# RAJYA SABHA COMMITTEE ON PETITIONS

# HUNDRED AND THIRTY FIRST REPORT ON

# PETITION PRAYING FOR INTREGRATION AND EMPOWERMENT OF LEPROSY AFFECTED PERSONS

(Presented on 24<sup>th</sup> October, 2008)



## RAJYA SABHA SECRETARIAT NEW DELHI

October, 2008

## **CONTENTS**

			PAGES				
1.	CO	MPOSITION OF THE COMMITTEE	i				
2.	IN.	TRODUCTION	ii-iii				
3.	RE	PORT	1-23				
<b>*4.</b>		PENDICES  Petition signed by Shri Ram Naik, former Union Minister of Petroleum and Natural Gas and five others, praying for integration and empowerment of leprosy affected persons.					
	II.	Comments on the petition received from the Ministry of Health & Family Welfare.					
	III	Minutes of the meetings of the Committee					
<sup>k</sup> 5.	AN	ANNEXURES					
	I.	List of Medical Colleges/Government Institutions having facility for Reconstructive Surgery					
	II.	List of ILEP Supported NGO Hospitals having facility for Reconstructive Surgery					
	III	State-wise census of last survey of Leprosy Affected Persons conducted in the country					
	IV.	State-wise Number of New cases detected during last 3 years					
	V.	List of existing Rehabilitation Home for Leprosy affected persons					
	VI	Study Report of the Committee on Petitions					

<sup>\*</sup>To be appended at printing stage

## COMPOSITION OF THE COMMITTEE (2008-09)

1. Shri M. Venkaiah Naidu - Chairman

#### **MEMBERS**

- 2. Shri Vijay J. Darda
- 3. Shri Dhram Pal Sabharwal
- 4. Shri Rama Chandra Khuntia
- 5. Smt. Maya Singh
- 6. Shri Virendra Bhatia
- 7. Shri Shyamal Chakraborty
- 8. Shri N.R. Govindarajar
- 9. Shri Subash Prasad Yadav
- 10. Shri Sabir Ali

#### **SECRETARIAT**

- 1. Shri Tapan Chatterjee, Joint Secretary
- 2. Shri J. Sundriyal, Joint *Director*
- 3. Shri Rakesh Naithani, *Deputy Director*
- 4. Shri Ashok Kumar Sahoo, Assistant Director
- 5. Shri Goutam Kumar, Committee Officer

#### INTRODUCTION

- I, the Chairman of the Committee on Petitions, having been authorised by the Committee to submit the Report on its behalf, do hereby present this Hundred and Thirty-first Report of the Committee on the petition jointly signed by Shri Ram Naik, former Union Minister of Petroleum and Natural Gas and following five persons, relating to integration and empowerment of leprosy affected persons (LAPs) (Appendix-I):-.
  - (i) Dr. P.K. Gopal, President, National Forum of Leprosy Affected Persons and President, IDEA INDIA, Erode, Tamil Nadu;
  - (ii) Smt. Rashmi Shirhatti, Chief Executive, International Leprosy Union(ILU), Pune, Maharashtra;
  - (iii) Shri Uday Thakar, Treasurer, Kusht Rog Nivaran Samiti, Raigad, Maharashtra;
  - (iv) Shri Shantaram Bhoir, President, Maharashtra Kushthapidit Sanghatana, Kalyan, Maharashtra; and
  - (v) Shri Bhimrao Madhale, President, Sanjay Nagar Rahiwashi Sangh, Mumbai

The petition was countersigned by Shri Ved Prakash Goyal, MP (Rajya Sabha).

- 2.0 The petition was submitted to Hon'ble Chairman, Rajya Sabha by the Member who had countersigned and the petitioners on 5 December, 2007 which was admitted by Hon'ble Chairman, Rajya Sabha on 2 May, 2008 under the provisions of Chapter X of the Rules of Procedure and Conduct of Business in the Council of States. As the member who had countersigned the petition had retired from the membership of the Rajya Sabha on 2 April, 2008, the petition was reported to the Council on 6 May, 2008 by Secretary-General in accordance with Rule 145 of the Rules *ibid*, after which it stood referred to the Committee on Petitions for examination and report in terms of Rule 150 *ibid*.
- 2.1 In its sitting held on 10 June, 2008 the Committee heard the petitioners. The Committee undertook study visit to Hyderabad, Tirupathi, Nellore, Chengalpattu and Chennai from 18 to 23 August, 2008 and Mumbai from 16 to 18 September, 2008 to see for itself a few self-settled LAPs colonies, Rehabilitation Homes for LAPs and Leprosy Hospitals and interacted with inmates of those colonies and rehabilitation Homes, the NGOs associated with rehabilitation of LAPs and the representatives of State Governments of Andhra Pradesh, Tamil Nadu & Maharashtra and Central Leprosy Training Research Institute, Chengalpatu, Tamil Nadu. The Committee heard the Secretary,

Ministry of Health & Family Welfare alongwith representatives of Ministries of Law and Justice (Legislative Deptt.) and Social Justice & Empowerment on 26 September, 2008 on the issues raised in the petition as well as feedbacks received by it during its study visits. It considered the draft Report in its sitting held on 21 October, 2008 and adopted the same.

3. For facility of reference and convenience, observations and recommendations of the Committee have been printed in bold letters in the body of the Report.

NEW DELHI
October 21, 2008
Asvina 28, 1930(Saka)

M. VENKAIAH NAIDU Chairman Committee on Petitions

### **Report**

The petition praying for integration and empowerment of Leprosy Affected Persons (LAPs) is jointly signed by the principal petitioner -Shri Ram Naik and five others. All of them have been working for leprosy affected persons for many years.

- 1.1 The petitioners have drawn the attention of the Council of States to the alienation and plight of leprosy affected persons in the country. Even though with the advancement of medical science the country has achieved spectacular success in eradication of leprosy to the extent of 95 percent, but the disease is still treated as a social stigma in the twenty-first century. Because of the social stigma, the LAPs have been residing in self-settled colonies in miserable conditions, far away from the main cities and have been begging for their sustenance. According to the petitioners, there are around 700 self-settled colonies of the LAPs which lack basic amenities like potable water, drainage, toilets, etc. Those who have been fully cured but have physical deformities are still treated as untouchable due to the social stigma. Even their wards staying in the self-settled colonies are denied admission to the educational institutions.
- 1.2 The eleven point prayer made in the petition reads as follows:-
  - (i) Formulation of National policy for empowerment of LAP;
  - (ii) Amendment to all Acts which harm the interests of LAP after taking into confidence NGOs working for LAP;
  - (iii) Public awareness campaign be launched to remove the social stigma attached to LAP and any offence violating it be treated as violation of human rights;
  - (iv) Sustenance allowance for LAP at Rs. 1,000-/-per month per person uniformly in all States;
  - (v) Free medical facilities be provided in LAP colonies;
  - (vi) Free civic amenities like safe drinking water, electricity, toilets and drainage to all self-settled LAP colonies;
  - (vii) Free education to children of LAP from primary school to degree and vocational diploma courses;
  - (viii) permits to operate auto-rickshaw to LAP;
  - (ix) Financial assistance for small-scale traders, poultry, land for cultivation, etc. to make LAP self-sufficient;
  - (x) Reservation for employment may be given to LAP; and
  - (xi) Extension of all benefits available to people below poverty line (BPL) to LAP.

