.

(a) the denial of, termination from, or the unfair treatment in, or in relation to, employment or occupation;

25 (b) the denial of, or the unfair treatment in, or in relation to, departmental promotions in employment or occupation;

(c) the denial or discontinuation of, or, unfair treatment, in healthcare services;

(d) the denial or discontinuation of, or unfair treatment in, educational establishments and services thereof;

30 (e) the denial or discontinuation of or unfair treatment with regard to access to, or the provision of, or the enjoyment of, or the use of any good, accommodation, service, facility, benefit, privilege, or opportunity dedicated to the use of the general public or customarily available to the public, whether or not for a 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;

35 (f) the denial, or, discontinuation of, or unfair treatment with regard to, the right of movement;

(g) the denial or discontinuation of, or, unfair treatment with regard to, the right to reside, purchase, rent, sale, transfer or otherwise occupy, any property;

40 (h) the denial or discontinuation of, or, unfair treatment in, the opportunity to stand for, or, hold public or private office;

(i) the denial of access to, removal from, or unfair treatment in, Government or private establishment in whose care or custody the person may be;

(j) the denial of, or unfair treatment in, the provision of insurance;

45 (k) the unfair treatment in, or in relation to, adoption, inheritance, and marital relations; and

(l) the isolation or segregation in any form.

Right to life and personal liberty.	<p>6. (1) The appropriate Government shall take necessary steps to ensure that persons affected by leprosy and members of the family of persons affected by leprosy enjoy the right to life with dignity, and respect for their personal liberty on an equal basis with others.</p>	
	<p>(2) No person shall be deprived of his personal liberty only on the ground of being affected by leprosy or being associated with a person affected by leprosy in any manner.</p>	5
Right to own property.	<p>7. (1) No person affected by leprosy, or a member of the family of a person affected by leprosy, shall be denied the right to own property or to reside, purchase, sale, rent, use, transfer or otherwise occupy any property, merely for reason of such person being affected by leprosy, or being a member of the family of a person affected by leprosy.</p>	
	<p>(2) No person affected by leprosy or a member of the family of a person affected by leprosy shall be removed, or evicted from an existing settlement occupied by other persons affected by leprosy and members of the family of such persons without prior sanction from the Ombudsperson, appointed under section 28 of this Act, and without being rehabilitated and adequately compensated.</p>	10
	<p>(3) The appropriate Government and local authorities shall take appropriate measures, as far as possible, to ensure full enjoyment of the rights as mentioned in sub-section (1) by:—</p>	15
	<p>(a) securing the tenure, title and ownership of property to each person affected by leprosy and member of the family of a person affected by leprosy, who are living in existing settlements that are occupied only by persons affected by leprosy and members of the family of persons affected by leprosy; and</p>	20
	<p>(b) ensuring that such existing settlements are accessible, as per the accessibility standards formulated by the Central Government under section 40 of the Rights of Persons with Disabilities Act, 2016, with sanitary and other community support services, including such the assistance necessary to support living, and inclusion within the community, as may be prescribed.</p>	49 of 2016. 25
Right to form a family.	<p>8. No person affected by leprosy, or any member of the family of a person affected by leprosy shall be denied the right to marry, or form a family, including the right to adoption, or assisted procreation, including donor insemination.</p>	
Right to participation.	<p>9. The appropriate Government and local authorities shall take appropriate measures to ensure the participation of persons affected by leprosy, members of the family of persons affected by leprosy or the representatives of such persons in the decisions that directly affect such persons under this Act.</p>	30
Access to medical treatment.	<p>10. (1) No healthcare provider shall deny a person affected by leprosy access to any form of treatment for leprosy.</p>	35
	<p>(2) Every healthcare provider shall ensure that every person affected by leprosy has access to all healthcare facilities, goods and services that are available with the healthcare provider and which are necessary for recovering from leprosy and its consequent wounds, deformities and disabilities.</p>	
Access to welfare measures by the Central and State Government.	<p>11. No person or establishment shall deny a person affected by leprosy or member of the family of a person affected by leprosy, access to welfare schemes, provided under Chapter V of this Act.</p>	40
Protection from torture, or cruel, inhuman or degrading treatment or punishment.	<p>12. No person or establishment shall subject a person affected by leprosy or a member of the family of persons affected by leprosy to torture, or cruel, inhuman or degrading treatment, or punishment.</p>	45

13. (1) No person or establishment shall subject a person affected by leprosy or a member of the family of persons affected by leprosy, to any form of abuse, violence or exploitation, both within and outside of home.

Protection from abuse, violence and exploitation.

(2) The appropriate Government and local authorities shall take all appropriate administrative, social, educational and other measures to protect persons affected by leprosy and members of the family of persons affected by leprosy, from all forms of abuse, violence and exploitation, both within and outside of home.

