

SUDA

STATE URBAN DEVELOPMENT AGENCY

HEALTH WING

"ILGUS BHAVAN"

H-C BLOCK, SECTOR-III, BIDHANNAGAR, CALCUTTA-700 091
West Bengal

Ref No. **SUDA-Health/65(Pt.V)/13/146**

Date **26.08.2015**

From : Director, SUDA

To : Sri M. Chatterjee
Jt. Secretary
Department of Municipal Affairs
Writers' Building.

Sub. : Suggestions / recommendations on Eradication of Leprosy.

Sir,

I am to refer to your communication vide no. 540/MA/C-10/Misc-8/2015 dt. 10.08.2015 on the subject mentioned above. The suggestions / recommendations relevant in respect of the Department towards Eradication of Leprosy are enclosed at **Annexure – I**.

Thanking you.

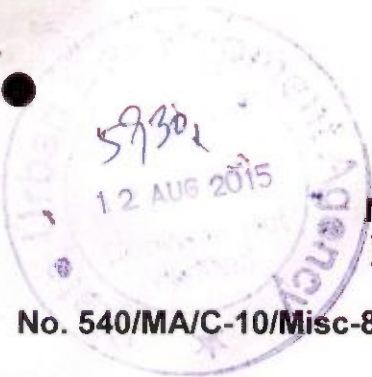
Encl. : As stated.

Yours faithfully,


Director, SUDA

**Suggestions / recommendations relevant in respect of the
Department towards Eradication of Leprosy**

Suggestions / recommendations	Responsible Department as identified	Opinion
At serial no. - 9 - Poverty Alleviation Scheme may also be linked to the Leprosy affected persons	P & RD / MA Department	<ul style="list-style-type: none"> • Leprosy affected families (persons) may be linked with Pension Scheme under NSAP considering them under Indira Gandhi National Disability Pension Schemes (INGNDPS). • Under NULM, they may be linked with (a) SHG formation & related activities (b) Self employment Programme as individual or group activities.
At serial no. - 16 - Early detection is needed through ASHA's	Social Welfare Department / Health & Family Welfare Department / Corporations / Municipalities / Panchayats	<ul style="list-style-type: none"> • As there is no ASHA in place, existing HHWs & FTSs may be entrusted with early detection of Leprosy cases while visiting house to house (BPL families). • As services of HHWs & FTSs are limited to BPL families, entire population of BPL families could not be covered. • Training of HHWs & FTSs will be required for such detection. • The said training shall be imparted by the Health Department through their designated officers. • Furthermore, early detection followed by treatment is essentially required in Leprosy cases, if identified. • For implementation, coordination among ICDS workers of Social Welfare Department, HHW & FTS of ULBs and designated officer for Leprosy eradication at District Health office are required.



**GOVERNMENT OF WEST BENGAL
MUNICIPAL AFFAIRS DEPARTMENT
WRITERS' BUILDINGS, KOLKATA-1**

POCH/1
12/8/15

No. 540/MA/C-10/Misc-8/2015

Dated, Kolkata, the 10th August, 2015.

From : The Joint Secretary to the Govt. of West Bengal.

To : ✓ The Director,
SUDA, ILGUS Bhavan,
HC Block, Sector-III,
Salt Lake, Kolkata-700 106.

Sub : Suggestions/recommendations on Eradication of Leprosy.

Sir,

I am directed to enclose a copy of letter No. 1436(13)-HS/HRC/Misc-18/15 dated 14.07.2015 along with other enclosures received from the Special Secretary, Home Department, Human Rights Branch on the subject stated above and to request you to opine on the suggestions/recommendations as relevant in respect of this Department.

Encl : As stated

Yours faithfully,

[Handwritten signature]
12/8/15

Joint Secretary to the Govt. of West Bengal

Dy. No. 85(e-10)
dt. 28-07-15

GOVERNMENT OF WEST BENGAL
HOME DEPARTMENT
HUMAN RIGHTS BRANCH
WRITERS' BUILDINGS, KOLKATA - 700 001

(13)

No.1436(13)-HS/HRC/Misc-18/15,

Dated, Kolkata, the 14th July, 2015.

From: Sri M.K. Kundu,
Special Secretary to the
Government of West Bengal.

JS (MC)

- To:
- 1) The Principal Secretary, Health & Family Welfare Department.
 - 2) The Principal Secretary, Women & Child Development & Social Welfare Department.
 - 3) The Secretary, Labour Department.
 - 4) The Principal Secretary, Department of Self-Help Groups.
 - 5) The Principal Secretary, School Education Department.
 - 6) The Principal Secretary, Housing Department.
 - 7) The Addl. Chief Secretary, Land & Land Reforms Department.
 - 8) The Principal Secretary, Municipal Affairs Department.
 - 9) The Principal Secretary, Panchayat & Rural Development Department.
 - 10) The Secretary, Land Department.
 - 11) The Principal Secretary, Information & Cultural Affairs Department.
 - 12) The Director General & Inspector General of Police, West Bengal.
 - 13) The Commissioner of Police, Kolkata.



Sub: Letter of West Bengal Human Rights Commission on 'Eradication of Leprosy', containing suggestions / recommendations emerged out in the National Conference on Leprosy, organized by National Human Rights Commission.

Ref: Letter No.82/WBHRC/3/15-16, dt.22.04.2015 from the O.S.D. & Ex-officio Special Secretary, West Bengal Human Rights Commission along with its enclosures.

Sir,

In drawing your kind attention to the subject and reference above, I am directed to state that, recently on 17th April, 2015, a National Conference was organized by the National Human Rights Commission at New Delhi, to formulate some suggestive actions to eradicate Leprosy, one of the most dreaded disease known to have plagued humanity from the ages.

In this connection, West Bengal Human Rights Commission, vide their Memo under reference, has supplied a Note of the Hon'ble Acting Chairperson of the said Commission and a background Note as also a few suggestions / recommendations of the National Human Rights Commission, in this regard.

A synopsis of the Department / Office-wise Action Points has also been prepared which may be applicable for the concerned Departments, as mentioned therein, including the District Authorities under their respective control.

In view of above, I am directed to transmit hereto a copy of the letter under reference, containing the Background Note and suggestions from National Human Rights Commission as also the suggested synopsis of the Action Points for examining them, taking necessary action without delay and furnishing feedback report to this Department at a very early date for onward transmission to the West Bengal Human Rights Commission.