- 1.3 According to the petitioners, the discriminatory provisions in certain Acts stand as barrier to their empowerment. Those Acts were enacted at a point of time, when the leprosy was considered as contagious and incurable. With the advancement of medical science and administration of Multi-Drug Therapy (MDT), the disease has become curable and is also found to be non-contagious but antiquated provisions about leprosy in the Statute Book have not undergone changes. They have also prayed to the Council to amend those Acts to keep pace with the development in the field of medical science, for leprosy. The petitioners have pointed out the following Acts which need amendment:
  - (i) Indian Railways Act, 1989;
  - (ii) Maharashtra State Road Transport Corporation Act, 1980;
  - (iii) Life Insurance Corporation Act, as amended in November 1987;
  - (iv) Hindu Marriage Act, 1955;
  - (v) Special Marriage Act, 1954;
  - (vi) Dissolution of Muslim Marriage Act, 1939;
  - (vii) Indian Christian Marriage Act, 1872;
  - (viii) Indian Divorce Act, 1869;
  - (ix) Prevention of Begging Act, 1959 (Maharashtra, Gujarat and Karnataka);
  - (x) Persons with Disabilities Act, 1995;
  - (xi) Industrial Disputes Act, 1947;
  - (xii) Bombay Municipal Corporation Act, 1888;
  - (xiii) Juvenile Justice and Care and Protection Act 2000;
  - (xiv) Motor Vehicles Act, 1988;
  - (xv) Hindu Adoption and Maintenance Act, 1956; and
  - (xvi) Rehabilitation Council of India Act, 1992
- 1.4 The Ministry of Health and Family Welfare, being the nodal Ministry for the subject-matter of the petition, in their initial comments, have conceded that due to some visible deformity and disfigurement in the body parts of leprosy patients, a social stigma has got attached with them, leading to their isolation from the social mainstream. Efforts are, however, being made to educate the people through mass media advocating that the disease is not contagious and completely curable with MDT. The Ministry have agreed that the LAPs need care, treatment and services through out their life. They have intimated to the Committee that financial assistance for undergoing Deformity Correction

Surgical treatment i.e. Reconstructive Surgery (RCS) and aids like MCR footwear are supplied to the patients.

- 1.5 With regard to amendments to the sixteen Acts, the nodal Ministry informed that those Acts were enacted long back with the then conception of non-curability and contagiousness of the disease of leprosy which needed amendment in the present day scenario. The matter has been taken up with the Ministries/State Govts. concerned.
- The petitioners during their deposition before the Committee submitted that the leprosy affected persons were leading a marginalized life mostly in selfsettled leprosy colonies far away from the villages and cities. A National policy on Rehabilitation of the LAPs was required to clear the social stigma attached with the LAPs which might lead to integration of the LAPs with the society. The people affected by leprosy should be involved in policy formulation as well as implementation of programmes under that policy. They had proposed that a National Summit on Rehabilitation might be conducted to formulate National Rehabilitation Policy for the LAPs. Besides that the short-term goals including removal of legal provisions that perpetuate discrimination, provision of reservation to the LAPs in employment, basic civic facilities like potable water, housing, nutrition, etc. to the LAPs might be undertaken by the Government. Referring to the impugned legislations having discriminatory provisions against the LAPs, one of the co-petitioners submitted that those Acts were enacted in the backdrop of leprosy being considered as non-curable and contagious. The words 'virulent' and 'incurable' still find place in the Statute Book even though the disease is curable with the application of Multi Drug Therapy (MDT). Citing example, he mentioned that virulent leprosy is considered to be a ground of divorce in the Hindu Marriage Act, 1955 and the Special Marriage Act, 1954 which needed amendment keeping in view the changed scenario with the advancement of medical science. The words "Leprosy cured" persons should be substituted by the words 'Leprosy Affected Person' in the Statute Book for the dignity of the LAPs. The monthly pension given to them in the country ranged from Rs.150/- to Rs.1000/- per month which was grossly inadequate to lead a dignified life for the LAP and his/her family. He pleaded that pension @ Rs.2000/-per family might be paid uniformly in all States for the LAPs staying in leprosy colonies as well as leprosy homes. The LAPs have been made to suffer from mental disability in addition to physical deformity due to social prejudice. The criterion of forty percent disability should not be applied in the case of the LAPs in obtaining disability certificate. Majority of the LAPs colonies are on the Govt. land. Ownership of the land might be transferred to them with proper housing facility. Financial support to the tune of Rs.3000/- per year to the children of the LAPs for study upto twelveth standard may be granted. Some seats in engineering and medical and other technical fields might be reserved for them and fees should be at par with that of the backward class students. Even driving licences had been requested for the children of the LAPs living in leprosy colonies.

- 2.0 The word "leprosy" is derived from the Greek words 'lepros' meaning a scaly and 'lepein' to peel. Leprosy is one of the world's oldest disease. The ancient medical treatise of India "Sushruta Samhita" offers therapeutic suggestions as early as 600 B.C. The Sloane-Dorland Annotated Medical-Legal Dictionary (1987) defines Leprosy as under:
  - " Leprosy, which is also known as Hansen's disease, is a mildly infectious degenerative disease caused by the micro-organism Mycobacterium leprae. The disease produces lesions in the skin, the mucous membranes, and the peripheral nervous system. In its more advanced stage, it affects internal organs and renders its sufferers vulnerable to other disease such as diabetes and cancer".
- 2.1 'Mycobacterium leprae' is the causative agent of leprosy which was discovered by G.H. Armauer Hansen in Norway in 1873. Leprosy is a communicable disease which spreads from an untreated infected person to a susceptible person through aerosol droplets from mouth and nose. It is transmitted by air. Even though it is infectious it has a low virulence or pathogencity. From the studies conducted in various population groups it is known that by adulthood at least 60 percent of the population in an endemic area would be infected with the organism 'Mycobacterium Leprae', but only a small proportion (less than one percent) may get the signs and symptoms of the disease. What triggers the transition from infection to disease is not known, even though specific immunological deficiencies are stated to be one of the offending factors. The organism is not transmitted by contact and also there is no evidence to say that it is hereditary. The disease manifests after long incubation period of twenty to thirty years.
- 2.2 Leprosy should be suspected in people with any of the following symptoms or signs:
  - pale or reddish patches on the skin (the most common sign of leprosy)
  - loss, or decrease, of feeling in the skin patch
  - numbness or tingling of the hands or feet
  - weakness of the hands, feet or eyelids
  - painful or tender nerves
  - swelling or lumps in the face or earlobes
  - painless wound or burns on the hands or feet
- 2.3 Leprosy is diagnosed by finding at least one of the following cardinal signs:
  - (i) Definite loss of sensation in a pale (hypopigmented) or reddish skin patch