(3) Any person, or registered organization who or which has reasons to believe that an act of abuse, violence or exploitation has been, or is being, or is likely to be committed against any person affected by leprosy or members of family of a person affected by leprosy, may give information about it to the Executive Magistrate in whose jurisdiction such incident occurs or is likely to occur, who, on receipt of such information, shall take immediate steps to stop it or prevent its occurrence as the case may be, or pass such order as he deems fit for the protection of such person including an order—

(a) to rescue such persons by authorizing the police or any reliable organisation working for the benefit of persons affected by leprosy to provide for the safe custody and rehabilitation of such persons;

(b) to provide protective custody to such persons if he or she so desires; or

(c) to provide compensation to such person, in such manner, as may be prescribed.

(4) No civil or criminal liability shall be incurred by any person, including a person affected by leprosy or a member of the family of a person affected by leprosy, who in good faith furnishes information under sub-section (3);

(5) Any police officer, who receives a complaint or otherwise comes to know of abuse, violence or exploitation towards a person affected by leprosy or a member of the family of a person affected by leprosy, shall take all steps necessary to ensure that the aggrieved person is:

(a) informed of and is able to exercise his or her right to report the abuse, violence or exploitation and apply for protection under sub-section (3);

(b) informed of the particulars of the Executive Magistrate having jurisdiction to provide assistance to such person;

(c) informed of and is directed to the nearest organization or institution working for the rehabilitation of persons affected by leprosy, who have been subjected to abuse, violence or exploitation.

(d) informed of and is able to exercise his or her right to access free legal services under the Legal Services Authorities Act, 1987 and any other service or services offered by the National Legal Services Authority or the State Legal Services Authority for the benefit of such person; and

(e) informed of and is able to exercise his or her right to file a complaint under the relevant provisions of the Indian Penal Code, 1860, or any other law dealing with such crimes:

Provided that nothing in this section shall be construed to free such police officer of his or her obligation to proceed in accordance with this Act, or any other law for the time being in force, upon the receipt of information as to the commission of a cognizable offence.

(6) If the Executive Magistrate determines that the alleged act or behaviour is an offence under the Indian Penal Code, 1860, or under any other law which imposes criminal sanctions on such acts, the Executive Magistrate shall forward a complaint to that effect to the Judicial or Metropolitan Magistrate, as the case may be, having jurisdiction in the matter,

whereupon the latter shall act on it in accordance with the law, and within six months from the date on which the information relating to the complaint is received by the former.

(7) The appropriate Government shall take all measures necessary to prevent all forms of abuse, violence and exploitation against persons affected by leprosy and members of the family of persons affected by leprosy by, *inter alia* providing information and raising awareness on: 5

(a) illegality of incidents of abuse, violence and exploitation against persons affected by leprosy and members of the family of persons affected by leprosy;

(b) the legal remedies available to persons affected by leprosy and members of the family of persons affected by leprosy against such incidents; 10

(c) the legal consequences of such incidents;

(d) the steps to be taken for avoiding such incidents;

(e) the procedure for reporting such incidents; and

(f) the steps required for the rescue, protection and rehabilitation of persons who have been victims of such incidents. 15

CHAPTER III

EDUCATION

Duty of educational institutions to provide inclusive education.

14. (1) The appropriate Government and local authorities shall ensure that all educational institutions that are wholly or partially funded, or recognized by the appropriate Government or local authorities, provide inclusive education, and *inter alia*— 20

(i) admit students affected by leprosy or those whose family member is affected by leprosy, without discrimination, and provide them education appropriate to their age, or mental or physical development, as also opportunities for sports, recreation and leisure activities on an equal basis with others:

(ii) provide reasonable accommodation that is tailored to the requirements of each student affected by leprosy; 25

(iii) provide necessary support in environments that maximize the academic and social development of each student affected by leprosy, and assist him or her in reaching his or her maximum potential; and

(iv) monitor participation, progress in terms of attainment levels, and completion of education, in respect of a student who is either affected by leprosy or is a member of the family of a person affected by leprosy. 30

(2) Where a child affected by leprosy above six years of age has not been admitted in any school or though admitted, could not complete his or her elementary education, then, he or she shall be admitted in a class appropriate to his or her age and shall be entitled to receive special training available under section 4 of the Right of Child to Free and Compulsory Education Act, 2009. 35 of 2009.

Reservations in primary, secondary and higher educational institutions.

15. (1) All Government institutions of primary, secondary and higher education, and all primary, secondary and higher education institutions receiving aid from the Government shall reserve seats in each class or course for persons affected by leprosy as provided for under the Right of Persons with Disabilities Act, 2016: 40 49 of 2016.