The issue may kindly be given its deserving urgency and importance.

Yours faithfully,

Encl.: As stated above.

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20/7/15

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14/7/15
[M.K. Kundu]
Special Secretary

No.1436(13)/1-HS/HRC/Misc-18/15,

Dated, Kolkata, the 14th July, 2015.

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As per instruction of the Special Secretary, the recommendations / suggestions of National Human Rights Commission are classified below Department-wise: ---

- 1) Wide circulation of the principles and guidelines of Human Rights Council, for the Leprosy affected people and their family members, to treat them as individuals with dignity. - [Health & Family Welfare Department + Information & Cultural Affairs Department + Social Welfare Department]
- 2) Eradication of discrimination being faced by persons suffered by Leprosy through IEC material and its wider dissemination. - [Health & Family Welfare Department + Information & Cultural Affairs Department + Social Welfare Department]
- 3) Generate awareness of the issue of Leprosy through seminars, workshops, drama, etc. - [Information & Cultural Affairs Department + Kolkata Police + West Bengal Police Directorate]
- 4) Suitable changes can be made either by repealing or by amending the discriminatory provisions in central and state laws which affect the Civil / Political / Economical / Social / Cultural Rights. - [Home Department / Law Department / Social Welfare Department]
- 5) Proper treatment and care for Leprosy patients in all Hospitals without discrimination. - [Health & Family Welfare Department]
- 6) No separate colonies for the Leprosy patients be exist, rather lands and housing may be provided to them for settling them in mainstream society. - [Social Welfare Department + Housing Department]
- 7) Living conditions of the Leprosy colonies may be improved by the Government. - [Social Welfare Department + Housing Department + District Magistrates]
- 8) Leprosy and its social effect be included in the School Syllabus for creating awareness among the future citizens. - [School Education Department]
- 9) Poverty alleviation Schemes may also be linked to the Leprosy affected persons. - [It's a scheme of Central Government] / P R R D Dept / M P A Affairs Dept
- 10) To provide adequate and reasonable level of pension to persons affected by Leprosy. - [Social Welfare Department + District Magistrate]

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- 11) Minimum disability criteria may be reviewed so that persons having Leprosy may obtain disability certificate easily. - [Health & Family Welfare Department + ~~Home Department~~ + Social Welfare Department + Labour Department]
- 12) Scope of employment should be generated for Leprosy affected persons. - [Home Department for recruitment in Police forces + Social Welfare Department + Labour Department]
- 13) Self-help groups may be developed for self care of their groups. - [Social Welfare Department + Labour Department + Self-Help Department]
- 14) Basic human rights (like education, work, health, food, housing, etc.) should be provided to the Leprosy affected persons and their families without discrimination. - [Social Welfare Department + School Education Department + Health & Family Welfare Department + Housing Department + All District Magistrates]
- 15) Leprosy specific schemes may be developed for allotment of land and employment to them. - [Land & Land Reforms Department + Labour Department]
- 16) Early detection is needed through ASHA's. - [Social Welfare Department + Health & Family Welfare Department + Corporations, Municipalities & Panchayats]

It requires mention, that, West Bengal Human Rights Commission has requested for a Report pertaining to Home Department only.



करिचदुःख भाग्भवेत्

WEST BENGAL HUMAN RIGHTS COMMISSION

PURTA BHAVAN (2ND FLOOR), BLOCK-DF,

SECTOR-I, SALT LAKE, KOLKATA - 700 091

PHONE : 2337-2655, EPBX : 2337-7707, FAX : 2337-9633

E-mail : wbhrc8@bsnl.in, hrcwb2013@gmail.com

Website : www.wbhrc.nic.in

7-10

Ref. No 82/WBHRC/3/15-16

Date: 22/04/15

From : Shri S. K. Haldar
O.S.D. & E.O. Special Secretary.

To : The Addl. Chief Secretary to the Govt. of West Bengal & Home Secretary,
Nabanna (13th floor), 325, Sarat Chatterjee Road,
P.S. Sibpur, Dist. Howrah-711 102.

HSF	HSL
	21/3/15 6-5-15

Sir,

Enclosed here please find a note of the Hon'ble Chairperson, West Bengal Human Rights Commission on the National Conference on 'Eradication of Leprosy' held in New Delhi on 17th April, 2015 which will speak for itself. Again as directed, I am enclosing herewith a Background Note of the National Human Rights Commission on the scheduled programme.

I am directed to request you to kindly send a report on certain points pertaining to Home Department at an early date.

Yours faithfully,

[Signature]
O.S.D. & E.O. Spl. Secretary

Encl: As above.

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sscmm

*Ref.
Pl. put up in
a new file
quickerly.
8/5/15*

*[Signature]
8/5/15*

Govt. of West Bengal
Home Department
Special Section

Diary No. 773 dt. 8/5/15

Date: 20. 04. 2015

On Friday, the 17th April, 2015, the National Human Rights Commission organized a National Conference on Leprosy on 'Eradication of Leprosy' in New Delhi. The background note paper is enclosed.

1. The National Human Rights Commission emphasized that all the State Human Rights Commission should seek a report from the Government about the implementation of suggestions and recommendations formulated by NHRC during the similar conference held on September 18, 2012. The formulations and recommendations are enclosed as Annexure to the Background Note of N.H.R.C.
2. To summarize, the NHRC in its conference of 2012, suggested that a wide circulation to the principles and guidelines prepared by the Human Rights Council, should be given utmost priority for eradication and discrimination being faced by persons affected by leprosy.
3. It was further emphasized that discriminatory legal provisions like that Hindu Marriage Act, Leprosy Act etc., should be done away by both Central and State Government.

The leprosy affected persons should be given equal civil, political, economic, social and cultural rights. It also suggested that a review be made of the criteria of minimum requirement of 40% disability under the PWD Act, 1995 for persons affected by leprosy to obtain disability certificate.

4. Further, important suggestions were like wide spread awareness programme through FM Radio, street place posture, advertisement in News paper etc. An important suggestion was to dismantle leprosy colonies so that the leprosy affected persons should live a normal life, efforts be made to settle such person in mainstream by allocating lands and housing and also give them pension.
5. Employment in government Sector can be provided as is done in Karnataka where about 130 Group 'D' employees among the leprosy person have been recruited.

Sd/-
Naparajit Mukherjee
Chairperson(Acting)

(8)

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

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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

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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

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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.

