

# ENDING DISCRIMINATION AGAINST PERSONS AFFECTED BY LEPROSY IN INDIA

Submitted for the consideration of the 22<sup>nd</sup> Session of the CRPD Committee

Submitted by:

**International Federation of Anti Leprosy Associations (ILEP)**

(The submission may be posted on the OHCHR website)

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This submission is made by the International Federation of Anti-Leprosy Associations (ILEP), a federation of 13 member associations working in leprosy-related activities in 69 countries. Its goal is zero leprosy, including zero stigma and discrimination against persons affected by leprosy and their family members. Persons affected by leprosy<sup>1</sup> play a significant role in organisational decisions through the operation of a high-profile Advisory Panel. Organisations of persons with disabilities took a lead in submissions for the List of Issues during the pre-session. This further submission is made by ILEP on behalf of stakeholders.

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1. Leprosy is endemic in India. Just under 60% of all new cases worldwide are in India. Over the years since adoption of the current treatment regimen, more than 10 million persons have been cured of leprosy in India, and it is estimated that as many as 2 million continue to live in the community with disabilities due to leprosy. It is projected that double this number are suffering from exclusion, stigmatisation and societal barriers to participation as a result of harmful stereotypes related to the label 'leprosy', whether they have physical impairments or not. This stigma and discrimination affect not only individuals with personal experience of leprosy but also their family members.
2. Noting the ongoing discriminatory practices, the Supreme Court in 2018 gave directions in its judgement in *Pankaj Sinha vs Union of India and others* [Writ Petition (Civil) No.767/2014] to address the various forms of discrimination against persons affected by leprosy. These directions relate, inter alia, to leprosy awareness programs, seminars at all levels to hear the views of persons affected by leprosy, prohibition of discriminatory behaviour within the health services and education services, ensuring available supply of leprosy medication, free supply of protective footwear, development of comprehensive community-based rehabilitation programs, and

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<sup>1</sup> Persons with personal experience of leprosy prefer this descriptive term. The alternative term 'persons with leprosy' is rejected as being more descriptive of persons currently suffering from the disease, rather than its consequential effects in terms of disability, stigma and discrimination.

attention to ensure that persons affected by leprosy are issued the correct identity and social entitlement cards.<sup>2</sup>

3. In the same judgement, the Supreme Court took note of writ petition 1151/2017, filed by Vidhi Centre for Legal Policy versus Union of India, which noted the existence of, and listed, 119 central and state laws that violate the fundamental rights of persons affected by leprosy under Articles 14, 19 and 21 of the Constitution. It also took note of Report 256 of the Law Commission of India<sup>3</sup>, which expressed concern at the number of Indian laws that continue to directly and indirectly discriminate against persons affected by leprosy. The Law Commission observed that these laws contravene India's obligations under the CRPD and also contradict India's membership of the UN General Assembly, which in 2010 had unanimously adopted a Resolution on the Elimination of Discrimination against Persons affected by Leprosy, accompanied by Principles and Guidelines listing measures to improve their living conditions. The Law Commission noted with concern that no action has been taken by the Central Government or by State Governments to modify or repeal any of the discriminatory laws, and proposed a comprehensive new law, referred to as the Elimination of Discrimination against Persons affected by Leprosy Bill, or EDPAL. The Rights of Persons Affected by Leprosy and Members of their Family (Protection against Discrimination and Guarantee of Social Welfare) Bill 2017, based on the structure of EDPAL, was subsequently drafted in line with other human rights legislations in India including the Rights of Persons with Disabilities Act 2016. This bill was set down for introduction in the Rajya Sabha on 15 December 2017 and is currently pending.
4. The CRPD Committee has recognised that the label of leprosy usually results in social exclusion and human rights abuses, including discriminatory legislation and discriminatory practices in the community. The Committee raised a number of questions related to leprosy in the List of Issues (LOI) in relation to the initial report of India (16 May 2019). The Government responded on 31 May 2019.
5. LOI 5(d) asks what progress has been made in implementing the judgement of the Supreme Court of 2018 in *Pankaj Sinha vs Union of India and others* to address discrimination against persons affected by leprosy. The response (para. 19) does not give information about progress in regard to the directions listed in paragraph 2 above other than the amending in February 2019 of 5 of the 119 discriminatory laws then in existence. **In accordance with Article 5, the government is again asked to report what progress has been made in implementing the various points of the Supreme Court judgement referred to.**
6. Referring to the Government's response (paragraph 19), in fact 13 discriminatory laws have been repealed or amended. This is commendable, but there still remain 106 discriminatory laws (listed in the Appendix) which, as pointed out by the Supreme Court, are in contravention of India's obligations under the CRPD. The Government has considered drafting an overarching law

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<sup>2</sup> The Supreme Court judgement noted that several instances had come to fore highlighting that the persons affected with leprosy are being provided with APL cards and not BPL cards, which prevented these people from claiming benefits under various schemes brought out by the Government, such as the Antyodaya Anna Yojana (AAY), which again deprives this section of the populace from claiming their right to food.