- (ii) A thickened or enlarged peripheral nerve, with loss of sensation and/or weakness of the muscles supplied by the nerve
- (iii) The presence of acid-fast bacilli in a slit skin smear
- 2.4 Leprosy is completely curable with Multi-Drug Therapy (MDT)<sup>2</sup>. MDT was introduced in India in the year 1983 and National Leprosy Eradication Programme (NLEP) was also launched in the same year with the overall objective of achieving eradication of the disease from the country. It is claimed that first dose of MDT drugs kills 99.9 percent of leprosy bacteria. MDT cures the disease in the six months (pauci-bacillary leprosy) and twelve months (multi-bacillary leprosy). Leprosy is associated with involvement of nerves which results in disability as well as physical deformity but early detection of the disease saves the patient from the disability. But those who start the MDT late, after irreversible loss of nerve functions, are left with deformities and become disabled physically. MDT cures the disease in 6 months (Pauci-bacillary leprosy) and 12 months (Multi-bacillary leprosy).
- 2.5 Following collateral methods of treatment are provided to mainly those leprosy affected persons, who develop complications-
  - Prednisolone (drug) therapy to those who develop leprosy reactions/neuritis.
  - Protective foot wears to those who have sensory loss over the soles.
  - Ulcer care & treatment of wound-surgical and medical.
  - Physiotherapy to prevent worsening of disabilities.
  - Training & counseling of LAP to adopt self care practices.
  - Supportive drugs to treat other general ailments/complications.
  - Reconstructive surgery for correction of disabilities.
- 2.6 Reconstructive surgery (RCS) is required for correction of disability of hands, feets and eyes caused due to the disease. It aims at restoring function and form as far as possible and preventing further disability. It is followed by the post-operative physiotherapy for at less 6 to 8 weeks. It plays an important role in medical rehabilitation process. From the year 2008-09, the Govt. of India has introduced the scheme for providing incentive of Rs.5000/- to the LAPs undergoing RCS for stay in the hospital and to compensate transportation charges alongwith one attendant for 4 to 5 visits to the hospital for post

<sup>&</sup>lt;sup>2</sup> MDT is a combination of two drugs (in PB case) and three drugs (In MB case) viz - Rifampicin, Dapsone and Clofazimin.

operative follow up and physiotherapy. The money is disbursed by the District Leprosy Officer(DLO) in installments at the place of surgery. An amount of Rs.5000/- for each constructive surgery conducted is also given to the identified Govt. institutions to meet expenditure on essential drugs, dressing materials, splints and other ancillary items required for surgery. 20 Medical Colleges/Physical Medicine and Rehabilitation (PMR) Centres and 32 NGOs are having the facility of RCS in the country (Annexures I & II).

2.7 The last survey of the LAPs in the country was conducted in 1981. A population of 685.185 million was covered and 3919337 leprosy cases were reported giving prevalence rate of 57.60 per ten thousand population. The State/UTs-wise information of prevalence rate of leprosy per ten thousand is given as **Annexure-III**. With the application of MDT the recorded cases of leprosy has come down from 57.6 per 10,000 population in 1980-81 to less than 1 case per 10,000 population at national level in December, 2005, which is considered to be the level of elimination by the Government of India which is short of total eradication. The comparative figures of leprosy patients at the launch of NLEP and the end of July, 2008 is given below in the table:

	Year 1983-84	As on 31 July,08
Registered cases	3200000	95272
Prevalence rate per 10,000 population	44.7	0.81
New case detected	482000	51209
Annual new Case Detection Rate per 10,000 population	6.7	1.7 (2007-08)

From the figures in the table it appears that new cases are being 2.8 reported. The Ministry of Health & Family Welfare has informed that the annual new case detection rate has been reduced from 4,82,000 (6.7/10,000 population) in 1983-84 to 1,37,685 (1.7/10,000 population) in the year 2007-08. By the end of March, 2008, 0.87 lakh cases were on record and during the year 2006-07 a total of 1.38 lakh new cases were detected out of which 2.5% were having visible deformity. Six States/UTs- (Bihar, Jharkhand, Chattisgarh, West Bengal, Chandigarh & Dadra Nagar Haveli) with 20.8% country's population contributed to 33% of recorded case load and 35% country's new case detection during 2007-08. Those States/UTs are far behind the set elimination target of 1 cases per 10,000 population. Out of 614 Districts, 132 Districts are yet to achieve the elimination level of leprosy. To a query of new cases detected during the last three years, the Ministry has submitted the State/UTs figures of new detected cases which indicates a total number of 1,61457; 1,39,352 and 1,37,685 new cases reported during the years 2005-06, 2006-07 and 2007-08, respectively. State/UTs wise figure are given at Annexure-IV.

2.9 The NLEP is a purely domestic funded programme since 2005. The budgetary provision for NLEP during XI Five Year Plan (2007-2012) is 216.92 crores. The year wise budgetary allocation is given below in the table:

				(	Rupees in crores)
	Total Budget				
2007-08	2008-09	2009-10	2010-11	2011-12	
39.98	46.84	44.46	43.32	42.32	216.92

- 2.10 An International NGO, namely, Federation Anti-Leprosy Association (ILEP) provides technical support to the programme at the State level. The World Health Organisation(WHO) provides MDT drugs free of cost.
- 2.11 The Committee was apprised that there are about 700 self-settled colonies, where more than 70,000 LAPs reside. The breakup of colonies are given below in the table:

Name of the State	Number of colonies
Andhra Pradesh	70
Bihar	57
Chattisgarh	33
Delhi	22
Gujrat	17
Haryana	21
Himachal Pradesh	1
Jharkhand	48
Jammu Kashmir	1
Karnataka	14
Kerala	4
Maharashtra	38
Madhya Pradesh	25
Orissa	57
Punjab	29
Rajasthan	14
Tamilnadu	38
Uttar Pradesh	61
Uttrakhand	26
West Bengal	30
Other States	113
Total	700

They have also submitted State-wise breakup of 63 rehabilitation homes for leprosy affected persons which is given at **Annexure-V**.