(2)

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 natak, 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.

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• 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.

• There 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.

SUDA

STATE URBAN DEVELOPMENT AGENCY

HEALTH WING

"ILGUS BHAVAN"

H-C BLOCK, SECTOR-III, BIDHANNAGAR, CALCUTTA-700 091

West Bengal

Ref No. SUDA-Health/65(Pt.V)/13/149

Date 31.07.2013

From : Director, SUDA

To : Shri B.C. Patra
The Jt. Secretary
Department of Municipal Affairs
Writers' Building.

Sub. : Implementation of the suggestions / recommendation emanating out of the National Conference on Leprosy organized by National Human Rights Commission at New Delhi on 18.09.2012.

Sir,

I am to refer to the communication of the Spl. Secretary, Home Department, Human Rights Branch vide no. 1354(5)-HS/HRC/Misc-20/12 dt. 5th July, 2013 addressed to the Secretary, Department of Municipal Affairs with the request to forward Action Taken Report directly to Shri J.S. Kochher, Jt. Secretary (Training), National Human Rights Commission along with a copy to the Home Department.

In this connection, this is to state that minutes of the National Conference on Leprosy held on 18th September, 2012 at New Delhi sent by the Spl. Secretary, Home Department vide no. 1904(5)-SL/HRC/Misc-20/12 dt. 04.12.2012 was forwarded to all the 127 Urban Local Bodies.

In this context, this is to mention here that primarily, ULBs are providing Primary Health Care Services with focus to Reproductive & Child Health Care. As there is no treatment facility available at the ULB for Leprosy patient, they directly visit to Government Health facility or any other private facility. Hence, Action Taken Report by the ULBs may not be available.

Thanking you.

Yours faithfully,



Director, SUDA

SUDA

STATE URBAN DEVELOPMENT AGENCY

HEALTH WING

"ILGUS BHAVAN"

H-C BLOCK, SECTOR-III, BIDHANNAGAR, CALCUTTA-700 091
West Bengal

Ref No. SUDA-Health/65(Pt.V)/13/149

Date 31.07.2013

From : Director, SUDA

To : *Joint*
The Secretary
Department of Municipal Affairs
Writers' Building.

Sub. : Implementation of the suggestions / recommendation emanating out of the National Conference on Leprosy organized by National Human Rights Commission at New Delhi on 18.09.2012.

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In this context, this is to mention here that primarily, ULBs are providing primary Health Care services with focus to Reproductive & Child Health Care. As there is no treatment facility available at the ULB for Leprosy patient, they directly visit to Government Health facility or any other private facility. Hence, Action Taken Report by the ULBs may not be available.

Thanking you.

J. S. Kochher

Yours faithfully,

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Director, SUDA

GOVERNMENT OF WEST BENGAL
HOME DEPARTMENT
HUMAN RIGHTS BRANCH
WRITERS' BUILDINGS, KOLKATA - 700 001



No.1354(5)-HS/HRC/Misc-20/12,

Dated, Kolkata, the 5th July, 2013.

From: Sri M.K. Kundu,
Special Secretary to the
Government of West Bengal.

- To: 1) The Principal Secretary,
Health & Family Welfare Department.
2) The Principal Secretary,
Municipal Affairs Department.
3) The Principal Secretary,
Panchyat & Rural Development Department.
4) The Secretary,
Women Child Development & Social Welfare Department.
5) The Secretary,
School Education Department.



Sub: Implementation of the suggestions / recommendations emanating out of the National Conference on Leprosy organized by National Human Rights Commission at New Delhi on 18.09.2012.

**Ref: No.1904(5)-SL/HRC/Misc-20/12,
dt.01.04.2013.**

dt.04.12.2012,

No.585(5)-SL/HRC/Misc-20/12,

Sir,

With reference to above, I am directed to request you kindly to send the required Action Taken Report directly to Sri J.S. Kochher, Joint Secretary (Training), National Human Rights Commission with an intimation and copy thereof to this Department.

Yours faithfully,


[M.K. Kundu]
Special Secretary

No.1354(5)/1-HS/HRC/Misc-20/12,

Dated, Kolkata, the 5th July, 2013.

Copy forwarded for information and necessary action to Smt. C.D. Lama, I.A.S., State Project Director, Sarbasiksha Mission, West Bengal, Bikash Bhawan, Salt Lake, Kolkata - 700 091.

Special Secretary

3739-SMHP/13
17/7/13

SUDA

STATE URBAN DEVELOPMENT AGENCY

HEALTH WING

"ILGUS BHAVAN"

H-C BLOCK, SECTOR-III, BIDHANNAGAR, CALCUTTA-700 091

West Bengal

Ref No. **SUDA-Health/65/08/275(127)**

Date **10.12.2012**

From : Director, SUDA

To : The Municipal Commissioner, Kolkata Municipal Corporation

: The Commissioner,

..... **Municipal Corporation**

: The Chairman / Chairperson,

..... **Municipality / NAA**

Sub. : Implementation of the suggestion / recommendations emanating out of the National Conference on Leprosy organized by N.H.R.C. at New Delhi on 18.09.2012.

Sir / Madam,

Enclosed kindly find herewith communication of the Special Secretary, to the Govt. of West Bengal, Home Department, Human Rights Branch, vide no. 1904(5)-SL/HRC/Misc.-20/12 dt. 04.12.2012 along with minutes of the National Conference on Leprosy, addressed to the Principal Secretary, Department of Municipal Affairs on the subject mentioned above.

You are requested to take / continue with the activities based on important suggestion / recommendations emanating out of the National Conference on Leprosy.

Thanking you.

Yours faithfully

Enclo. : As stated.


Director, SUDA

Contd. to P-2.

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SUDA-Health/65/08/275(127)/1(3)

Dt. .. 10.12.2012

CC

- 1. Shri B.C. Patra, Jt. Secretary, Dept. of Municipal Affairs**
- 2. Shri M. Chatterjee, OSD & Dy. Secretary, Dept. of Municipal Affairs**
- 3. PA to the Principal Secretary, Dept. of Municipal Affairs**


Director, SUDA

SUDA-Health/65/08/275(127)/2(1)

Dt. .. 10.12.2012

CC

**Shri G. Bhattacharya, Special Secretary, Home Department,
Human Rights Branch, Writers' Building, Kolkata – 700 001.**


Director, SUDA

Government of West Bengal
Home Department
Human Rights Branch
Writers' Buildings, Kolkata – 700001.

