NATIONAL HUMAN RIGHTS COMMISSION

National Conference on Leprosy

Date : **Friday, 17 April 2015**

Venue : **Committee Room A, Vigyan Bhawan Annexe, Maulana Azad Road, New Delhi**

(BACKGROUND NOTE)

Leprosy is one of the most ancient and dreaded diseases known to have plagued humanity throughout the ages. For a long time leprosy was considered to be a hereditary disease, a curse, or a punishment from God. Before and even after the discovery of its causes, leprosy patients were stigmatized and shunned. Because of the horrifying nature of physical disfigurement caused by leprosy and since no cure was discovered till the 20th century, leprosy has for centuries been a highly dreaded disease.

2. Leprosy is caused by bacteria known as mycobacterium leprae. The disease mainly affects the skin, the peripheral nerves, respiratory tract and also the eyes. It is known to occur at all ages ranging from early infancy to very old age. Timely diagnosis and treatment of leprosy before nerve damage occurs is the most effective way of preventing disability.

3. It was in 1970s when Multi Drug Therapy (MDT) consisting of Rifampicin, Clofazimine and Dapsone were identified as cure for leprosy which came into wide use from 1982 following the recommendations of World Health Organization. Since then there has been a shift in the treatment for leprosy patients from institutional to out-patients. Today, leprosy patients are accepted by the communities as a result of intensive health education and visible successful results of MDT.

4. The **United Nations Convention on the Rights of Persons with Disabilities** condemns discrimination against any person on the basis of disability. The **United Nations General Assembly has also adopted Principles and Guidelines for the**

Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members. In 2010, it unanimously adopted a Resolution on Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members. These represent powerful new tools for addressing leprosy-related human rights violations by calling upon governments to abolish discriminatory legislation and remove discriminatory language from official publications; provide quality health care to persons affected by leprosy; and promote their social inclusion.

5. India has made strides in the field of detection and treatment of leprosy and in 2005 achieved the WHO elimination level of having less than one patient per 10,000 population at the national level. With the objective to control the disease activity in all known cases of leprosy, the Ministry of Health and Family Welfare, Government of India started the **National Leprosy Eradication Programme** (NLEP) with the active support of State Governments and Union Territory Administrations. As a result of the hard work and meticulously planned and executed activities, the country has achieved the goal of elimination of leprosy as a public health problem, defined as less than 1 case per 10,000 population, at the National Level in 2005.

6. According to the figures released by the NLEP, leprosy prevalence has drastically reduced in India and as per latest statistics there is a prevalence ratio of 0.73 per 10,000 population. By March 2013, almost 528 districts (81.4%) out of a total of 649 districts have been successful in eliminating leprosy. Barring a few districts – mostly in Chhattisgarh and Odisha – all Indian States have attained significant reduction in new incidence of leprosy cases.

7. Besides NLEP, the **Urban Leprosy Control Programme** is being implemented since 2005. Under this programme, assistance is being provided by Government of India to urban areas having population size of more than 1 lakh. **Deendayal Disabled Rehabilitation Scheme** (DDRS) is another scheme providing financial assistance to voluntary organizations to make available the whole range of services necessary for rehabilitation of persons with disabilities. The project concerning the persons affected by leprosy under DDRS is the Project for

Rehabilitation of Leprosy Cured Persons. It aims to empower leprosy cured persons with skills to enable them to improve their socio-economic condition.

8. Despite the fact that leprosy is easily curable, **the stigma and discrimination faced by the people affected by leprosy continues to be a serious problem.** Even today, people who have contracted leprosy often spend their lives completely isolated from the society, although they may have been cured. They and members of their families many a time find it difficult to receive education, marry or to find work. They are still facing stigma and discrimination in their employment, marital and social relationships, educational opportunities, job prospects and community participation. The stigma attached to leprosy has the potential to disrupt people's lives in ways that no drug can cure. Even members of the medical profession have been known to discriminate against patients with leprosy.