<sup>3</sup> Refer <http://lawcommissionofindia.nic.in/reports/Report256.pdf>

that repeals or amends all the remaining discriminatory laws, but it has not done so. **In accordance with Article 5, the government is asked**

- a. **To take immediate steps to repeal or amend the discriminatory provisions in each of these Acts; and**
  - b. **To introduce and pass the anti-discriminatory provisions of the proposed Elimination of Discrimination against Persons affected by Leprosy (EDPAL) legislation.**
7. LOI 8(a) asks for information about awareness raising programs to eliminate and combat stigma. The response (paras. 38-42) provides information about provisions in the Rights of Persons with Disabilities Act 2016. **Given that persons affected by leprosy face a particularly high prevalence of stigma and discrimination related to the label 'leprosy', the government is asked to provide information specific to leprosy.**
8. LOI 14(a) asks for information on measures for deinstitutionalising persons affected by leprosy living in leprosy colonies. Law Commission Report 256 states that there are 850 leprosy colonies in India where persons affected by leprosy continue to live. Although segregation is no longer enforced as in the past, a combination of poverty, fear, self-stigma and lack of awareness perpetuate the isolation of the colonies. Moreover, because of ignorance and fear of social exclusion, persons affected by leprosy are often kept hidden by family members or are compelled to live apart from other members of the community. The government's response (para 73) refers to the right to equality but not to measures being taken to protect that right. **The government is asked to provide information on concrete measures being taken in this regard.**
9. LOI 28(a) asks for information about the percentage of persons with disabilities, including persons affected by leprosy, covered by social housing schemes. The government's response (paras. 133-139) does not provide specific information on this topic aside from reference to a policy prescription. This is a matter of importance for the many thousands of persons affected by leprosy, and their family members, residing in the leprosy colonies. In very many cases, title to the properties in which they are living has not been passed to them, resulting in a major insecurity for persons affected by leprosy and their family members. **In accordance with Article 28, the government is asked to ensure that ownership of the houses in which persons affected by leprosy live, within the leprosy colonies, is transferred into their names.**
10. The UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members were adopted by the Human Rights Council in 2010. They broadly mirror the CRPD and provide a valuable roadmap for countries seeking to reduce discrimination and promote the human rights of persons affected by leprosy. **The Committee is asked to urge the Government of India, in line with its recognition (para. 28) that persons affected by leprosy are one of the categories of disability, to implement the Principles and Guidelines as a significant contribution to enabling persons affected by leprosy to live with dignity.**

## APPENDIX

### Schedule of laws in force in India as at July 2019 that discriminate against persons affected by leprosy

LAW	CATEGORY	DISCRIMINATORY PROVISIONS
Karnataka Rajya Dr Gangubai Hangal Sangeetha Mattu Pradarshaka Kalegala Vishwavidyalaya Act, 2009	Segregation/ separation	Removal of persons affected from membership of the university.
Visva Bharati Act, 1951	Segregation/ separation	Removal of teaching or non-teaching academic staff on the grounds of having contagious leprosy.
Karnataka Samskrita Vishwavidyalaya Act, 2009	Segregation/ separation	Removal of persons affected from membership of the university.
Sri Venkateswara Vedic University Act, 2006	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University.
Dravidian University Act, 1997	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University.
Andhra Pradesh Universities Act, 1991	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority.
Kannada University Act, 1991	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority.
University of Health Sciences Act, 1986	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University.
Pondicherry University Act, 1985	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority for non-teaching staff and academic staff.
Potti Sreeramulu Telugu University Act, 1985	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University.
Telugu University Act, 1985	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University.
Alagappa University Act, 1985	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University.
Goa University Act, 1984	Segregation/ separation	Suffering from contagious leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority for non-teaching staff and academic staff.
Mother Teresa Women's University Act, 1984	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University.