No. 1904 (5)-SL/HRC/Misc-20/12

Date : 04/12/2012

From : Shri G. Bhattacharya
Special Secretary

- To : 1. The Principal Secretary,
Health & Family Welfare Department.
2. The Principal Secretary,
Municipal Affairs Department.
3. The Principal Secretary,
Panchayet & Rural Development Department.
4. The Secretary, WCD & Social Welfare Department.
5. The Secretary, School Education Department.

Sub : Implementation of the suggestions/recommendations emanating out of the National Conference on Leprosy organized by N.H.R.C at New Delhi on 18/09/2012.

Sir,

In enclosing hereto a copy of the D.O letter No. 11/3/2012-PRP & P dated 05/11/2012 of Shri J.S. Kochher, Joint Secretary (Training), N.H.R.C alongwith a copy of the minutes of the National conference on above-mentioned subject, I am directed to inform that the implementation of the suggestions/recommendations emanating out of the said conference requires active involvement of the Health & Family Welfare Deptt. as also the WCD & SW Deptt., Panchayet & RD Deptt., the Municipal Affairs Deptt. & the School Education Department.

It has also been decided by the Govt. in the Home Deptt. that the Health & Family Welfare Department will act as the "Nodal Department" in implementation of the suggestions/recommendations of the said Conference organized by N.H.R.C and co-ordinate with the WCD & SW Deptt., Panchayet & RD Deptt. the Municipal Affairs Deptt. & School Education Department in the process of implementation, there may be need to involve some other Departments/organizations.

I am, therefore, directed to request all the departments kindly to examine the suggestions/recommendations and take necessary actions for its proper implementation while the Health & Family Welfare Department is requested to act as the Nodal Department of the issue for its implementation.

Action taken on the suggestions/recommendations emanating out of the said "National Conference" should be intimated by other departments to the Health & Family Welfare Department, who, in turn, will consolidate the same alongwith Health & Family Welfare Deptt's action and send the 'Action Taken Report' directly to Shri J.S. Kochher, Joint Secretary (Training), N.H.R.C under intimation to Home Department. Interim appraisal may also be sent by the Health & Family Welfare Department as the Nodal Department of this Govt. to N.H.R.C directly under intimation to this Department.

Copy of this letter is being endorsed to Shri J. S. Kochher, Joint Secretary (Training), N.H.R.C for his kind information.

The matter may kindly be given its deserving urgency and importance.

Encl: As stated

Yours faithfully,

(G. Bhattacharya)
Special Secretary

जयदीप सिंह कोचर
संयुक्त सचिव (प्रशिक्षण)
Jaideep Singh Kochher
JOINT SECRETARY (TRAINING)



राष्ट्रीय मानव अधिकार आयोग
फरीदकोट हाऊस, कोपरनिकस मार्ग
नई दिल्ली- 110 001 भारत
National Human Rights Commission
Faridkot House, Copernicus Marg,
New Delhi-110 001 INDIA

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88-OSD
12.11.12.

D.O. No. 11/3/2012-PRP&P

5 November 2012

Dear Shri Ghosh,

The Commission has been deeply concerned about human rights of people affected by leprosy. The Commission with a view to discuss the issues concerning rights of persons affected by leprosy organized a one-day National Conference on Leprosy on 18 September 2012 at India International Centre (New Building), 40 Max Muller Marg, New Delhi.

In this Conference, representatives of States/UTs dealing with the issue, State Human Rights Commissions, Union Ministries and NGOs working in the leprosy sector participated. The minutes of the meeting are annexed (Annexure-I) for necessary action at your end.

You are requested to issue directions so as to ensure implementation of important suggestions/recommendations emanating out of the National Conference under intimation to the Commission.

HS

With regards,

Yours sincerely,

(J.S. Kochher)

Shri Samar Ghosh
Chief Secretary,
Govt. of West Bengal,
Civil Secretariat,
Kolkata- 700001

JS(MK)
2668/35(MK)
14/11/12

HSF	HSL
	30/10/12
	14/11/12

Govt. of West Bengal
Home Department
Special Section
Diary No. 1801 dt. 16.11.12

Minutes of the National Conference on "Leprosy" held on 18 September 2012 at India International Centre (IIC), New Delhi

Inaugural Session

Shri J.S. Kochhar, Joint Secretary (Training), NHRC welcomed the participants of the meeting. He stated that although in India, headway had been made in the eradication of leprosy, many other associated issues require the attention of the stakeholder. He mentioned that persons affected by leprosy still faces stigma and discrimination because of which they are forced to live in colonies, roadsides and religious places, facing financial constraints with no opportunity for education. He also referred to the discriminatory provision in laws on account of which human rights of the persons affected by leprosy are violated. Shri Kochher while referring to the principles and guidelines drafted by Human Rights Council and endorsed by the UN General Assembly, stated that the rights enshrined in the Universal Declaration of Human Rights and international covenants are also available to persons affected by leprosy and their families. He stated that the objective of this conference is to bring out certain specific suggestions to protect the rights of persons affected with leprosy.

Justice Shri KG Balakrishnan, Chairperson, National Human Rights Commission (NHRC) in his inaugural address stated that leprosy affected persons suffered human rights violations on various counts including their rights to life of dignity and equality. Jobs are denied to them, which affects their right to dignity. He stated that although leprosy is curable, the physical deformity caused by it coupled with certain myths about the disease result in discrimination. Although, leprosy is the least infectious of all the communicable diseases, yet social prejudice, and discrimination that stems from it, remains deep-rooted. He stated that persons affected by leprosy are routinely denied their basic rights including food, housing, education, health, employment opportunities and full participation. As a consequence, they suffer from poverty and lack of resources. Some of the most insidious of discrimination come with the stigma and social barriers they face – a root cause of their exclusion and marginalization. He stated that leprosy should not be a ground for divorce and that those affected by leprosy should enjoy rights like right to marry, right to hold office, right to work on an equal basis with others.