9. Despite the fact that most of them are cured, **they – and their children – are forced to settle in one of the leprosy colonies due to stigma and discrimination** against people who have had leprosy. Many of these colonies are being supported or provided facilities by NGOs and only some of the NGOs are running rehabilitation centers for leprosy cured persons for their reintegration in the society. **The water, sanitation and living condition in these colonies is an area of concern**.

10. Under Section 2 (t) of **The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995** (PWD Act, 1995), a person with disability means a person suffering from not less than forty per cent of any disability as certified by a medical authority. The disability under Section 2 (i) includes leprosy-cured. As per Section 2 (n) of the Act "Leprosy cured person" means any person who has been cured of leprosy but is suffering from (i) loss of sensation in hands or feet as well as loss of sensation and paresis in the eye and eyelid with no manifest deformity, (ii) manifest deformity and paresis but having sufficient mobility in their hands and feet to enable them to engage in normal economic activities, (iii) extreme physical deformity as well as advanced age

which prevents him from undertaking any gainful occupation, and the expression "leprosy cured" shall be construed accordingly.

11. The affirmative action of the State which are available to a person with disability are also available to leprosy cured person having more than 40% disability and in possession of such certificate from designated medical authority. It has been observed that **there are still big gaps regarding issue of disability certificate to persons affected by leprosy.** It in turn hinders the person affected with leprosy to avail the facilities being provided. There is a need to identify reasons and take remedial action to facilitate issue of disability certificates without harassment to the persons affected by leprosy.

12. **Many States are including persons affected by leprosy under the BPL and *Antyodaya Anna Yojana* (AAY) schemes of the Union Government**. But to avail it, the persons affected with leprosy must have a certificate from the concerned authorities. **The access to get the necessary certificate is an area of concern.**

13. As per the information available with the Commission, **only few State Governments, viz. Delhi, Karnataka, Rajasthan and Haryana are providing financial assistance in the form of pension to the persons affected by leprosy. Most of the State Governments do not have such a scheme.** Besides, **there is no uniformity in the amount of pension being given**; it ranges from ₹ 1,800 to ₹ 400 per month. In the light of high cost of living and inflation, there is a need to provide respectable financial assistance to the persons affected by leprosy. Moreover, State has a duty to protect the rights of persons affected by leprosy and in this regard it cannot hide behind the veil of economic incapacity. As such all the States/Union Territories must strive to evolve appropriate pension scheme to enable the persons affected by leprosy to live their life with dignity.

14. The **other issue of concern is the discriminatory provisions in the laws**. Under Section 13 (v) of the **Hindu Marriage Act, 1955** if one party has been suffering from a virulent and incurable form of leprosy, it is one of the grounds for divorce. Under section 18 (2) (c) of the **Hindu Adoption and Maintenance Act, 1956**, if a person is suffering from a virulent form of leprosy, his wife is entitled to live separately from her husband without forfeiting her claim to maintenance.

There are similar provisions in other personal laws which need amendment to prevent discrimination.

15. The matter of personal laws falls under List III Concurrent List of the Seventh Schedule to the Constitution of India. As such, the State Governments are important stakeholder in this regard. Moreover, **there are many other laws which have discriminatory provisions concerning persons affected with leprosy,** which need further discussion.

16. **The National Human Rights Commission** has been concerned about the protection and promotion of human rights of people affected with leprosy. In order to discuss the issues highlighted above **the Commission organized a one-day National Conference on Leprosy on 18 September 2012** at New Delhi. Many important suggestions/recommendations emanated out of this National Conference like giving a wide circulation to the principles and guidelines prepared by the Human Rights Council, eradication of discrimination being faced by persons affected by leprosy by developing appropriate IEC material and ensuring its wider dissemination, the discriminatory provisions in Central and State laws affecting civil and political rights and economic, social and cultural rights may either be repealed or suitably amended, and review the criteria of minimum requirement of 40 per cent disability under the PWD Act, 1995 for persons affected by leprosy to obtain disability certificate. These recommendations were forwarded to all the State Governments and Union Territory Administrations for compliance. A copy of the recommendations is annexed.

17. **The Commission in partnership with Sasakawa India Leprosy Foundation (SILF) is also organizing the Young Partners Program** (YPP) **to sensitize school children on the issue of leprosy**. The objective of the programme is to create awareness about leprosy among the school children so as to eradicate the stigma and discrimination being faced by persons affected by leprosy.