Provided that such persons shall not to be prevented from competing for seats which are not reserved for them.

(2) For the purposes of sub-section (1), reservations for leprosy-cured persons with benchmark disabilities as envisaged under sub-section (1) of section 32 of the Rights of Persons with Disabilities Act, 2016, shall also include persons affected by leprosy, who have been administered with the first dose under MDT. 45 49 of 2016.

CHAPTER IV

SKILL DEVELOPMENT AND EMPLOYMENT

5 **16. (I) The appropriate Government shall, within a period of one year from the commencement of this Act, formulate schemes and programmes to facilitate and support the employment of persons affected by leprosy and members of the family of persons affected by leprosy, including measures to facilitate vocational training and self-employment of such persons.**

Vocational training and self employment.

10 **(2) The appropriate Government shall institute mechanisms for providing loans at concessional rates to persons affected by leprosy or members of the family of persons affected by leprosy for self employment ventures, and for the marketing of their products, as the case may be as provided for under the Right of Persons with Disabilities Act, 2016.**

49 of 2016.

17. (I) The appropriate Government shall reserve, in every establishment owned or controlled by the appropriate Government, posts that are meant to be filled by direct recruitment, for persons affected by leprosy:

Reservations of Posts.

15 Provided that such persons shall not to be prevented from competing for posts which are not reserved for them.

49 of 2016. **(2) For the purposes of sub-section (I), reservations for leprosy-cured persons with benchmark disabilities as envisaged under clause (c) of sub-section (I) of Section 34 of the Rights of Persons with Disabilities Act, 2016, shall also include persons affected leprosy, who have been administered with the first dose under MDT.**

20

18. The appropriate Government shall provide incentives to employers in the private sector in order to enable them to progressively include persons affected by leprosy as part of their workforce within a period of five years from the commencement of this Act.

Incentives to employers in the private sector.

25 **19. The appropriate Government shall ensure that a person affected by leprosy is provided reasonable accommodation in the place of his or her employment, which is tailored to the requirements of such person:**

Reasonable accommodation in employment.

Provided that the concerned person affected by leprosy shall be consulted in the provision for reasonable accommodation.

30 **20. (I) The appropriate Government may, by notification, specify that the employer in every establishment shall furnish such information or return, as may be prescribed in relation to vacancies appointed for persons affected by leprosy, that have occurred, or are about to occur in that establishment to the special employment exchange notified and established by the Central Government under section 36 of the Rights of Persons with Disabilities Act, 2016.**

49 of 2016.

Special Employment Exchange.

35 **(2) The form, manner, and time period of providing such information or return shall be as prescribed by the Central Government under clause (e) of sub-section (2) of section 100 of the Rights of Persons with Disabilities Act, 2016.**

49 of 2016.

CHAPTER V

SOCIAL INCLUSION, HEALTHCARE AND REHABILITATION

40 **21. (I) The appropriate Government shall promulgate necessary schemes and programmes to,—**

Social Security.

(a) safeguard and promote the rights of persons affected by leprosy, and members of the family of persons affected by leprosy; and

(b) ensure that persons affected by leprosy and members of the family of persons affected by leprosy have access to adequate standard of living and living conditions.

45 **(2) The schemes under sub-section (I) shall, *inter-alia* provide,—**

(a) financial assistance for income generating activities and market based vocational training for such persons affected by leprosy who have no families, or have been abandoned, or are without shelter or livelihood;

(b) access to safe drinking water and appropriate and accessible sanitation facilities especially in urban slums and rural areas, including settlements where only persons affected by leprosy and members of the family of persons affected by leprosy reside;

(c) pension to persons affected by leprosy or members of the family of persons affected by leprosy subject to such income ceiling as may be notified. 5

(d) unemployment allowance to unemployed persons affected by leprosy, who are registered with special employment exchange, which is notified and established by the Central Government under Section 36 of the Rights of persons with Disabilities Act, 2016 and have been unemployed for more than two years; 10

(e) community-based rehabilitation to persons affected by leprosy and members of the family of persons affected by leprosy as may be prescribed;

Healthcare facilities.

22. (1) The appropriate Government and local authorities shall take all necessary measures to ensure that each person affected by leprosy has barrier-free access to healthcare facilities and schemes available under section 25 of the Rights of Persons with Disabilities Act, 2016. 15
49 of 2016.

(2) The appropriate Government and local authorities shall take all measures necessary to ensure that healthcare providers do not subject persons affected by leprosy to;

(a) inhumane treatment or abuse during the course of medical treatment; or

(b) unethical or involuntary medical procedures or research, including in relation to vaccines, treatments or microbicides for terminal or such other diseases; 20

(3) The appropriate Government shall take all steps necessary to provide aids and appliances, medicine, diagnostic services and corrective surgery free of cost to each person affected by leprosy with such income ceiling as may be notified.