He expressed his concern about the living conditions in colonies where the persons affected by leprosy and their children are forced to live due to the stigma and discrimination. Chairperson, NHRC further stated that the Commission has collected information from State Governments regarding the financial assistance being provided by them to the persons affected by leprosy. A few States are providing financial assistance in the form of pension, but most of the State Governments do not have such a scheme. Besides, there is no uniformity in the amount of pension being given. He observed that in the light of the fact that stigma and discrimination faced by the people affected by leprosy result in lack of economic capacity. Coupled with high cost of living and inflation, it results in pushing these people below poverty. As such, there is a need to provide decent level of financial support to the persons affected by leprosy. He also stated that there is need to consider if an appropriate pension scheme to enable the persons affected by leprosy to live their life with dignity is required to be put in place uniformly across the

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country. He stated that there is a need to change public attitude by awareness campaigns, education etc. He hoped that the conference would help in bringing out suggestions towards this objective. He also stated that the NHRC would collaborate with any organization to help those affected with leprosy.

Dr. Savita Bhakry, Deputy Secretary (Research), NHRC gave the Vote of Thanks for this session. She thanked the Hon'ble Chairperson, NHRC for enumerating issues of human rights faced by people affected with leprosy and their families. She also thanked all the Members of the NHRC and Joint Secretary (Training), NHRC for giving the overall background of this Conference. She expressed her thanks to representatives of State Governments, Special Rapporteurs of the NHRC, NGOs and the media for participating in the Conference.

Session- II Rights of Persons Affected by Leprosy: Sharing of Best Practices

This session was chaired by Justice Shri GP Mathur, Member, NHRC. He stated that leprosy was also called Hansen's disease. It is caused by Mycobacterium leprae and Mycobacterium lepromatosis and 95% of people are naturally immune to them. He also stated that the progress of leprosy is slow and may take years to develop. He mentioned that the United National General Assembly vide its resolution No.65/215 dated 25.3.11 reaffirms that the persons affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and laws.

He also stated that, as per statistics till April, 2011, the Prevalence Rate (PR) of leprosy is 0.69 per 10,000 populations. As such our country has made good progress in terms of eradication of the disease but lot more needs to be done. He prescribed that by education and employment, it is possible to break the barriers and curb the violations of human rights of those affected by leprosy. He stated that there are two provisions of the Hindu Marriage Act, 1955 that are causing ambiguity. Under section 13 (iv) of the said Act, if one party had been suffering from virulent and incurable form of leprosy, it is a ground for divorce. He said that the meaning of the word "virulent" is strong, poisonous and extremely infectious. The second is section 18 (2) of the same Act is which states that if a person is suffering from a virulent form of leprosy, the wife became entitled to live separately from him without forfeiting her claim to maintenance. These provisions, however, did not become grounds for automatic dissolution of marriage. Before 1956, there were no such provisions, but after 1956, society underwent a sea change.

Justice Mathur then explained about the Deendayal Disabled Rehabilitation Scheme of the Government of India. He stated that it provides aid to voluntary organizations to give a wide range of services for rehabilitation of persons with disabilities. The project dealing with persons with leprosy is the project for Rehabilitation of Leprosy Cured Persons. He said that despite leprosy being easily curable, persons with leprosy and their families faced widespread discriminations. They found it difficult to get education, find employment and marry. Even medical professionals discriminate them because of the stigma attached to it. As such they are forced to settle in separate

colonies. Section 2 (t) of the PWD Act, 1995, states that a person with disability meant a person suffering from not less than 40% of any disability certified by a medical authority. As per Section 2 (i) of the Act, persons with disability includes leprosy cured. But, gaps still remained regarding the issue of disability certificates to persons affected with leprosy, preventing a person affected by the disease from taking advantage of the facilities being provided. This needed to be rectified so that there is no harassment caused to the people affected by leprosy.

Thereafter the representatives of States/Union Territories made presentations focusing on welfare schemes for persons affected by leprosy in their respective States/Union Territories.

Andhra Pradesh

Dr. Ranganath Rao, representative from Andhra Pradesh, gave a presentation on Welfare Schemes on Persons Affected by Leprosy- Health and Social Justice on behalf of Dr. T. Tarachand, State Leprosy Officer, Andhra Pradesh. He said that the Leprosy Programme had been integrated into general health care system in Andhra Pradesh and that the Prevalence Rate in the state is 0.63/10,000. He said that there were 99 leprosy colonies in the state.

He stated that the Government of Andhra Pradesh is providing services such as Multi Drug Therapy, Supportive Drugs, Dressing Materials, Self-Care Services and Management of Ulcers through weekly clinics. Micro Cellular Footwear (MCR) is also being provided to protect anesthetic feet. All the families living in the colonies are covered under the Antyodaya scheme. Pension is also given @ Rs.200 per month and disability persons is given @ Rs. 700/- month. Besides, NGOs are also giving support by setting up Vocational Training Centres. Other projects like LEPRO Chetana Project-SLAP, Scholarships to the children of Persons Affected with Leprosy are also there. Besides there are various RCS Centres also set up. Dr. Rao stated that some of the challenges that lay ahead are increase in disability pension, extension of Indiramma Houses allotted to BPL families to be extended to people affected by leprosy. Besides, there is persistence of stigma attached to these people resulting in discrimination at schools, workplace and hospitals. He stated that the way forward is by sensitizing the Department of Social Justice and Social Welfare on Leprosy, inter-sector coordination, inclusion of leprosy affected persons in consultation and monitoring of Services.

Arunachal Pradesh

Dr. Hage Tabyo, Joint Director Health Services (DHS) cum State Leprosy Officer, Arunachal Pradesh in his presentation stated that in the state of Arunachal Pradesh, there are 38 Leprosy Affected Persons and 58 persons are residing within 4 Leprosy Colonies of Tawang, Aalo, Pasighat and Senua (Tirap District). He also said that free ration and medicines were being provided to the inhabitants of the colonies. Medical and para-medical officers are visiting these colonies on weekly basis.

Bihar

Dr. Yantreshwar Jha, Deputy Director Health Services- cum- State Programme Officer gave a presentation on the National Leprosy Eradication Programme (NLEP) in Bihar. He stated that the Multi Drug Therapy (MDT) came into wide use from 1982 and

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was started in Bihar in a phased manner. It was launched in the whole state in 1996-97. He also said that at present, the NLEP is fully integrated into the General Health Care System from sub centres to district hospitals/ medical colleges. He said that the Prevalence Rate in the state was 1.12 as on 31/03/2011, 0.89 as on 31/03/2012 and 1.07 as on 31/07/2012.