- 3. The Committee undertook study visits to Hyderbad, Nellore, Tirupati, Chennai, Chengalpattu and Mumbai to see for itself a few self-settled colonies and rehabilitation homes and hospitals and interacted with the LAPs in those colonies/homes/hospitals and NGOs associated with rehabilitation of the LAPs and representatives of State Govts. including State/District Leprosy Officers. The following issues have been flagged by the Committee during the visits (see Study Report at **Annexure-VI**):-
  - (i) Enhancement of monthly sustenance allowance to Rs.2000/to help the LAPs to lead honorable life and not to depend upon begging for livelihood;
  - (ii) Issue of disability certificate to the LAPs by waiving off disability criterion fixed by the Govt. in view of social stigma attached to the disease in addition to physical deformity;
  - (iii) Free Rail and Bus passes to the LAPs;
  - (iv) Resumption of fresh survey of leprosy cases;
  - (v) Two pair MCR footwears to the LAPs in a year in the place of one pair as at present;
  - (vi) Increase of sustenance allowance from Rs. 5000/- to Rs.10,000/- for the LAPs as incentive for undergoing RCS;
  - (vii) Extension of facilities given to the Below Poverty Line (BPL) families to the families of the LAPs;
  - (viii) Antodaya card to the families of the LAPs staying in selfsettled colonies;
  - (ix) Issuance of caste certificate to the LAPs belonging to SC/ST;
  - (x) Transfer of ownership of land on which the LAPs have constructed their colonies;
  - (xi) Financial assistance/Bank loans for poultry, cultivation and small scale trading for self-employment of the LAPs and their families;
  - (xii) Reservation of seats in higher education for the wards of LAPs staying in self-settled colonies/rehabilitation homes and scholarship to their wards;
  - (xiii) Proper sanitation, drainage, potable water in self-settled colonies of the LAPs;

- (xiv) Provision of old age home/Anganwadi Centre in the self-settled colonies of the LAPs;
- (xv) Mandatory visit of doctors and para-medical staff to the leprosy colonies for treatment of general ailments in addition to leprosy;
- (xvi) subsidised electricity to the families of the LAPs in self-settled colonies;
- (xvii) Driving license to the LAPs who are fully cured and have ability and fitness to drive;
- (xviii) Generation of awareness of the disease in the society to dispel disbeliefs with a view to removal of social stigma; and
- (xix) Exemption of Value Added Tax (VAT) on the small items produced by the LAPs.
- 4. The Committee heard the Secretary, Ministry of Health & Family Welfare and representatives of Ministries of Law & Justice (Legislative Deptt.) and Social Justice and Empowerment. The responses of the concerned Ministries as to the amendment of the impugned Acts having discriminating provisions, were made available to the Committee.

## **Fresh Survey of LAPs**

- 5.0 The last survey of the LAPs in the country was conducted in the year 1981 in accordance of which 3919337 cases were reported having the prevalence rate of 57.6 per 10,000 population. As per information made available to the Committee, the incidence of leprosy has drastically declined to the level of elimination (one case per 10,000 population) but fresh cases are also reported in allmost all States. As per figures submitted to the Committee, a total of 4,38,394 new cases have been reported during the last three years. The Ministry has clarified that new cases will continue for sometime which will gradually get reduced over the years because of long incubation period of the disease. It may take another twenty five to thirty years before Government could declare complete eradication of leprosy.
- 5.1 The Committee understands that the survey of leprosy has been stopped with the integration of MDT with general health services which is available free of cost in all Public Health Centres. The age old social stigma associated with the disease poses major obstacle to self reporting and early treatment and thus persons in the initial stage of leprosy might not be coming to the PHC for treatment voluntarily. Since the number of fresh cases is increasing, the early detection of the disease is needed to check the physical deformities. Further, the Government should have official updates figures of the LAPs in the

country to formulate any policy for their rehabilitation which calls for a fresh survey by the Government. The Committee is of the view that the Panchayati Raj Institutions (PRIs) may be of great help in this venture. The Ministry in their latest written submissions have mentioned that they are considering to conduct one time multi-centric study to estimate the burden of leprosy cases i.e. active cases and leprosy cured persons with different grades of disabilities. This would help them in planning and strengthening of services to the LAPs. The Ministry agreed to involve the PRIs for such survey to gather authentic data/ information. The Committee appreciates the decision of the Ministry and urges upon it to start the survey without further loss of time.

## <u>Formulation of National Policy for Empowerment of Leprosy Affected</u> <u>Persons</u>

- 6.0 As to formulation of National Policy for empowerment of leprosy affected persons, the Ministry of Health & Family Welfare has replied that they have integrated the National Leprosy Eradication Programme with the general health care services to bring persons affected with leprosy in the mainstream of healthcare delivery system in the country since 2001-02. Under this programme person affected with leprosy can avail services from any of the health institution, like patient of any other diseases. Guidelines on reduction of stigma and discrimination have been formulated and disseminated to States/UTs for implementation. For socio economic rehabilitation, the Ministry of Health and Family Welfare is in the process of consultation with the Ministry of Social Justice and Empowerment in respect of provisioning other social welfare benefits to persons affected with leprosy.
- The Committee notes the measures taken by the Ministry of 6.1 Health & Family Welfare for Disability Prevention and Medical Although leprosy is on retreat, the stigma Rehabilitation (DPMR). attached to it still persists in human psyche. Utter discrimination and isolation has pushed the LAPs into the shackles of poverty. There is also need for socio-economic rehabilitation of LAPs in the post leprosy elimination era. The socio-economic empowerment of the LAPs and their families would help them to lead honorable life and discard the demeaning and dehumanising profession of begging. The Committee notes with concern that the issue of empowerment of LAPs is tossed between the Ministries of Social Justice & Empowerment and Health & Family Welfare. There is in fact greater need for a well defined policy for these unfortunate lot of people who are alienated from the mainstream of society. The Committee therefore strongly recommends that the final survey, involving Panchayati Raj institutions may be undertaken so that the Government can have realistic figures to devise a national leprosy policy. The Government should also involve the leprosy affected persons in the formulation of the National policy.