(4) The appropriate Government shall make schemes and programmes for the coverage of medical expenses and therapeutic interventions by a comprehensive insurance scheme for persons affected by leprosy with such income ceiling as may be notified. 25

Rehabilitation.

23. (1) The appropriate Government and local authorities shall undertake or cause to be undertaken services and programmes of rehabilitation, particularly in the areas of health, education and employment for all persons affected by leprosy and members of the family of persons affected by leprosy, based on the assessment of issues faced by such persons: 30

Provided that the appropriate Government shall give due consideration to the diversity of disabilities that affect persons affected by leprosy, and to the gender, age, and socio-economic status of such persons and the members of the family of such persons. 35

(2) The services and programmes under sub-section (1) shall be initiated at the earliest, and no later than one year from the date of commencement of this Act.

(3) For purposes of sub-section (1) and sub-section (2), the appropriate Government and local authorities shall, subject to fulfillment of financial and other norms, and availability of budgetary allocation, grant financial assistance to non-governmental organizations, working for the benefit of persons affected by leprosy, to provide rehabilitation services to such persons and the members of the family of such persons. 40

(4) Prior to the formulation of rehabilitation schemes under sub-section (1), the appropriate Government and local authorities shall consult the representatives of persons affected by leprosy, or associations of persons affected by leprosy, or non-governmental organizations working for the benefit of persons affected by leprosy. 45

24. (1) The appropriate Government shall conduct and promote suitable training and awareness programs for healthcare providers, public servants, and members of the general population to emphasize the importance of early treatment of leprosy through MDT and dispel misconceptions surrounding leprosy.

Promotion of training and awareness programs on leprosy.

5 **(2) For the promotion of training and awareness under sub-section (1), the appropriate Government shall formulate and disseminate leprosy-related information in English and in regional languages and shall ensure that such information is easy to understand, age-appropriate, gender-sensitive, non-stigmatising, non-discriminatory and is revised from time to time.**

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CHAPTER VI

MULTI-DRUG THERAPY FOR PEOPLE LIVING WITH LEPROSY

25. The Central Government and every State Government, as the case may be, shall take all measures as it deems necessary and expedient for the prevention of the spread of leprosy, in accordance with the guidelines and protocols on leprosy under the National
15 Leprosy Eradication Program and the National Health Mission.

Central Government and State Government to take measures.

26. The measures to be taken by appropriate Government and local authorities under sub-section (1) of Section 22 of this Act shall include provision for free-of-cost MDT to persons affected by leprosy.

Multi-Drug Therapy by Central and State Government.

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CHAPTER VII

DISCLOSURE OF MEDICAL RECORDS

27. (1) Notwithstanding anything contained in any other law for the time being in force—

Disclosure of medical records.

25 *(i)* no person affected by leprosy shall be compelled to disclose his medical records except by an order of a competent Court that declares the disclosure of such information to be necessary in the interest of justice and for the determination of issues in the matter before the Court;

30 *(ii)* no person or establishment shall disclose or be compelled to disclose the medical records or any other private information of a person affected by leprosy, who has imparted such information to the person or establishment, in confidence, or in a relationship of a fiduciary nature, except with the informed consent of such person affected by leprosy or of the representative of such person obtained earlier in writing;

(2) The informed consent for disclosure of medical records under sub-section (1) is not required where the disclosure is made—

35 *(a)* by a healthcare provider to another healthcare provider who is involved in the care, treatment or counseling of a person affected by leprosy, when such disclosure is necessary to provide care or treatment to such person;

(b) by an order of a competent Court that declares such disclosure as necessary in the interest of justice and for the determination of issues in the matter before the Court;

40 *(c)* in suits or legal proceedings between persons, whether or not any of such persons, who is a party to the suit, is affected by leprosy, and where the disclosure of such information is necessary in filing suits or legal proceedings or for instructing their counsel;

45 *(d)* in relation to statistical or other information of a person affected by leprosy that could not reasonably be expected to lead to the identification of such person; and

(e) to the officers of the Central Government or the State Government, as the case may be, for the purposes of monitoring, evaluation or supervision of the incidence of leprosy within the population:

Provided that, in case of disclosure under clauses (d) and (e) the name and identity of the person affected by leprosy shall not be disclosed.

