

**GOVERNMENT OF INDIA
DEPARTMENT OF EMPOWERMENT OF PERSONS WITH DISABILITIES (Divyangjan)
MINISTRY OF SOCIAL JUSTICE & EMPOWERMENT**

LOK SABHA

**UNSTARRED QUESTION NO. 4175
TO BE ANSWERED ON 28.03.2017**

Leprosy Patients

4175. SHRI B. SRIRAMULU

Will the Minister of SOCIAL JUSTICE AND EMPOWERMENT be pleased to state:

- (a) the total number of leprosy patients in the country, State-wise;
- (b) whether the leprosy patients feel disenchanting due to negligence by the society;
- (c) if so, the details thereof and the steps taken/being taken by the Government to examine the complexities that arise with regard to their jobs, housing, healthcare etc.;
- (d) whether any special scheme/ programme has been initiated/is being initiated by the Government for cure, rehabilitation and welfare of such patients and to bring them into the mainstream of the society and if so, the details thereof; and
- (e) the various schemes/programmes under implementation for leprosy patients in the country, including Karnataka State, scheme-wise ?

ANSWER

MINISTER OF STATE FOR SOCIAL JUSTICE AND EMPOWERMENT

(SHRI KRISHANPAL GURJAR)

- a) The State-wise details of number of persons affected by leprosy in the country is at **Annexure-A**.
- (b) & (c) Ministry of Health and Family Welfare has informed that earlier, when there was lack of awareness about the nature of leprosy and stigma was associated with the disease, patients were isolated from the community which led to the formation of leprosy colonies. Further, late detection and consequentially, larger number of patients with disability also contributed to the segregation of leprosy patients from the community.

In the recent past it has been observed that newly detected leprosy patients are not being segregated / isolated from their family / society. This is because of early detection of cases, timely administration of treatment, greater accessibility of Multi Drug Therapy services, decrease in stigma and increased awareness about the nature of the disease and its curability. The findings of NSS report 2013 by ICMR on felt stigma is at **Annexure-B**.

The Central Government has notified the Rights of Persons with Disabilities Act, 2016 which envisages reservation in Government jobs for various categories of persons with benchmark disabilities including leprosy cured persons.

(d) & (e) Ministry of Health and Family Welfare has informed that the National Leprosy Control Programme was launched by the Govt. of India in 1955. Multi Drug Therapy came into wide use from 1982 and the National Leprosy Eradication Programme was introduced in 1983. Since then, remarkable progress has been achieved in reducing the disease burden. India achieved the goal set by the National Health Policy, 2002 of elimination of leprosy as a public health problem, defined as less than 1 case per 10,000 population, at the National level in December 2005.

- Following are the programme components :
 - Case Detection and Management
 - Disability Prevention and Medical Rehabilitation
 - Information, Education and Communication (IEC) including Behaviour Change Communication (BCC)
 - Human Resource and Capacity building
 - Programme Management

Details about the programme are at **Annexure-C** and details about State of Karnataka are at **Annexure-D**.

Further, Department of Empowerment of Persons with Disabilities (Divyangjan) under this Ministry implements a central sector scheme, namely, Deendayal Disabled Rehabilitation Scheme (DDRS) under which grant-in-aid is provided to Non-Governmental Organizations(NGOs) running projects for the welfare of Persons with Disabilities(PwDs) aimed at enabling them to reach and maintain their optimal, physical, sensory, intellectual, psychiatric or social functional levels. The scheme is applicable to all the States/UTs in the country. The Scheme envisages support to total number of 18 projects including project for rehabilitation of leprosy-cured persons (LCPs).

Annexure A

Annexure referred to in reply to part (a) of the Lok Sabha Unstarred Question No. 4175 for answer on 28.03.2017 regarding "Leprosy patients"

State wise National Leprosy Eradication Programme (NLEP) Report (Status up to Dec 2016)