## **Amendments to antiquated Legislations**

- 7.0 In accordance with Section 2 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, the term "Disability" *inter-alia* includes the terms "*Leprosy-cured*". The petitioners have held the view that if leprosy cured person is treated as disabled under the aforesaid Act, there is no reason as to why the person who is suffering from leprosy should not be considered as disabled. Accordingly, they have proposed that in Section 2 (iii), the words "*leprosy cured*" should be replaced by the words "*leprosy whether cured or not*".
- 7.1 Physical deformity or paralysis caused by leprosy, attaches stigma to the person concerned and subjects him to all sorts of discrimination and he losses many a opportunity that may be available to the normal person as well as to the person suffering from other diseases including the diseases that are contagious and infectious. Opportunities to engage in normal economic activities may be taken away from him/her if his/her past or present leprosy affliction gets manifested by physical deformity or paralysis caused by leprosy. Therefore the petitioners have proposed that the expressions "leprosy cured" should be replaced by "leprosy affected person" in Section 2(n) of the Act.
- 7.2 Section 2(t) of the Act *ibid* defines the person with disability" as a person suffering from not less than forty per cent of any disability as certified by a medical authority. But deep-rooted prejudices against leprosy in the society makes the leprosy-affected person, disabled even if he is cured. There is every possibility that opportunities of getting education or employment may be denied to him on account of leprosy. There is no question of how much disability he suffers on account leprosy; he may be having slight or even no medical disability but social prejudices make him disabled. Therefore the condition of forty percent disability should not be made applicable in case of leprosy affected person.
- 7.3 In accordance with Section 2 (C) of the Rehabilitation Council of India Act, 1992 the term "Handicapped" means a person who is-
  - (i) visually handicapped;
  - (ii) hearing handicapped;
  - (iii) suffering from locomotor disability; or
  - (iv) suffering from mental retardation.

Leprosy leaves its mark on the person in many ways and makes him disabled. Loss of sensation in hands or feet as well as loss of sensation and paralysis in the eye and eye-lid are very common manifest effects on the person who gets afflicted with leprosy. Coping with this disability and carrying out every day activities needs training and coaching. It is, therefore, proposed that this disability also should get specifically reflected in law. Therefore it is proposed that the Act should be suitably amended for this purpose.

- 7.4 The representative from the Ministry of Justice & Empowerment clarified before the Committee that the Ministry recognizes only disability which may be due to any disease. The definition, therefore, does not include name of any disease including leprosy. The Ministry is however in the process of making certain changes in the existing Acts.
- 7.5 Section 56 of Indian Railways Act, 1989 gives power to railway authorities to refuse to carry persons suffering from infectious or contagious disease. In accordance of the provision of the sub-Section(1) of Section 56 of the Act ibid, a person suffering form such infectious or contagious diseases, as may be prescribed, shall not enter or remain in any carriage on a railway or travel in a train without the permission of a railway servant authorized in this behalf. The railways servant giving permission under sub-section(1), shall arrange for the separation of the person suffering from such disease form other persons in the train and such person shall be carried in the train subject to such other conditions as may be prescribed. Any person who enters or remains in any carriage or travels in a train without permission as required under sub-section (1), in contravention of any condition prescribed under sub-section(2), such person and person accompanying him shall be liable to the forfeiture of their passes or tickets and removal from railway by any railway servant. It is possible that person afflicted or alleged to be afflicted by contagious disease may contend that his/her fundamental right to equality, right to move freely throughout the territory of India and right to life guaranteed, respectively under Articles 14, 19 (d) and 21 of the Constitution get affected. Amendment is therefore required in the Act to make it clear that leprosy per se should not be treated as contagious disease. The Ministry of Railways has clarified that no change may be required as leprosy is not reflected in the Act.
- 7.6 Section 48(2) of the Juvenile Justice (Care and Protection of Children) Act, 2000 mentions that where a juvenile or child is found to be suffering from leprosy, sexually transmitted disease, Hepatitis B, Tuberculosis and such other diseases or is of unsound mind, he shall be dealt with separately through various specialised referral services or under the relevant laws as such. The petitioners have submitted that it is well established now that leprosy is curable and its infectious state could be eliminated in a very short time. The disease may however need prolonged treatment. It may not be therefore be necessary to send the child for treatment to other place or to segregate the child in Children's Home itself. The stigma attached to leprosy is however so deep

seated that if the child suffering from it or who has suffered from it, is given discriminatory treatment, it may leave an inedible scar on his/her personality. The relevant provision of law therefore needs to be amended so that the juvenile/child is not subjected to segregation or discrimination.

- 7.7 The Ministry of Health & Family Welfare in their written submission mentioned that leprosy is classified in the Act as a disease that is communicable and inherently risky. Since leprosy is non-contagious and fully curable with MDT, the Act should be revised accordingly.
- 7.8 Section 27 (1) of the Special Marriage Act, 1954 states that subject to the provisions of this Act and to the rules made thereunder, a petition for divorce may be presented to the District Court either by the husband or the wife on the ground that the respondent has been suffering from leprosy, the disease not having been contracted from the petitioner.

The petitioners have submitted that the provision is discriminatory and is violative of marital right of an individual.

- 7.9 Section 13 of the Hindu Marriage Act, 1955, contains the words 'virulent and incurable form of leprosy' as one of the grounds of divorce, which needs suitable amendment.
- 7.10 Section 10(1) of the Indian Divorce Act, 1869 states that any marriage solemnized, whether before or after the commencement of the Indian Divorce (Amendment) Act, 2001, may, on a petition presented to the District Court either by the husband or the wife, be dissolved on the ground that the respondent has, for a period of not less than two years immediately preceding the presentation of the petition, been suffering from a virulent and incurable form of leprosy. The petitioners have submitted that 'leprosy' as a ground for divorce and separation should be deleted.
- 7.11 Section 2 of the Dissolution of Muslim Marriages Act, 1939 states that a woman married under Muslim Law shall be entitled to obtain a decree for the dissolution of her marriage, if her husband has been insane for a period of two years or is *suffering from leprosy* or a virulent venereal disease. This provision classified leprosy as incurable disease which is contrary to the fact. Thus the Act needs amendment.
- 7.12 Section 18 (c) of the Hindu Adoption and Maintenance Act, 1956 states that a Hindu wife shall be entitled to live separately from her husband without forfeiting her claim to maintenance, if he is suffering from a virulent from of leprosy. As no form of leprosy is virulent at present, it would be incorrect for the wife to claim maintenance on that ground.