CHATER VIII

APPOINTMENT OF OMBUDSPERSONS

Appointment of Ombudspersons. **28. (I) Every State Government and U.T. Administration shall appoint one or more Ombudspersons—** 5

(a) possessing such qualifications and experience as may be prescribed, or

(b) designate any of its officers not below such rank, as may be prescribed, by the State Government,

to exercise such powers and discharge such functions, as may be conferred on the Ombudsperson under this Act. 10

(2) The terms and condition of the service of an Ombudspersons appointed under sub-section (I) shall be such as may be prescribed by the Government or the U.T. Administration.

(3) The Ombudsperson appointed under sub-section (I) shall have such jurisdiction in respect of such area or areas as the State Government or the U.T. Administration may, by notification, specify. 15

Powers of Ombudspersons. **29. (I) The Ombudsperson shall, upon a complaint made by any person, inquire into the violations of any of the provisions of this Act.**

(2) The Ombudsperson may require any person to furnish information on such points or matters, as he or she consider necessary, for inquiring into the matter, and any person so require shall be deemed to be legally bound to furnish such information. 20

(3) Any person who fails to furnish such information as required under sub-section (2) shall be punishable under sections 176 and 177 of the Indian Penal code, 1860. 45 of 1860.

(4) The Ombudsperson shall maintain record of the inquiries conducted by him or her in such manner as may be prescribed by the State Government or the U.T. Administration. 25

Procedure of complaint. **30. A complaint may be made to an Ombudsperson under sub-section (I) of Section 29 in such manner as may be prescribed by the State Government or the U.T. Administration.**

Orders of Ombudspersons. **31. (I) The Ombudsperson shall, within a period of thirty days from the receipt of the complaint under sub-section (I) of Section 29, and after giving an opportunity of being heard to the parties, pass such order, as he or she deems fit, giving reasons therefor and in such manner as may be prescribed by the State Government or the U.T. Administration.** 30

(2) Prior to passing an order under sub-section (I), the Ombudsperson shall consult such persons or organizations, including experts on leprosy, as he or she may deem appropriate.

Authorities to assist Ombudspersons. **32. All authorities, including the civil authorities functioning in the area for which an Ombudsperson has been appointed under Section 28, shall assist the Ombudsperson of that area in the execution or orders passed by such Ombudsperson under Section 31.** 35

Report by Ombudsperson. **33. Each Ombudsperson shall, after every six months, report to the State Government or the U.T. Administration as the case may be the number and nature of complaints received, the action taken and orders passed in relation to such complaints and such report shall be published on the website of Ombudsperson and a copy thereof be forwarded to the Central Government.** 40

CHAPTER XI

OFFENCES AND PENALTIES

Penalty for contravention. **34. Notwithstanding any action that may be taken under any other law for the time being in force, whoever contravenes the provisions of Section 5 shall be punished with imprisonment for a term which shall not be less than three months but which may extend to two years and with fine which may extend to one lakh rupees, or with both.** 45

35. Whoever, by words, either spoken or written, voluntarily or knowingly, publishes, propagates, advocates or communicates by signs or by visible representation or otherwise the feelings of hatred against any person affected by leprosy or member of the family of person affected by leprosy in general, or specifically, or disseminates, broadcasts or displays any information, advertisement or notice, which may reasonably be construed to demonstrate an intention or propagate hatred, or which is likely to expose persons affected by leprosy or members of the family of persons affected by leprosy to hatred, discrimination of physical violence, shall be punished with imprisonment for a term which shall not be less than three months but which may extend to two years and with fine which may extend to one lakh rupees, or with both.
36. Whoever fails to comply with the order or an Ombudsperson passed under Section 31, within such time as may be specified in such order, shall be liable to pay a fine which may extend to ten thousand rupees, and in case the failure continues, with an additional fine which may extend to five thousand rupees for every day during which shall failure continues.
37. Notwithstanding any action that may be taken under any law for the time being in force, whoever discloses information regarding the medical record of a person affected by leprosy to any person or entity, without the informed consent of such person or this or her representatives, shall be punishable with fine which may extend to one lakh rupees, unless such disclosure is made pursuant to any of the grounds mentioned under sub-section (2) of Section 27.
38. Whoever fails to produce any book, account or other document or to furnish any statement, information or particulars which, under this Act, or any order, regulation, or direction made, or given thereunder, which he or she is duty bound to produce or furnish, or to answer any question put in pursuance of the provisions of this Act, or of any order, regulation, or direction made, or given thereunder, shall be punishable with fine which may extend to twenty-five thousand rupees in respect of each offence, and in case of continued failure or refusal, with further fine which may extend to one thousand rupees for each day of continued failure, or refusal after the date on which the original order imposing punishment of fine was passed.
39. (1) Where any offence under this Act has been committed by an establishment, every person who, at the time the offence was committed, was the appointed head or was directly in charge of, and was responsible for the day to day functioning of the establishment, including its conduct of business, shall be deemed to be guilty of an offence, and shall be liable to be proceeded against and punished accordingly:
- Provided that nothing contained in Section 34, shall render any such person liable to any punishment provided in this Act, if it is proved that the offence was committed without the knowledge of such person, or that all due diligence was exercised by such person in order to prevent the commission of the offence.
- (2) Notwithstanding anything contained in Section 34, where an offence under this Act has been committed by an establishment, and it is proved that the offence has been committed with the consent, or connivance of, or is attributable to any neglect on the part of any other officer of the establishment, such person shall also be deemed to be guilty of such offence and shall be liable to be proceeded against and punished accordingly.
40. No person shall subject any other person, or persons to any detriment on the ground that such person, or persons have taken any of the following actions, namely: —
- (a) made a complaint under this Act;
 - (b) brought proceedings under this Act against any person or establishment;
 - (c) furnished any information, or produced any document to any authority exercising or performing any power or function under this Act; or
 - (d) appeared as a witness in a proceeding under this Act.