18. In continuation of its effort towards addressing the issue of stigma and discrimination, **the Commission signed and endorsed the "Global Appeal Launch on Leprosy - 2014" to end stigma and discrimination against People Affected by**

Leprosy organized by SASAKSAWA Foundation and Indonesian Human Rights Commission at Jakarta, Indonesia.

19. In order to discuss further the status of action taken by the concerned Department of various State Governments/Union Territory Administrations and Union Ministries, the Commission is organizing a one-day **National Conference on Leprosy** in **Committee Room A, Vigyan Bhawan Annexe, Maulana Azad Road, New Delhi – 110 003** on **17 April 2015.**

Objectives

20. The main objectives of the National Conference will be to:

i. follow up of the suggestions/recommendations of National Conference on Leprosy organized by National Human Rights Commission on 18 September 2012; and

ii. address issues of concerns related to Leprosy and suggest appropriate strategies to deal with them.

Participants

21. The participants to the National Conference will include concerned officials/representatives of Central Government, State Governments and Union Territory Administrations, National Commissions, State Human Rights Commissions, other State Commissions, health experts and health scientists, legal experts, representatives of technical organizations, international organizations, non-governmental organizations and civil society organizations dealing with the problem of leprosy.

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Annexure

National Conference on Leprosy
Important Suggestions/Recommendations
(18 September 2012)

- There is need to give wide circulation to the principles and guidelines prepared by the Human Rights Council and which emphasize that persons affected by leprosy and their family members should be treated as individuals with dignity.

- State Governments must take steps to eradicate discrimination being faced by persons affected by leprosy by developing appropriate IEC material and ensure its wider dissemination.

- There is need to generate awareness on the issue of leprosy by way of organizing training programmes, workshop, lectures, nukkad nataks, TV spots, radio talks, puppetry, etc. for all sections of the society.

- The discriminatory provisions in central and state laws affecting Civil and Political Rights and Economical, Social and Cultural Rights may either be repealed or suitably amended. Research study would be carried out to suggest suitable changes.

- Leprosy affected persons should be given proper care treatment in all the hospitals without discrimination.

- In order to provide an enabling environment for leprosy affected persons and their families, there should not be separate colonies for leprosy affected person. Efforts must be made to settle them in the mainstream society by allocating lands and housing. They should live in a sporadic manner in the society.

- The State Governments must take steps to improve living conditions in the colonies where people affected by leprosy reside.

- Leprosy should be included in the school syllabus so that children are sensitive towards leprosy affected/cured persons and their familiar.

- The Central Government must ensure inclusion of persons affected by leprosy in the poverty alleviation schemes.

- There is a need to provide adequate and reasonable level of pension to persons affected by leprosy keeping the best practice followed by government of Delhi as a model.

- There is a need to review criteria of minimum requirement of 40 per cent disability under the PWD requirement Act, 1995 for persons affected by leprosy to obtain disability certificate. Most of the LAPs are having 30 per cent disability and hence are not eligible for disability certificate.

- Employment in Government can be provided as is done in Karnataka where 130 Group D employees have been recruited. In Kerala, they are employed as hospital attendants. Such practices can be replicated.

- Steps must be taken to ensure easy availability of disability certificate to persons affected by leprosy by organizing special camps.

- The state must take steps to motivate the persons affected by leprosy in developing self help groups for selfcare like dressing of their ulcers.

- Leprosy affected and cured persons and their families should live a dignified life. For this, they need to be empowered with basic human rights like right to education, right to work, right to health, right to food, right to housing and other economic, social and cultural rights. They should have access to all these rights without facing any kind of discrimination.

- There are no leprosy specific schemes and these should be designed. There is no scheme for allotment of land to them. Further, reservation with in persons with disabilities is required as they are most vulnerable with little say.

- These is need for early detection and ASHAs may be provide incentive across the country as is being done in some States like Karnataka. This States also has Swarna Arogya Chatanya Programme for early detection which may be implemented elsewhere.

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