- 7.13 It is now well established that leprosy is no longer an incurable disease. Not only that, with new therapies like multi drug therapy, duration of infectious stage of the disease can be drastically curtailed. Most important aspect is that leprosy is no longer virulent; no doubt it leaves its mark in the form of deformity. Surgical procedures in many cases can made good the damage to very large extent. In view of this, the petitioners have suggested that leprosy as a ground for divorce and separation in the marriage laws mentioned above, should be deleted.
- 7.14 The Legislative Deptt. (M/o Law & Justice) which is the nodal Department for administration of personal laws, have informed that action has already been initiated by them to modify these Acts. However all these subjects are in the Concurrent List, which need consultations with the State Governments. The Department has already invited comments of all the State Governments/UT administrations in the matter. So far, the Department has received comments of three State Governments and two UTs. The process may take some more time till the amendment Bills are brought before Parliament.
- 7.15 Section 8(4) of the Motor Vehicles Act 1988 states that if the applicant is suffering from any disease or disability which is likely to cause the driving by him of a motor vehicle of the class which he would be authorised by the learner's licence applied for to drive, to be a source of danger to the public or to the passengers, the licensing authority shall refuse to issue the learner's licence. Getting licence to drive the motor vehicle provides an LAP and his family bread and butter. It is necessary therefore to provide legal safeguard to such a person. The petitioners have proposed that the person suffering form leprosy or who has suffered from leprosy and is not in the infectious stage, shall not be considered as source of danger to the public or disable to drive the vehicle only on the ground of his past or present affliction of the leprosy. The Ministry of Road Transport and Highways have clarified that no change in the law may be required since leprosy is not specified in the Act.
- 7.16 Section 11 of the Industrial Disputes Act, 1947 *inter-alia* provides termination of service of workman on the ground of continued ill-health. The petitioners apprehend that the person who is suffering from leprosy or the one who has in the past suffered from leprosy, attract social stigma and the employers may try to get rid of him by resorting to the above mentioned legal provision of the Act. It is therefore necessary to provide safeguard in the law for protection of the leprosy affected person.
- 7.17 Section 12 of the Life Insurance Corporation Act, 1956 provides for charging of very high premium rates to the patients suffering from leprosy. There is no scientific reason for assuming higher risk to life for a person suffering from leprosy. In view of this the LIC should be asked to amend its rules or to change its policy as it unnecessarily penalizes leprosy patients and

perpetuates unscientific fear and stigma regarding leprosy. The Ministry of Finance has clarified that the primary reason for extra premium charges on LIC of the leprosy affected persons, is shortened life expectancy.

- 7.18 Section 421 of the Bombay Municipal Corporation Act, 1888 requires information to be given of existence of dangerous disease or continuous pyrexia of unknown origin to the Health Officer by the medical practitioner for prevention of spread of the disease. This provision is resorted to in respect of the person affected by leprosy whether he is cured or not. The person affected by leprosy may be removed to premises reserved for him. However, the fact remains that leprosy is no more a dangerous disease. On the other hand, leprosy is now curable and its infectious stage can be curtailed to a very short period with the help of modern drugs. It therefore, needs to be specified in the Act itself that this provision should not be made applicable for leprosy.
- 7.19 Section 8(3) of the Bombay Prevention of Begging Act, 1959 permits the court to order detention of persons wholly dependent on begging. In accordance with the provisions of the Act the child may be ordered to be detained in a certified institution until it attains the age of five years. It is inhuman to remove the child from the mother or its guardian unless it is in the best interests of the child. There is also no reason as to why a child who is under the age of five years, should be removed form the mother suffering form leprosy. The whole section therefore should be deleted.
- 7.20 Section 9(4) of the Act provides for issue of orders for the detention of incurably helpless beggars. It is violative of Article 21 of the Constitution to detain any person indefinitely for begging. Detaining a person idefinitely because he is incurably helpless is also violation of human rights. It is therefore appropriate that the provision regarding indefinite detention be deleted.
- 7.21 The Maharashtra State Road Transport Corporation Act, 1980 provides concession to the extent of 75% to non-infectious leprosy persons. The Committee was informed during its visit to Mumbai that the concession is not available in the buses run by BEST. The Ministry of Road transport and Highways on 19 August, 2008 have written to Vice- Chairman, MSRTC, Mumbai to extend the concession to all LAPs.
- 7.22 Once more State specific law has had a far reaching implication. The Committee learnt that Section 16 of the Orissa Municipal Act of 1950 bars people suffering from tuberculosis and leprosy from holding civic posts. The Supreme Court in a recent ruling in the case of *Dhirendra Pandua vs State of Orissa & others (2008)* has upheld judgments of an Election Tribunal and the Orissa High Court sending that leprosy patients cannot contest civic election or hold a municipal office in the State of Orissa. The two judge bench of the

Supreme Court has reportedly upheld the disqualification of a councillor on the ground that his debarment under the said Act was not discriminatory and violative of Article 14. At the same time the Court has observed that having regard to the change in concept and knowledge gained about the disease of leprosy, on the recommendation of the Working Group on Eradication of Leprosy, appointed by the Government of India, many State Governments and Union Territories have repealed the antiquated Lepers Act, 1898 and subsequent similar State Acts, providing for the segregation and medical treatment of pauper lepers suffering from infectious type of disease. In that context, the Supreme Court has observed that keeping in view the present thinking and researches carried on leprosy as also on tuberculosis, and with professional input, the Legislature may seriously consider whether it is still necessary to retain such provisions in the statutes.

7.23 Notwithstanding the status of the Acts as informed by the nodal Ministry and the concerned administrative Ministries, the Committee observes that the discriminatory provisions in the statutes have hampered the empowerment of this marginalized section of the society. It is high time that those Acts be amended to ensure integration of LAPs in the mainstream. The Committee hopes that the concerned Ministries and State Governments would urgently consider amendments to such anachronistic and discriminatory provisions in the concerned legislations.

## **Waiver of Disability Criteria for the LAPs**

The criteria for issuing disability certificate for purpose of getting Government job is governed by the Persons with Disabilities (Equal Opportunities, Protection of Right and Full Participants) Act, 1995 in accordance with which a person with disability means a person suffering from not less than 40 percent of any disability, as certified by the medical authority. The same criterion is made applicable for issuing disability certificate to the LAPs. To a query of the Committee, the Ministry of Health & Family Welfare clarified that they do not have record of number of LAPs having been issued disability certificates for the purpose of Government job. During the study visits, majority of LAPs appealed to the Committee for issuance of disability certificate irrespective of their degree of disability which would help them get Government job. Disability due to leprosy carries with it social disgrace for the LAPs as a result of which they suffer both physically and psychologically. The loss of sensation due the leprosy does not get reversed even after RCS. The Committee therefore strongly recommends that disability of LAPs should be treated on a separate footing and they should be given disability certificate irrespective of the degree of disability, which would offer them gainful opportunities to lead a dignified life.