He enumerated that some of the major highlights of NLEP in Bihar are that there is involvement of ASHA for referring suspected cases followed by confirmation of cases at all General Health Care Services (GHCS) centers. All confirmed cases get MDT free of cost and there is provision of treatment of intercurrent illnesses and provision of MCR shoes for patients having insensitive feet and ulcers and also an incentive of Rs.5000 to each leprosy cured patient undergoing reconstructive surgery (RCS) for wage loss. As far as the role of supporting agencies was concerned, he said that in addition to providing technical support to the state, associations and organizations like International Federation of Anti Leprosy Association, DFIT, NLR and LEPROA India also provided aid like provision of hand pumps and conducting public awareness programmes by audio visual methods to make people aware of leprosy and its causes.

Gujarat

Dr. K.R. Pujara, State Leprosy Officer in his presentation stated that there are several facilities that are being made available to Leprosy patients under the Social Welfare Scheme. These include distributors of MCR shoes to patients free of cost, Reconstructive surgery is being done free of cost, patients under leprosy treatment and persons with leprosy related disability being rehabilitated free of cost with the help of NGOs. He mentioned about Antyodya scheme for Weak and Old persons under which Rs.200 per month was given to those above 60 years has been extended to persons affected by leprosy. Besides, they are being provided free medical aid and free bus pass. He also stated that needy leprosy patients are being provided economic rehabilitation with the help of NGOs and other donor agencies on voluntary basis. He mentioned that approximately 1490 leprosy patients were staying in 17 leprosy colonies and were being provided free medical and Disability prevention and Medical rehabilitation (DPMR) services.

Haryana

Dr. Rakesh Shel, State Leprosy Officer, Haryana made a presentation on behalf of Government of Haryana. He stated that the Prevalence Rate of leprosy in the state is 0.22. The total number of colonies of leprosy affected persons was 21, out of which 5 are government aided. MDT are distributed free of cost to all persons and Self care kits are also being provided. Besides, free Reconstructive Surgeries are being done along with the provision of Rs. 30,000 to each patient and Rs. 5,000 to the institution.

Jharkhand

Dr. H.B. Barwar, State Leprosy Officer, Jharkhand in his presentation stated that in the state of Jharkhand the prevalence rate is 0.68. Free diagnosis and treatment of leprosy is available on all working days in government health care facilities (195 CHCs, District Hospital & Skin Department of Medical College). MCR footwears are being provided to persons having anesthetic sole. Facilities for reconstructive surgeries are being provided through four tertiary health care facilities. Besides, in order to reduce

stigma and discrimination, awareness in the community is created through gram goshtis, stalls in health melas, publicity during village hat, folk dances, wall writings, hoarding, banner, posters and also through public meetings on special occasions. He also stated that some NGOs are providing educational support to children of persons affected by leprosy. Antoyadaya card are given to 1556 persons and pension card have been given to 1490 persons affected by leprosy

Karnataka

Dr. Shivaram, State Leprosy Office, Karnataka stated that 3718 new cases of leprosy were detected in year 2011-2012. He also mentioned that the state is focusing on early detection and treatment by involving all government health care institutions, ASHAs, nursing homes, private hospitals and NGOs. He stated that there are 20 leprosy colonies in the state having a population of 2401. He also informed about the welfare measures taken by the state government, namely a leprosy hospital with 120 beds in Bangalore having OPD, IPD, physiotherapy and ulcer care services. The state is providing pension of Rs.400 to the persons affected by leprosy with less than 40% disability and Rs. 1000 having more than 70% disability

Kerala

Dr. B Sreelatha, Deputy Director (PH) and State Leprosy Officer, Government of Kerala in her presentation stated that efforts are being made in the state to reduce stigma attached to leprosy by broadcasting short messages and talks through radio, television and other means of mass media, folk shows, magic shows in all districts, health education classes in schools and community by the health staff, counseling for patients to avoid self stigmatization and for family members to accept the patients. She stated that during 2011-2012, efforts for early detection were made through out reach camps. As a result, in 504 outreach camps 138 cases were detected.

Madhya Pradesh

Dr. K.L. Sahu, Director, Health Services, Government of Madhya Pradesh in his presentation stated that confidentiality and privacy of patients affected by leprosy are preserved. He stated that in the state there are 28 leprosy colonies having 3311 inhabitants. He stated the state government is training one member of each colony in self care and first aid procedure to make the colony self dependent. Besides, sub health centre have been established in the colonies. Skill development of colony dwellers have been done in collaboration with the Nippon Foundation, Anganwadi centres have been established in the colonies and amount of pension has been raised.

Maharashtra

Shri T.C. Benjamin, Secretary, Public Health and Dr. B.D. Nanaware, State Leprosy Officer, Government of Maharashtra made presentations. In their presentation, it was stated that the prevalence rate in the state is 1.06 and the annual new case detection rate is 15.96/lakh compared to national average of 10.35. The figures are high probably due to active screening and large scale migration. During the year 2011-12, 17892 new cases of leprosy were detected in the state. There are 32 self settled colonies having 10,798 inhabitants. The state government last year has announced two schemes. As per it an identified dessor of the colony is paid an amount of Rs. 1000 to 3000/ month depending upon the number of patients. Besides, the grant being given to ngo has been

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increased from 480/patient/month to Rs. 2200/patient/month. It was also informed that the steps taken by the state government has reduced stigma and discrimination in terms of isolation and rejection of persons affected with leprosy from community. But it still existed in rural areas as is evident from the fact that 2674 leprosy cured persons residing in leprosy colonies never went home because of stigma. Besides, the persons affected by leprosy have been given direct benefits under Sanjay Gandhi Niradhar Yojna and Antyodya Anna Yojna. He also stated that full pay leave of two years is given to the State Govt. Employees in case he/she is affected with leprosy.