Dr B.R Ambedkar Open University Act, 1982	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University.
Bharathiar University Act, 1981	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University.
Tamil University Act, 1982	Segregation/ separation	Removal of persons affected from membership of the university.
Bharathidasan University Act, 1981	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority.
Sri Krishnadevaraya University Act, 1981	Segregation/ separation	Suffering from contagious leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority for non-teaching staff and academic staff.
Nagarjuna University Act, 1976	Segregation/ separation	Suffering from contagious leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority for non-teaching staff and academic staff.
University of Hyderabad Act, 1974	Segregation/ separation	Suffering from contagious leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority for non-teaching staff and academic staff.
North-Eastern Hill University Act, 1973	Segregation/ separation	Suffering from contagious leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority for non-teaching staff and academic staff.
Jawaharlal Nehru University Act, 1966	Segregation/ separation	Suffering from contagious leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority for non-teaching staff and academic staff.
Madurai- Kamaraj University Act, 1965	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University.
Osmania University Act, 1959	Segregation/ separation	Suffering from leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority.
Madras University Act, 1923	Segregation/ separation	Suffering from contagious leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority.
Banaras Hindu University Act, 1915	Segregation/ separation	Suffering from contagious leprosy is a ground for disqualification from nomination or membership of any authority of the University and also removal from a position of authority for non-teaching staff.
Coimbatore City Municipal Corporation Act, 1981	Segregation/ separation	Duty to expel persons suffering from leprosy from market areas leading to segregation.

Punjab Municipal Corporation Act, 1976	Segregation/separation	Duty to expel persons suffering from leprosy from market areas leading to segregation.
Puducherry Municipalities Act, 1973	Segregation/separation	Duty to expel persons suffering from leprosy from market areas leading to segregation.
Karnataka Municipalities (Regulation and Inspection of Lodging and Boarding Houses) (Model) Bye-Laws, 1966	Segregation/separation	No person affected by leprosy to be allowed inside, to occupy, handle or work in the designated areas under the Act.
Karnataka Municipalities Act, 1964	Segregation/separation	Duty to expel persons suffering from leprosy from market areas leading to segregation.
Andhra Pradesh Municipalities Act, 1965	Segregation/separation	Not eligible to stand for election or continue on a post in the municipality if suffering from leprosy and also to expel persons affected from market places leading to segregation and denial of political participation.
Delhi Municipal Corporation Act, 1957	Segregation/separation	Duty to expel persons suffering from leprosy from market areas leading to segregation.
Orissa Municipal Act, 1950	Segregation/separation	Leprosy patients are not eligible to stand for election or continue in a post in the municipality and can also be expelled from market places
Tamil Nadu District Municipalities Act, 1920	Segregation/separation	People affected by leprosy are not eligible to stand for election or continue in a post in the municipality and can also be expelled from market places
Jammu and Kashmir Motor Vehicles Act, 1998	Segregation/separation	People affected by leprosy are not eligible to obtain a driving license or drive a public service vehicle
Chennai Municipal Corporation Act, 1919	Segregation/separation	People affected by leprosy are not eligible to stand for election or continue in a post in the municipality and can also be expelled from market places
The Rajasthan Rehabilitation of Beggars or Indigents Act, 2012	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.
Sikkim Prohibition of Beggary Act, 2004	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.
Andhra Pradesh Prevention of Begging Act, 1977	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.
Uttar Pradesh Prohibition of Beggary Act, 1975	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.
Karnataka Prohibition of Beggary Act, 1975	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.
Madhya Pradesh Bhiksha Vrittinivaran Adhiniyam, 1973	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.
Goa, Daman and Diu Prevention of Begging Act, 1972	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.
Haryana Prevention of Beggary Act, 1971	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.
Maharashtra Prevention of Begging Act, 1959	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.
Assam Prevention of Begging Act, 1964	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.
Gujarat Prevention of Begging Act, 1959	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.