Penalty for certain actions of individuals.

Penalty for failure to comply with orders of Ombudspersons.

Penalty for breach of confidentiality.

Penalty for failure to furnish information.

Offences by Establishments.

Prohibition of victimisation.

Court to try offences. **41.** No court other than the court of a judicial Magistrate of the First Class shall take cognizance of an offence under this Act.

Offences to be cognizable and bailable. **42.** Notwithstanding anything contained in the Code of Criminal Procedure, 1973, offences under this Act shall be cognizable and bailable. 2 of 1974.

CHAPTER X

5

REPEAL OF CERTAIN ENACTMENTS

Substitution of certain terms. **43.** 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 (f) of section 2, the term 'leper' and such other terms in national, regional and local languages, shall be substituted by the term 'persons affected by leprosy', or any other term that bears the same meaning in the national, regional or local language. 10

Amendments to certain enactments. **44.** The statutes and provisions enumerated in column I of the Schedule shall stand amended in accordance with the respective entries in column II of the Schedule.

Act to have overriding effect. **45.** The provisions of this Act shall have effect notwithstanding anything inconsistent therewith contained in any other law for the time being in force, or any instrument having effect by virtue of any such law. 15

CHAPTER XI

MISCELLANEOUS

Central Government to provide funds. **46.** The Central Government shall, after due appropriation made by Parliament in this behalf, provide adequate funds, from time to time, for carrying out the purposes of this Act. 20

Act to be in addition to and not in derogation of any other law. **47.** The provisions of this Act or the rules made thereunder shall be in addition to and not in derogation of any other law, rules, orders or instructions which provide any entitlement or benefit to persons affected by leprosy. 25

Action taken in good faith. **48.** No suit, prosecution or other legal proceeding shall lie against any person for any action or omission which is done in good faith or intended to be done in pursuance of the provisions of this Act and the rules made thereunder.

Power to remove difficulties. **49.** (1) 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 may appear to it to be necessary or expedient for removing the said difficulty: 30

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

(2) Every order made under this Section shall be laid, as soon as may be after it is made, before each House of Parliament. 35

Power to appropriate Government to make rules. **50.** (1) Subject to the other provisions of this Act, the appropriate Government may, by notification in the official Gazette make rules for carrying out the provisions of this Act.

(2) In particular, and without prejudice to the generality of the foregoing power, such rules may provide for all or any of the following matters, namely:— 40

(a) form, manner and the value of compensation that may be awarded to a person affected by leprosy or a member of the family of persons affected by leprosy under clause (c) of sub-section (3) of section 13;

(b) form, manner and content of information required to be reported to the special employment exchange under sub-section (1) of section 20;

5 (c) form and manner of community-based rehabilitation for persons affected by leprosy and members of the family of such persons under clause (e) of sub-section (2) of section 21;

(d) form, manner and content of information required to be disclosed to obtain informed consent under clause (ii) of sub-section (1) of section 27;

(e) the composition, the requisite qualifications of the Ombudsperson and manner of appointment of Ombudspersons under sub-section (1) of section 28;

10 (f) the terms and condition of service of Ombudspersons under sub-sections (2) and (3) of Section 28;

(g) form and manner in which Ombudspersons are required to maintain records under sub section (3) of section 29;

15 (h) the form, manner and procedure for making a complaint to Ombudspersons under section 30; and

(i) the form, manner and content of orders that Ombudspersons can pass under section 31.

20 (3) Prior to the formulation of rules, the appropriate Government shall make available the draft of the rules in accessible formats to the members of the public and invite their suggestions and objections to the same.

25 (4) Every rule made by the Central Government under this Act 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 sessions aforesaid, both Houses agree, in making any modification in the rule, or 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:

Provided that any such modification or annulment shall be without prejudice to the validity of anything previously done under that rule.