## Public Awareness Campaign

- 9.0 To the guery about the steps taken to dispel the misconception amongst the general masses about leprosy, the Ministry of Health & Family Welfare replied that as per the independent evaluation of Information Education and Communication (IEC) under National Leprosy Eradication Programme (NLEP) by Centre for Media Study(CMS)-an independent agency, the majority of the population were aware of at least one symptom of leprosy, curability of the disease, treatment duration and availability of free treatment. It was found by the CMS that awareness level of general public regarding leprosy has improved during last decade. Folk media, Inter Personal Communication (IPC), mass media and outdoor media are being used to communicate the key message across the country. IEC in the leprosy program seeks to bring behavioural change by overcoming the barriers which include inequitable access to services and the stigma associated with leprosy. IEC under NLEP is decentralized to the States/UTs who make their own plan and implement the same. Central Leprosy Division of the Union Minister of Health and Family Welfare is providing broad quidelines with allocated budget to the States/UTs, who have the flexibility to earmark funds to districts as per local priority areas and target groups. An campaign towards achieving "Leprosy free India" has been started from the 30th January, 2008 which has the following key message:
  - Leprosy is caused by a germ. It is neither hereditary nor a curse
  - Leprosy can be easily diagnosed from clinical signs alone. A pale or reddish skin patch that lacks sensation is a tell-tale sign of the disease
  - MDT kills germs and stops the spread of leprosy after the first dose.
     Patients on treatment do not spread leprosy
  - MDT is available free of charge at the health facilities
  - Leprosy can be completely cured
  - Early and regular treatment prevents deformities. Patients can lead completely normal lives during and after their treatment
- 9.1 The Ministry has also furnished the year wise budgetary allocation for Information Education and Communication (IEC) during the XI Plan Period (2007-08 to 2011-12) which are produced below in the table:

## (Rupees in cores)

Medium		Year				Total	
		2007-08	2008-09	2009-10	2010-11	2011-12	
Mass (TV, Press)	Media Radio,	2.00	2.00	2.00	2.00	2.00	10.00

Outdoor Media	2.03	2.03	2.03	2.03	2.03	10.15
Rural Media	1.80	1.80	1.80	1.80	1.80	9.00
Advocacy Meetings	0.40	0.40	0.40	0.40	0.40	2.00
Total	6.23	6.23	6.23	6.23	6.23	31.15

Besides, under the National Rural Health Mission (NRHM), the Village Health & Sanitation Committee utilizes the funds in organizing health melas, health programme etc.

- 9.2 The Government of Andhra Pradesh has enumerated the following IEC activities for removal of social stigma associated with leprosy:
  - (i) Wall writing
  - (ii) Quiz Competitions & Essay writing
  - (iii) Folk Songs
  - (iv) Public announcement
  - (v) Sensitization of local leaders and group discussions in the community
- 9.3 The Committee observes that as per common belief leprosy is an incurable disease and there are lot of misconceptions about it in the public psyche due to which the people affected by leprosy are discriminated, segregated and isolated from the community and forced to live in groups at distant places. The Committee recommends that the Ministry of Health and Family Welfare in coordination with Ministry of Information and Broadcasting and Publicity Departments of the State Governments, should launch a nation wide campaign advocating the curability of leprosy and the humanitarian aspect of leprosy affected persons, so that people appreciate their problems and come forward with a helping hand, to their cause. The Committee feels that the Films Division of I & B could prepare documentaries for dissemination of positive messages across the masses. The Committee is optimistic that such a campaign would help in reducing the age old fallacies attached with the disease and the persons affected by it.

## **Uniform Sustenance Allowance for LAPs**

10.0 During its field visits, the Committee found that LAPs and their families have no source of income and they are treated more as a burden on our society. They are deprived of employment opportunities and have no way of surviving except begging. Though some States have the provision of monthly pension for LAPs but the amount varies from State to States which is a pittance. The petitioners have requested for a monthly sustenance allowance of Rs.2000/- to the LAPs uniformly in all State. On the issue of uniform sustenance allowance to

persons affected with leprosy living in leprosy colonies, the Ministry of Social Justice and Empowerment has responded as follows:-

- (i) "In pursuance of Section 68 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, some States/UTs are giving unemployment allowance to persons with disabilities. However, their rates and other parameters vary considerably. In addition to unemployment allowance, some States are giving disability pension also.
- (ii) 'National Policy on Persons with Disabilities', under the heading 'Social Protection' (Para 52) provides that for providing adequate social security to the persons with disabilities. State Governments and UT Administrations will be encouraged to rationalize the amount of pension and unemployment allowance. Accordingly, the States/UTs are requested from time to time to do so. The States/UTs are now being requested in this regard in the conference of the State Secretaries to be held in October, 2008".
- 10.1 The Committee strongly recommends that LAPs who are not able to earn their livelihood, should be given allowance @Rs. 2000/- per month, uniformly in all States for maintenance. Since the number of LAPs is limited, the Committee feels that this sum would not be a burden on the national exchequer. The maintenance allowance could be shared on 50:50 basis between the Central Government and the States.

### **MCR Footwear**

11. The LAPs in the States of Tamil Nadu and Andhra Pradesh have asked for two pairs of footwear in place of one pair as at present. The Committee has been informed that MCR sheets and chappals are being prepared at Schefellin Leprosy Research and Training Institute, Karigiri (Vellore, Tamil Nadu); Central Leprosy Training Research Institute (CLTRI); Chengalpatu(Tamil Nadu); (which the Committee visited); the Leprosy Mission Hospitals in Purulia (West Bengal) and Vijaynagaram (Andhra Pradesh). There are 20 NGOs which have the facility of making MCR footwear. The estimated expenditure in preparing on pair of MCR chappal is approximately Rs. 250/- and the average time taken by the institution to supply MCR chappals is one month. The Govt. of India provide funds for procurement of 35,000 to 40,000 MCR chappals to the States. The Committee desires that Government may consider enhancing the budget so that the genuine demand of LAPs for two pairs of MCR chappal could be met.

## **Exemption of VAT on the Items Produced by the LAPs**

12.0 During the visit of the Committee to Mumbai, the LAPs engaged in the production of durries, bags, etc. pointed out that imposition of VAT on their

products has increased the price of those items and it has become very difficult for them to sell their products in the competitive market. They prayed to the Committee that their products should be exempted from the VAT to enable them to sell the same in the open market.

12.1 The Committee recommends that the products being directly produced by LAPs, be exempted from levy of VAT which would greatly help them to earn livelihood and ensure their economic empowerment.

## **Free Medical Facilities in LAP Colonies**

- 13.0 During its field visits, the Committee found that medical facilities in the self settled LAP colonies are not adequate. The LAPs do not get medical assistance through general hospitals and primary health centres. The medical and nursing authorities at some places remain indifferent to their medical needs. Due to deformities of hands and feet and loss of sensation, a leprosy affected person become physically very weak and his normal resistance to various infections/diseases becomes very low. Hence free medical facility for all kinds of treatment and tests should be the mandatory responsibility of the State.
- 13.1 The Committee wishes to state that it is the duty of the Nation in general and the medical fraternity in particular, to take care of this helpless section of the society. It recommends that primary health centres be designated as nodal agencies to take care of the medical needs of LAPs. Under such arrangements the Medical Officer of the nearby primary heath centre or Government hospital must visit the LAPs colony at least once a week to attend to medical requirements of LAPs. It is equally important that medicines are supplied by Central and State authorities for treatment of LAPs. Instead of depending only on international agencies and missionary services, the Govt. should arrange free medicine to LAPs through its designated medical stores.