The Telangana Prevention of Begging Act, 1977	Segregation/separation	Removal of people affected by leprosy from beggary homes to leprosy asylums.
Tamil Nadu Prevention of Begging Act, 1945	Segregation/separation	Removal of persons affected by leprosy from beggary homes and/or juvenile homes to leprosy asylums for indefinite periods.
Bengal Vagrancy Act, 1943	Segregation/separation	Separation of people affected by leprosy from other vagrants in the home.
Jammu and Kashmir Shri Amarnath Ji Shrine Act, 2000	Segregation/separation	Disqualification from membership on the Board for persons suffering with contagious leprosy.
Hindu Religious Institutions and Charitable Endowments Act, 1997	Segregation/separation	Disqualification from membership and removal from continuation on the Board for persons suffering from leprosy.
Shri Sanwaliaji Temple Act, 1992	Segregation/separation	Disqualification from membership on the Board for persons suffering from leprosy.
Haryana Shri Mata Mansa Devi Shrine Act, 1991	Segregation/separation	Disqualification from membership on the Board for persons suffering with contagious leprosy.
Jammu and Kashmir Shri Mata Vaishno Devi Shrine Act, 1988	Segregation/separation	Disqualification from membership on the Board for persons suffering with contagious leprosy.
Andhra Pradesh Charitable and Hindu Religious Institution and Endowments Act, 1987	Segregation/separation	Disqualification from membership or continuation on the Trust for persons suffering from leprosy.
Nathdwara Temple Act, 1959	Segregation/separation	Disqualification from membership on the Board for persons suffering from leprosy.
Tamil Nadu Hindu Religious and Charitable Endowments Act, 1959	Segregation/separation	Disqualification from membership or continuation on the Trust for persons suffering from leprosy.
Madhya Bharat Shri Mahakaleshwar Temple Act, 1953	Segregation/separation	Disqualification from membership on the Board for persons suffering with contagious leprosy and removal of any panda (pandit working at the temple) if suffering from leprosy.
Shri Shiv Khori Shrine Act, 2008	Segregation/separation	Disqualification from membership on the Board for persons suffering with contagious leprosy.
Delhi Prisons (Treatment of Convicts Sentenced to Simple Imprisonment, Death, Female Prisoners, Youthful Prisoners, Leper Prisoners and Lunatic Prisoners) Rules, 1988	Segregation/separation	Provides for the segregation and separation of prisoners affected by leprosy and destruction of clothing and bedding used by such prisoner.
Andhra Pradesh Habitual Offenders Rules, 1965	Segregation/separation	Provides for sending prisoners suffering from leprosy to a leprosy asylum.
Kerala Habitual Offenders Rules, 1963	Segregation/separation	Provides for a registered offender to be sent to a leprosy asylum on his/her choice with restriction of movement out of there.
Madhya Pradesh Gram Panchayat (Regulation of Slaughter House) Rules, 1998	Segregation/separation	Restrictions on persons suffering from leprosy to enter slaughterhouse premises.
Kerala Places of Public Resort Rules, 1965	Segregation/separation	Restriction on allowance of people affected by leprosy in public resorts and for mandatory reporting to health officer.
Travancore Cochin Public Health Act, 1955	Segregation/separation	Allows for the segregation of person suffering from leprosy from public conveyances, schools, colleges,

		public libraries, reading rooms and creation of separate segregation areas.
Madhya Pradesh Public Health Act, 1949	Segregation/ separation	Allows for the segregation of person suffering from leprosy from schools, colleges, playgrounds, public library and creation of separate segregation areas.
Bihar Prevention Of Beggary Act, 1951	Segregation/ separation	Maybe segregated on the grounds infectious and contagious diseases, which ordinarily includes leprosy.
Orissa Municipal Corporation Act, 2003	Voting related	Not eligible to stand in elections of a corporator if affected by leprosy at the time of nomination leading to segregation and denial of political participation.
Sikkim Panchayat Act, 1982	Voting related	Not eligible to stand for election for gram panchayat if suffering from an infectious form of leprosy leading to segregation and denial of political participation.
Chhattisgarh Municipalities Act, 1961	Voting related	Not eligible to stand for election if suffering from an infectious form of leprosy leading to segregation and denial of political participation.
Madras Panchayats Act, 1958	Voting related	Not eligible to stand for election or continue in office if suffering from leprosy leading to segregation and denial of political participation.
Greater Hyderabad Municipal Corporation Act, 1955	Voting related	People affected by leprosy are not eligible to stand for election.
Delhi Land Reforms Act, 1954	Voting related	Not eligible to stand for election or continue in office if suffering from leprosy leading to segregation and denial of political participation.
Delhi Panchayat Raj Act, 1954	Voting related	Not eligible to stand for election or continue in office if suffering from leprosy leading to segregation and denial of political participation.
Chennai Metro Railway (Carriage and Ticket) Rules, 2014	Public transportation	Restriction on travel of persons with leprosy.
Metro Railways (Carriage and Ticket) Rules, 2014	Public transportation	Restriction on travel of persons with leprosy.
Bangalore Metro Railway (Carriage and Ticket) Rules, 2011	Public transportation	Restriction on travel of persons with leprosy.
Inland Steam Vessels (Madhya Pradesh) Rules, 1962	Public transportation	Restriction and separation of person suffering from leprosy aboard vessels.
Hindu Marriage (High Court of Meghalaya) Rules 2013	Marriage/ Divorce	Virulent and incurable form of leprosy is a ground for divorce.
Family Courts (Patna High Court) Rules, 2000]	Marriage/ Divorce	Virulent and incurable form of leprosy is a ground for divorce.
Jammu and Kashmir Dissolution of Muslim Marriages Act, 1999	Marriage/ Divorce	Suffering from leprosy is a ground for divorce.
Jammu and Kashmir Hindu Marriage Act, 1980	Marriage/ Divorce	Virulent and incurable form of leprosy is a ground for divorce.
Jammu and Kashmir Hindu Adoptions and Maintenance Act, 1960	Marriage/ Divorce	The wife shall have the right to live separately from her husband if he is suffering from a virulent form of leprosy.
Kerala Fishermen Welfare Societies (Determination of Strength of Committees and	Employment	Disqualification from being a member of the committee if affected by leprosy.