Odisha

Smt. Kasturi Mahapatra, State Commissioner for Persons with Disabilities, attended the conference on behalf of the government of Odisha. She stated that the prevalence rate in Orissa is 0.99. She further stated that Odisha was the first State in the country to achieve leprosy elimination target on 31st July 2006. All the leprosy cases are being diagnosed and treated by General Health Care system. Over 11 lakhs cases of leprosy have been cured with Multi Drug Therapy (MDT) in Odisha so far since 1983. Leprosy is considered as one of the categories of disability. Those affected by Leprosy are provided disability certificate by the District Disability Board. On the basis of certificate, a leprosy cured person is given the same benefit as other PWDs. There are nearly 30000 leprosy cured persons with disabilities in Odisha. All these cases were provided services under Disability Prevention & Medical Rehabilitation Programme (DPMR). 4,500 Leprosy deformities had been corrected with reconstructive surgery (RCS). After each surgery Rs.5,000/- is being paid to each patient. More than 35000 pairs of Micro Cellular Rubber (MCR) foot wear were distributed to the leprosy persons during last 5 years. The Health & Family Welfare Department, Odisha is providing MDT as well as other medicines free of cost and is available in all Government Hospitals. The State Government is also providing free foods to the indoor patients @ Rs50./- per day per patient. Old Age Pension @ Rs.300/- per month under Madhubabu Pension Yojana is being provided to those who were above 60 years of age and Rs.500/- per month to those who were above 80 years of age. Most of the leprosy patients were covered under BPL category and are availing different facilities meant for the BPL. The leprosy cured persons were getting Traveling Concession @50%. The leprosy patients who were staying at in the colonies are provided street lights, water, road etc. by the concerned Municipality. In places like Balasore and Mayurbhanj people affected with leprosy living in slums had been provided land patta and their houses had been constructed under Indira Awas Yojana. Besides, the children of leprosy affected persons were given assistance as follows-

- | | |
|-------------------|--------------------|
| • Upto Class-V | Rs.200/- per month |
| • Upto Class-VIII | Rs.250/- per month |
| • Upto Class-X | Rs.300/- per month |
| • +2 and +3 | Rs.350/- per month |
| • Technical | Rs.350/- per month |

Punjab

Dr. Balbir Singh, State Leprosy Officer, Punjab informed the Commission that the prevalence rate in the state is 0.26. Most of the affected persons are the migrants from the Eastern States He further stated that there were 33 colonies in the state in which 2298

inmates are residing. District Magistrates visit these colonies at least once in a year. The colonies are visited by a medical officer once in a week.

Uttarakhand

The representative from Uttarakhand stated that the state has achieved the target of elimination of leprosy in March 2005. The annual new case detection rate is 5.10 per 1,00,000 of population and the prevalence rate is 0.38 as on August 2012. It was mentioned that there were 29 Kushth Ashrams in the state where a total of 726 persons affected by leprosy are residing. The welfare measures undertaken in these Ashrams are dressing materials and supportive medicines for ulcer cases and minor ailments, MCR footwear for people having anaesthetic feet, aids and appliances like crèches and sun protective glasses. All persons affected by leprosy are being given training for self care. For stigma reduction and to increase awareness in the community, services of health workers and ASHAs have been taken. Disability certificates are issued to the disabled persons as per norms and pension is being given to the disabled, widows and old aged persons affected by leprosy.

Discriminatory Laws: Need for Amendment

In this session, Dr. P.K. Gopal, President, International Association of Integration Dignity and Economic Advancement (IDEA) made a presentation. In his presentation he stated that leprosy has two faces, one is medical and the other is social. Cure has no meaning unless the leprosy cured person returned to the community and led a normal life. The fight against leprosy, as a disease, had been successful with the availability of the effective Multi-Drug Therapy. He further stated that Leprosy, the second most disabling disease, has been the first in the world to divide the affected people from family and community. The social fabric of the leprosy affected individuals had been ruined by the disease- thus creating another face to the disease. He explained that the disease attacked the nerves, causing loss of sensation in the affected body parts. The feeling of pain is a great protection from injuries to the body parts. But the leprosy affected persons did not have the benefit of pain. The deformities in leprosy made people to be afraid of leprosy. There are many wrong notions about the disease. The unscientific beliefs among the people became the very basis of stigma in leprosy. The persons lose their social and economic positions and are driven away to the streets and forced to beg for their living. They started to live together in places away from the community and these places were called as leprosy colonies or leprosy villages.

He thanked the efforts of Nippon Foundation, Japan for providing the drugs free of cost worldwide which was followed later by the Novartis Foundation. He also informed that, with the support of Nippon Foundation, IDEA India, in the year 2005, conducted a survey to know the number of leprosy colonies in different States of India. The study revealed that there are about 850 leprosy colonies, leprosy homes and leprosy hospitals in India. The number of leprosy affected persons in India has always been the highest in the world. More than 12 million patients had been cured from leprosy in the last three decades since introduction of Multi Drug Therapy. Many among them are still living a marginalized life, silently undergoing the sufferings. He stated that in India, though there is no law to segregate them, the family and community abandoned the affected persons or forced them to leave. These persons had to resort to begging for their

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living. When there is a leprosy affected person in a family, the entire family is socially and economically affected. People refuse to marry a girl from these families. When the person had visible deformities, it was very difficult for the family to find a house for rent to live. Leprosy affected person's still face problems to find an alliance for marriage of their sons and daughters.

He stated that many laws have been enacted to segregate the leprosy affected persons from the community. The provisions of the laws are discriminatory and unscientific in the light of modern concepts of science. He named various laws that have discriminating provisions for the leprosy affected persons:

1. Indian Railways Act 1989, Sec.56.
2. Maharashtra State Road Transport Corporation Act 1980
3. Life Insurance Corporation Act as amended in Nov.1987
4. Hindu Marriage Act 1955, Sec13 (IV)
5. Hindu Special Marriage Act 1954, Sec.27 (1) (g)
6. Dissolution of Muslim Marriage Act 1939
7. Indian Christian Marriage Act, 1872
8. Indian Divorce Act, 1869
9. Prevention of Begging Act 1959 (Maharashtra, Gujarat, Karnataka)
10. Persons with Disabilities Act, 1995
11. Industrial Disputes Act, 1947
12. Bombay Municipal Corporation Act ; Sec.419
13. Juvenile Justice, Care & Protection Act 2000; Sec.48
(This Act has been amended.)
14. Motor Vehicles Act 1988
15. Hindu Adoption & Maintenance Act, Sec.18
16. Rehabilitation Council of India Act 1992.

Dr Gopal suggested that all the discriminating provision in the above laws need to be changed. During the presentation, he stated that IDEA, India is conducting Socio-Economic Empowerment Workshops for persons affected by leprosy in different states. In some cities it was difficult to get a venue and accommodation facilities to conduct such workshops. People refused to give their places when they came to know that the place would be used by persons affected by leprosy. He further added that the Swaminathan Committee of Government of India, 1982 had recommended that all derogatory Acts adversely affecting the fundamental rights of a leprosy affected person, should be repealed or amended where needed, without any delay. He informed that with the efforts of Mr. Yohei Sasakawa, Chairman, Nippon Foundation, Japan, the UNHRC passed a resolution to end stigma and discriminations which had been adopted by the UN General Assembly in March 2011. He suggested that the Government should take measures involving NGOs and persons affected by leprosy to implement the resolution. This would also help the leprosy affected persons to know their rights. He said that the fight against discriminations experienced by the people affected by leprosy, the fight against stigma in leprosy needed to start now on a large scale.