### **Civic Amenities in Self settled Colonies**

- 14.0 The Committee was given to understand that while civic amenities like drinking water, electricity, toilets and drainage have been provided in Government rehabilitation homes free of charge, the LAPs are required to pay the electricity bills in self-settled colonies.
- 14.1 The Committee would like the Central Government to advise State Governments and local authorities to provide civic amenities in all self-settled colonies free of charge. The Committee recommends that where no colonies have been identified, the LAPs should be given housing sites under the Indira Awas Yozana and electricity provided under the 'Rajiv Gandhi Grameen Vidyutikaran Yojana'.

### Free Education to the Children of LAPs

- 15.0 Education to dependents of LAPs is not being attended to properly. Such children are required to travel long distances to attend schools and that too under the burden of social stigma. The Committee notes that Sarva Shiksha Abhiyan has adopted a zero reduction policy i.e. no child having special need should be deprived of the right to education. The Committee presumes that the objectives of SSA are being implemented in letter and spirit. The Committee was however disappointed to note that the facilities for higher education to the children of LAPs are almost non-existent.
- 15.1 The Committee recommends that Government should ensure education upto higher secondary level, free of charge, for the dependent children of LAPs. It would like the Government to arrange vocational and degree courses to the dependent children of LAPs for their self-sustenance in future. The Committee would urge upon the Ministry of Human Resource Development to take up the matter with the State Governments and impress upon them to attend to the educational needs of the children of LAPs with the kind of compassion and urgency they desrve.

## **Permit to Operate Auto Rikshaw**

- 16.0 Given the fact that employment opportunities are negligible for LAPs and their dependents it is important that they are assisted, to the extent possible, for some gainful employment including the operation of auto-rickshaw. It was noted that LAPs face lot of difficulties in getting permit for auto rickshaw.
- 16.1 The Committee recommends that LAPs who are eligible for driving license, should be provided liberal loans through banks on a reasonable and affordable rate of interest under DRI Scheme for purchasing auto rickshaws. All possible assistance should be rendered to provide permits for operating their vehicles without any hindrance. This would enable LAPs access to affordable means of sustenance.

#### **Financial Assistance for Small Scale means of Sustenance**

- 17.0 The Committee notes that even if some of the leprosy affected persons are able to do work, they are unable to get employment because of the social discrimination and dishonour. Economic independence would enable LAPs to integrate into the community. Formulation of grants-in- aid programme exclusively dedicated to the needs of the LAPs and their family, is the need of the hour.
- 17.1 The Committee would like the Ministry of Finance to advise banks for granting loans under affordable rate of interest to LAPs engaged in

employment generation programmes such as dairying, poultry, sheepgoat breeding, weaving, etc. The Government may even consider granting financial assistance to those LAPs capable of cultivating land where Government land is available.

## Free Pass facility to LAPs by Railways

18. The petitioners have prayed for free railways passes to the leprosy affected persons. The Committee understands that the Ministry of Health & Family Welfare had taken up the matter with the Ministry of Railways. In response the Railway Board, have intimated that they are already issuing free Railway Pass in favour of large number of categories like Arjun, Dronacharya and Gallantry Awardees, etc. Due to financial & other considerations, it has not been found feasible to extend the scope of extant schemes to include other categories of persons/awardees, Non-infectious Leprosy patients are already being extended facility of 75% concession in Ist, IInd/Sleeper Class train fare by Railways. The Committee has noted the reply of the Ministry.

## **General**

The Committee has been given to understand that individuals with 19. Hansen's disease have been known as lepers. However, this term is falling into disuse due to the pejorative connotations of the term. Mahatma Gandhi once said that the word "leper" is a word with bad odour<sup>3</sup> and should not be used. In 1948 International Leprosy Congress held at Havana recommended for not using the word "leper". In no other disease, the person is called by name of the disease of which he is suffering. Even the 'disabled' are now called 'people with disability' or 'differently abled people'. The blind and deaf are called in a dignified way as "visually handicapped" and "hearing impaired people", respectively. Instead of addressing persons as "AIDS patients", many publications now talk about "people with AIDS". The word 'leper' has become almost synonymous with 'outcast'. Using the words like "leper" or "ex-leprosy patient" perpetuates the humiliation and discrimination. There was a strong feeling that, if someone who has (had) leprosy is always being labelled as a "leprosy patient", "ex-patient" or even just as a "patient", it will have negative consequences for that person. Given the social stigma against leprosy, this label wrongly gives the impression that an affected person will always remain a patient and, thus, is never really cured. From a rehabilitation point of view it would be desirable to change terminologies used in the field. The attitude conveyed by the behaviour of the health workers towards patients is also very important in this context. The term most widely used amongst people and agencies working in the field of Hansen's disease is

<sup>&</sup>lt;sup>3</sup> Mehendale, M.S.-"Gandhi looks at Leprosy"(1971) Bharatiya Vidya Bhavan, (Bombay) p.31

"leprosy affected persons" which is a dignified expression. Therefore, the word "leper" and its equivalents derivatives in regional languages should not be used in the official record. The Committee therefore strongly endorses the usage of positive terminology for the leprosy affected persons.

20. The Committee urges upon the Government to take up the plan of action suggested by it through its recommendations, seriously and implement the same in coordination with the concerned Ministries of the Central Government, State Governments, PRIs, NGOs and the leprosy affected persons in a time bound manner. The Committee feels that governmental efforts alone are not going to address the cause of the people affected by leprosy; it is the mindset of the society that would make the difference. All of us need to appreciate that these unfortunate brethren, need special care, attention and service from the society. They should not be treated as social outcasts. It is, therefore, the duty of each one of us to render all possible help and care to those people keeping in mind our Indian ethos "Manav Seva is Madhav Seva". The members of the Committee considered it a privilege to address the issues concerning the people affected by leprosy. The Committee appreciates the initiative of the petitioners in bringing those issues to Parliament through this petition. The Committee would take this opportunity to appeal all sections of the society to do a little bit, in the service of persons affected with leprosy so that they would be integrated into of the mainstream. The Committee would also urge upon the media to highlight the issues concerning persons affected with leprosy and give due coverage to the advocacy programmes of both Government & non-Government organizations.