Conduct of Election) Rules, 1980		
Andhra Pradesh Medical Practitioners Registration Act, 1968	Employment	Disqualification from being a member of the council if affected by leprosy.
Bye-Laws of Pradeshik Co-Operative Dairy Federation Limited, 1979	Employment	Disqualification for being or continuing as a member of the Board of Directors if suffering from leprosy.
Andhra Pradesh Public Libraries Act, 1969	Employment	Disqualified from being a member of the Zilla Grandhalaya Samstha if suffering from leprosy.
Kerala Document Writers' Licence Rules, 1960	Employment	A leper to be disqualified from getting a license leading to loss of employment opportunity.
Kerala Kahadi and Village Industries Board Act, 1957	Employment	Disqualified from being or continuing as a member of the Board if suffering from leprosy.
The Andhra Pradesh Ayurvedic and Homeopathic Medical Practitioners Registration Act, 1956	Employment	Disqualified from being or continuing as a member of the committee if suffering from
Nurses and Midwives Act, 1953	Employment	Disqualification for being or continuing as a member of the council if affected by leprosy.
Andhra Pradesh Co-Operative Societies Act, 1964	Employment	Disqualified from being or continuing as a member of the committee if suffering from leprosy.
Uttar Pradesh Co-operative Societies (45th Amendment) Rules, 2006	Employment	Disqualified from being or continuing as a member of the committee if suffering from leprosy.
Telangana Micro Brewery Rules, 2015	Employment	Bar on persons suffering from leprosy to acquire a license if they are to personally handle the stocks leading to denial of employment.
Orissa Professional Typists for Civil and Criminal Courts (Registration) Rules, 1981	Employment	Not eligible to register or continue as a typist if a leprosy patient.
Orissa (Licensing of) Deed Writers' Rules, 1979	Employment	Disqualification from grant of license to a person suffering from leprosy.
Andhra Pradesh Indian Liquor & Foreign Liquor Rules, 1970	Employment	Bar on persons suffering from leprosy to acquire a license if they are to personally handle the stocks and for employment in this business.
Bihar Document Writers Licensing Rules, 1968	Employment	Disqualification from grant of license if affected by leprosy.
Allahabad High Court Rules, 1952	Employment	A person suffering from leprosy is disqualified from enrolment as a pleader or mukhtar.
Delhi Petty Offences (Trial by Special Metropolitan Magistrates) Rules, 1998	Employment	A person suffering from leprosy is disqualified from continuing in the post.
Andhra Pradesh Excise (Grant of Licence of Selling by In-House and Conditions of Licence) Rules, 2005	Employment	Bar on persons suffering from leprosy to acquire a license if they are to personally handle the stocks.
Tamil Nadu Excise Act, 1971	Employment	Provides for non-employment of persons suffering from leprosy.

Pondicherry Excise Rules, 1970	Employment	Discontinuation of the licence if the person is suffering from leprosy and restriction on employing person suffering from leprosy.
Andhra Pradesh Excise (Lease of Right to Sell Liquor in Retail) Rules, 1969	Employment	Prohibition on persons suffering from leprosy to enter auction houses leading to segregation and disqualification from getting a lease to a person suffering from leprosy especially where the person is directly handling liquor.
Andhra Pradesh Excise Act, 1968	Employment	Prohibition on employment of persons suffering from leprosy with the prescription of a punishment for contravention.