S.N	State/UT	PR/10,000 population	New case detection	Among newly detected cases			
				Multi bacillary%	Female%	Child%	Visible deformity%
1	Andhra Pradesh	0.55	2836	45.77	44.89	9.59	5.11
2	Arunachal Pradesh	0.18	22	90.91	22.73	13.64	27.27
3	Assam	0.31	781	72.73	29.19	7.04	8.45
4	Bihar	1.33	15766	36.70	42.93	14.42	2.57
5	Chhattisgarh	3.36	9927	47.00	16.99	6.42	5.00
6	Goa	1.17	90	87.78	22.22	1.11	0.00
7	Gujarat	1.03	6027	41.91	45.48	6.67	1.87
8	Haryana	0.18	353	80.74	32.00	2.55	4.53
9	Himachal Pradesh	0.21	103	41.07	20.39	0.97	14.56
10	Jharkhand	1.26	4866	42.87	41.86	11.24	2.14
11	Jammu & Kashmir	0.16	97	81.44	14.43	0.00	12.37
12	Karnataka	0.38	1904	71.11	36.24	7.09	3.05
13	Kerala	0.18	342	72.51	29.53	8.19	13.45
14	Madhya Pradesh	0.77	5309	59.60	37.45	5.12	4.20
15	Maharashtra	0.98	10908	52.04	45.36	10.74	2.50
16	Manipur	0.05	10	80.00	10.00	10.00	10.00
17	Meghalaya	0.10	24	75.00	25.00	4.17	29.17
18	Mizoram	0.20	5	80.00	0.00	0.00	0.00
19	Nagaland	0.32	30	73.33	16.67	6.67	23.33
20	Odisha	1.89	8258	45.06	40.68	8.16	4.66
21	Punjab	0.21	507	76.33	39.45	11.64	0.00
22	Rajasthan	0.17	692	92.20	27.60	1.73	4.62
23	Sikkim	0.26	16	81.25	18.75	0.00	0.00
24	Tamil Nadu	0.48	3644	39.00	42.78	19.07	3.68
25	Telangana	0.53	1795	66.41	37.94	6.91	7.41
26	Tripura	0.18	23	69.57	34.78	0.00	13.04
27	Uttar Pradesh	0.78	16661	40.24	34.01	5.85	2.48
28	Uttarakhand	0.29	267	62.92	32.21	5.62	1.12
29	West Bengal	1.08	9292	56.47	38.41	7.96	2.88
30	A & N Islands	0.43	10	70.0	20.00	10.00	0.00
31	Chandigarh	1.23	96	63.54	30.21	5.21	3.13
32	D & N Haveli	6.64	290	24.48	50.00	19.66	1.38
33	Daman & Diu	0.65	7	0.00	0.00	0.00	14.29
34	Delhi	1.26	1276	78.37	25.24	3.92	12.70
35	Lakshadweep	0.75	0	0.00	0.00	0.00	0.00
36	Puducherry	0.13	21	52.38	61.90	0.00	14.29
	Total	0.84	102255	47.57	37.62	9.02	3.46

Annexure referred to in reply to part (b) & (c) of the Lok Sabha Unstarred Question No. 4175 for answer on 28.03.2017 regarding "Leprosy patients"

The findings of NSS report 2013 by ICMR on felt stigma

- 1) It is observed that the extent of self stigma is small and patient is at ease with his immediate family. However, 30% of the patients still did not tell their family about the disease. Whenever family was told about the disease they were supportive of the patient.
- 2) In a majority of cases there is no discrimination even at the working place and fellow workers are supportive. However, a small percentage (13%) are experiencing discrimination at the workplace.
- 3) The LAPs are invited to social functions and children of most of them study in common schools as with the general public. In a third of them however their children go to separate schools.
- 4) Majority of patients are emotionally balanced and do not suffer from self stigma. Some members of the community still believe that the patients should be kept at a distance even when on treatment and not socialize with them. This showed that there was still fear and misbeliefs about the disease.

Annexure referred to in reply to part (d) & (e) of the Lok Sabha Unstarred Question No. 4175 for answer on 28.03.2017 regarding "Leprosy patients"

Activities under NLEP:

- **Diagnosis and treatment of leprosy-** Services for diagnosis and treatment (Multi drug therapy) are provided by all primary health centres and govt. dispensaries throughout the country free of cost. Difficult to diagnose and complicated cases and cases requiring reconstructive surgery are referred to district hospital for further management.
- **Training-** Training of general health staff like medical officer, health workers, health supervisors, laboratory technicians and ASHAs are conducted every year to develop adequate skill in diagnosis and management of leprosy cases.
- **Urban leprosy control-** To address the complex problems in urban areas, the Urban Leprosy control activities are being implemented in urban areas having population size of more than 1 lakh. These activities include MDT delivery services & follow up of patient for treatment completion, providing supportive medicines & dressing material and monitoring & supervision.
- **IEC-** Intensive IEC activities are conducted for awareness generation and particularly reduction of stigma and discrimination against leprosy affected persons. These activities are carried through mass media, outdoor media, rural media and advocacy meetings. More focus is given on inter personnel communication.
- **NGO services-** The various activities undertaken by the NGOs are, IEC, Prevention of Impairments and Deformities, Case Detection and MDT Delivery. From financial year 2006 onwards, Grant-in-aid is being disbursed to NGO through State Health (Leprosy) Societies.
- **Disability Prevention and Medical Rehabilitation** –For prevention of disability among persons with insensitive hands and feet, they are given dressing material, supportive medicines and micro-cellular rubber (MCR) footwear. The patients are also empowered with self-care procedure for taking care of themselves. More emphasis is being given on correction of disability in leprosy affected persons through reconstructive surgery (RCS). To strengthen RCS services, GOI has recognized 112 institutions for conducting RCS based on the recommendations of the state government. Out of these, 60 are Govt. institutions and 52 are NGO institutions.
- **Special Activity in High Endemic Distt.-.** Special activity for early detection and complete treatment in the form of Leprosy case detection campaign, Focussed Leprosy campaign and activity in hard to reach areas , Capacity building and extensive IEC, Adequate availability of MDT, Strengthening of distt. nucleus, Regular monitoring & supervision and review, Regular follow up for neuritis and reaction, Self care practices, Supply of MCR footwear in adequate quantity and Improvement in RCS performance through camp approach are planned in the high priority districts to reduce the disease burden.

- **Supervision and Monitoring** – Programme is being monitored at different level through analysis of monthly progress reports, through field visits by the supervisory officers and programme review meetings held at central, state and district level. For better epidemiological analysis of the disease situation, emphasis is given to proportion of grade II disability among new cases and Treatment Completion Rate.

Initiatives in 2015-17:

- In order to detect the hidden leprosy cases, Leprosy Case Detection Campaigns (LCDC), a unique initiative of its kind under NLEP, is being implemented in high endemic districts of the country, in line with Pulse polio Campaign by Central Leprosy Division. In this campaign each and every person in a house in the selected high endemic districts is examined to detect all hidden cases in the community. This will interrupt the transmission of the disease in the community, and expedite achievement of elimination status at district and sub-district level. The important activities under LCDC are micro planning, selection of male volunteer for house to house search teams, training of field level staff and intensive IEC activities. All activities related to LCDC will be monitored by CLD and coordinated by States through various subcommittees formed at State and District level.
- Involvement of ASHA**– A scheme to involve ASHAs was drawn up to bring out leprosy cases from their villages for diagnosis at PHC and follow up cases for treatment completion. To facilitate involvement, they are being paid an incentive as below:
 - On confirmed diagnosis of case brought by them – Rs. 250/-
 - On completion of full course of treatment of the case within specified time – Pauci bacillary (PB) leprosy case – Rs. 400/- and Multibacillary (MB) Leprosy case – Rs. 600/-.
 The scheme has been extended to involve any other person who brings in or reports a new case of leprosy.
 - An early case before onset of any visible deformity – Rs 250
 - A new case with visible deformity in hands, feet or eye – Rs 200
- E Newsletter-** is a *Quarterly publication from the house of CLD*. NLEP Newsletter shares guidelines, feedback/best practices, experiences and activities undertaken in the programme in coordination with partner/ States/NGOs/Institutes/Medical Colleges & Associations etc. Newsletter serves as one of the important tools for communication to keep informed, updated and educate our stakeholders as well as target groups. This will be a platform for States/UTs/NGOs/A PAL to join their hands and share relevant articles which will be a source of inspiration for readers.
- In order to strengthen planning, implementation and monitoring of activities in Central Leprosy Division, **GIS Mapping has been initiated** .

Annexure referred to in reply to part (d) & (e) of the Lok Sabha Unstarred Question No. 4175 for answer on 28.03.2017 regarding "Leprosy patients"

Initiatives taken in 2016-17 in Karnataka

- 1) **Leprosy Case Detection Campaign (LCDC)** was conducted in 2 high endemic districts in September-October 2016, in which 9412 suspects were identified, 9412 examined and 137 new leprosy cases were confirmed.
- 2) **Chemoprophylaxis** was administered to contacts of cases identified during LCDC in order to stop transmission to contacts.
- 3) 60 Grade II disability cases have been **operated** upon upto January 2017.
- 4) 30th January is Anti Leprosy Day every year, wherein a nationwide message on leprosy awareness is spread through print and other media. In addition the IEC activities for leprosy elimination run for a fortnight. In 2017, this day was celebrated as '**Sparsh Leprosy Awareness Campaign**' wherein GramSabhas were organized in cooperation and coordination with allied sectors of health department/ ministries i.e. Panchayati Raj Institutions, Rural Development, Urban Development, Women and Child Development and Social Justice and Empowerment etc.