30 (5) Every rule made by the State Government under this Section shall be laid, as soon as may be after it is made, before each House of the State Legislature, where it consists of two Houses, or where such legislature consists of one House, before that House.

SCHEDULE
(See Section 45)
AMENDMENT TO CERTAIN ENACTMENTS

Legislation	Amendment
16 of 1915.	<p>1. The Banaras Hindu University Act, 1915</p> <p>In sub-clause (a) of clause (1) of Section 12B, the words “or suffers from contagious leprosy” shall be removed, and the sub-clause will read as, namely:</p> <p><i>(a) if he is of unsound mind or is a deaf-mute;</i></p> <p>In sub-clause (a) of clause (1) of Section 32, the words “or suffers from contagious leprosy” shall be removed, and the sub-clause will read as, namely:</p> <p><i>(a) if he is of unsound mind or is a deaf-mute;</i></p>
29 of 1951.	<p>2. The Visva Bharati Act, 1951</p> <p>In sub-clause (a) of clause (3) of Section 38B, the words “or suffers from contagious leprosy” shall be removed, and the sub-clause will read as, namely:</p> <p><i>(a) is of unsound mind or is a deaf-mute; or</i></p>
53 of 1966.	<p>3. The Jawahar Lal Nehru University Act, 1966</p> <p>In sub-clause (a) of clause (1) of Section 23, the words “or suffers from contagious leprosy” shall be removed, and the sub-clause will read as, namely:</p> <p><i>(a) if he is of unsound mind or is a deaf-mute</i></p> <p>In sub-clause (a) of clause (1) of Section 31, the words “or suffers from contagious leprosy” shall be removed, and the sub-clause will be read as, namely:</p> <p><i>(a) if he is of unsound mind or is deaf-mute;</i></p>
39 of 1987.	<p>4. Legal Services Authorities Act, 1987</p> <p>After sub-clause (d) of Section 12, the following sub-clause shall be inserted namely:</p> <p><i>(dd) a person who suffers from, or has previously suffered or has been cured of Leprosy; or</i></p>
59 of 1988.	<p>5. The Motor Vehicles Act, 1988</p> <p>After the first proviso to sub-section (4) under Section 8 of the Act, the following proviso shall be inserted, namely:</p> <p><i>Provided further that the licensing authority shall not refuse to issue a learners 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.</i></p>
Kerala Act No. X of 1953.	<p>6. The Nurses and Midwives Act, 1953</p> <p>In clause (c) of Section 6, the words “a leper” shall be removed, and the sub-clause will read as, namely:</p> <p><i>(c) if he is of unsound mind and stands so declared by a competent Court, or a deaf-mute;</i></p>
Karnataka Act No. 33 of 2001.	<p>7. The Hindu Religious Institutions and Charitable Endowments Act, 1997.</p> <p>In sub-clause (ii) of clause (5) of section 25, the words “or is suffering from leprosy” shall be removed, and the sub-clause will read as, namely:</p> <p><i>(ii) if he is of unsound mind and stands so declared by a competent courts or if he is a deaf or mute or any virulent or contagious disease.</i></p>

STATEMENT OF OBJECTS AND REASONS

The spread of leprosy and discrimination faced by persons affected by leprosy is a matter of grave concern. In 2015, India had the largest number of new leprosy cases, comprising 60% of all the cases reported globally. Approximately 1.25 to 1.35 lakh new cases are being reported every year in India for over a decade. The problem which is even more serious is that of discrimination and stigma faced by persons affected by leprosy and their families. They continue to face segregation, restrictions and exclusions within and outside family structures, in communities and public spaces, including public transportation systems. It is highly unfortunate that the discrimination being faced by these persons primarily stems from their affliction of a particular disease and its consequent effects on their body.

The General Assembly of the United Nations recognised the marginalised status of persons affected by leprosy and their family members and unanimously adopted a Resolution on the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members in 2010. The Principles and Guidelines, which are appended to the Resolution of the General Assembly, direct Member States to accord to persons affected by leprosy and their family members certain protections and provisions that are necessary to bring them at par with others. Additionally, the United Nations Convention on the Rights of Persons with Disabilities, 2007 (“UNCRPD”) also promotes the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, while laying emphasis on the respect for their inherent dignity. Since India is a member of General Assembly of the United Nations as well as a signatory to both of these documents, it is under an obligation to address the concerns and eliminate discrimination against persons affected by leprosy and their family members.

Although the recently passed Rights of Persons with Disabilities Act, 2016 (“RPD Act”), intends to give effect to India’s obligations under the UNCRPD, it falls short of covering all persons affected by leprosy. In fact, only those persons who are cured of leprosy and who have 40% or above disability are covered within the ambit of the RPD Act. Hence, in terms of discrimination as well as State action, there is a pressing need to undertake a range of actions for the benefit of persons affected by leprosy and their family members. For one, it is imperative that, affirmative action and anti-discrimination measures be applicable to a range of persons, who may either be affected by leprosy, may be undiagnosed, may be under-going treatment, or may have been cured, as well as family members of such persons to holistically address the impact of stigma, fear, exclusion and invisibility faced by such persons. Another change that is necessary is the repeal and amendment of discriminatory provisions in various civil and criminal laws of India that legitimise discrimination and segregation of persons affected by leprosy on the grounds that leprosy is an incurable and highly infectious disease. As noted by the World Health Organisation, leprosy is now fully curable through Multi-Drug Therapy, which renders the infected individual non-contagious with its very first dose of treatment, and which is made available free of cost under the National Leprosy Eradication Programme of India. Consequently, the object and purpose sought to be served through these discriminatory provisions no longer hold ground and constitute a violation of the right of persons affected by leprosy to equality before law and equal protection of laws under the Indian Constitution. Since persons affected by leprosy continue to remain a highly marginalised, vulnerable and invisible section on the fringes of society, there is also a need for implementing positive steps to provide them with effective care, support and treatment, and Promote their social inclusion.

The Law Commission of India took note of the disparate situation of persons affected by leprosy and their families and came out with a study on the condition of persons affected by leprosy in India in its Report No. 256, titled “Eliminating Discrimination Against Persons Affected by Leprosy”. This comprehensive report, which deals with discriminatory laws as

well as positive measures for persons affected by leprosy and their family members, was submitted to the Ministry of Law & Justice on 9th April 2015, along with a model draft law to eliminate discrimination faced by persons affected by leprosy. However, little or no action seems to have been taken to either enact the model law, or modify or repeal any law that directly or indirectly discriminates against persons affected by leprosy.

While the Lepers Act, 1898, which sanctioned arrest and segregation of persons affected by leprosy into leper asylums, was repealed by Parliament in 2016, the provisions under some other enactments and legislations which discriminate against persons affected by leprosy continue to exist on the statute books, despite the fact that leprosy is completely curable, as mentioned by the Law Commission in its Report.

The long-standing discrimination faced by persons affected by leprosy and their families has continued to exclude such persons from participating in society and have resulted in the violation of their fundamental rights that are guaranteed to them under the Constitution of India. Moreover, term 'leper', which continues to be used in the provisions of several Central and State enactments, is nothing less than a profanity for persons affected by leprosy. Hence, enacting a law that promotes anti-discrimination measures and the social inclusion of persons affected by leprosy and their family members is imperative and urgent. Without the protection of human rights, there can be no democracy or justification for democracy. Undoing years of discrimination that the persons affected by leprosy and their family members have faced, requires immediate interventions by the State.

Hence this Bill.

K.T.S. TULSI

FINANCIAL MEMORANDUM

Clause 16 of the Bill provides for vocational training and self employment to persons affected by leprosy. Clause 18 provides for incentives by the appropriate Government to employers in the private sector in order to enable them to include persons affected by leprosy. Clause 21 provides for social security including financial assistance for income generating activities and market based vocational training for such persons affected by leprosy. Clause 22 empowers the appropriate Government and local authorities to take all necessary measures to ensure that each person affected by leprosy has barrier-free access to healthcare facilities. Clause 23 also seeks to provide services and programmes of rehabilitation, particularly in the areas of health, education and employment for all persons affected by leprosy and members of the family of persons affected by leprosy. Clause 24 provides for conducting training and awareness programmes for health care providers, public servants and general public. Clause 26 provides for provision of free of cost MDT to persons affected with leprosy. Clause 28 provides for appointment of ombudspersons for every State and UT. Clause 47 says that the Central Government after due appropriation by Parliament will provide adequate funds, from time to time, for carrying out the purposes of the Bill.

The Bill, therefore, if enacted would involve expenditure from the Consolidated Fund of India. The recurring and non-recurring expenditure on this count cannot be estimated at this stage, but has to be worked out by Central Government while implementing the provisions of the Act.

MEMORANDUM REGARDING DELEGATED LEGISLATION

Clause 51 of the Bill empowers the appropriate Government to make rules for carrying out the purposes of this Bill. The rules will relate to matters of details only.

The delegation of legislative power is of normal character.

RAJYA SABHA

A

BILL

to protect the human rights of persons affected by leprosy, to eliminate discrimination against them and their families to promote their social welfare, to take steps for the prevention and control of leprosy and for matters connected therewith or incidental thereto.

(Shri K.T.S. Tulsi, M.P.)