Session III Economic and Social Rights : Current Scenario and Challenges

This session was chaired by Justice Shri BC Patel, Member, NHRC. Justice Patel in his introductory remark stated that the persons affected by Leprosy could be helped by the medical professionals and NGOs. He also said that the persons affected by leprosy faced a lot of discrimination in their daily lives. Justice Patel then asked Shri Sunil Anand, Director, Leprosy Mission Trust of India to make his presentation.

In his presentation, Shri Anand enumerated the rights of persons affected by leprosy. He stated that the Right to Health included good quality, affordable care close to place of stay. He said that the denial of this right is often a result of discrimination in access, self stigma and non-availability or lack of expertise. He mentioned that the right to education includes appropriate opportunities for low income leprosy families where discrimination still existed. State must take affirmative action to ensure children have access to education. Under the right to housing and sanitation, the focus should be on the leprosy colonies where they are forced to live resulting in marginalization and segregation. He said that the right to food and livelihood are inherently related to other rights as they have a persistent pattern of discrimination. He suggested that the Government schemes should be formulated to ensure food security.

During his presentation Shri Anand suggested that using of the word 'leper' should be stopped, Elimination, according to him, does not mean end of the problem. As such intensive awareness campaigns should be organized. Funding should be ensured for leprosy services/research and further studies/research on discriminatory laws should be facilitated. In addition, full access to rights should be ensured to build an inclusive society; Greater involvement of persons affected by leprosy should be encouraged. Greater emphasis should be put on right to education and regional public hearings should be held involving civil society organizations. Shri Sunil Anand, also highlighted that in some cases, doctors were even refusing to touch the leprosy patients.

Dr. R.C. Gupta, Vice Chairperson, Hind Kusht Nivaran Sangh in his presentation stated that the symptoms of leprosy were first seen in 1400 BC in Egypt and there is also a mention of this disease in Indian literature of that period. He stated that in India, the most affected states are Tamil Nadu, Orissa, Andhra Pradesh and Maharashtra. He further stated that in past, almost in all societies, the people affected by leprosy were segregated and were sent outside the community. But now, owing to availability of MDT, they can live their life normally during and after treatment. He mentioned that as per NLEP report for the year 2010-2011, 32 states and union territories have eliminated leprosy. In Delhi, the prevalence rate is 0.68. He stated that doctors and NGOs working in the field need to be congratulated for their efforts. He referred to recent media report about the rise in cases of leprosy and stated that after its eradication in 2005, owing to lack of monitoring, the disease seems to be rising its head again. He also stated that efforts must be made to economically and socially rehabilitate the persons affected by leprosy. Although, efforts have been made to rehabilitate persons with other disabilities but very little efforts have been made for rehabilitation of leprosy affected persons. The policy makers and NGOs must work towards it. He suggested that there should not be separate colonies for leprosy affected person, they should be provided land or housing, the products prepared by them should be sold through exhibitions and fairs, a chapter in

17

the school textbooks on leprosy be added to tackle the myth and remove stigma about the disease and awareness be created through seminar and conferences about the issue.

It was followed by the presentation by Dr. Vineeta Shankar, Director, Sasakawa – India Leprosy Foundation. She stated that the major challenge in eliminating the leprosy is the lack of efforts put in to eliminate it. Besides, leprosy has a social and medical impact and all efforts must be made to help persons affected with leprosy take their rightful place in society. One of the ways of doing it is through the economic empowerment and by providing them with educational opportunities. She said that if proper opportunities are provided, they could even be persuaded to give up begging. But this is not easy. She stated that persons affected by leprosy must be trained in technical skills to ensure they have sustainable livelihoods. The aim must be not to supplement begging, but to end its practice altogether. She said that the youth could also help in building the confidence and self assertiveness of persons with leprosy and support in their transition to a normal life after being cured.

Session IV Review of Implementation of Central Schemes for Persons Affected by Leprosy

This session was chaired by Shri Satyabrata Pal, Member, NHRC. The first presentation was made by Dr. A.K. Puri, Assistant Director General (Leprosy), Union Ministry of Health and Family Welfare. Dr Puri highlighted the work done by the Ministry in regard to Leprosy. He explained about the strategy under National Leprosy Eradication Programme which is early detection of cases by increasing voluntary reporting through intensive IEC, treatment with full course of MDT within a specified period, prompt treatment and medical rehabilitation.

He stated that the Disability prevention and medical rehabilitation programme was introduced in the year 2007-2008. Services are being provided to persons affected with Leprosy through General Health Care Service Centres. 51 hospitals/medical colleges and 41 leprosy institutions run by NGOs are providing RCS services. An amount of Rs. 5000/- is provided as incentive to leprosy affected persons from BPL family for undergoing major reconstructive surgery to compensate loss of wages. Support is also provided to Institutions in the form of Rs. 500/- per RCS conducted, for procurement and supply & material and other ancillary expenditure required for the surgery. For prevention of disability among persons with insensitive hands and feet, dressing material, supportive medicines and MCR footwear are being provided.

According to him, 43016 leprosy affected persons were provided with self care kit during 2011-2012. During the same period, 2548 reconstructive surgeries have been conducted and MCR footwear were provided to 55126 persons.

Guidelines to reduce stigma and discriminations against the persons affected by leprosy were issued in March 2012. The Ministry is also coordinating with other Ministries and Departments for the welfare of the persons affected by leprosy and for amendment of discriminating laws and Acts. IEC campaigns through print and electronic media have been intensified. IEC activities are now being integrated with NRHM for

wider dissemination. State Health Secretaries are directed to ensure weekly visit by medical and para-medical personnel to leprosy colonies for providing free medical services. Dr. Puri further informed that the Ministry is coordinating with other ministries and departments to take appropriate action for the amendment of Persons with Disabilities (Equal Opportunity, Protection of Right and Full Participation) Act, 1995 and make a provision for uniform sustenance allowance for persons affected by leprosy.

Shri O.P. Dogra, Deputy Secretary, Ministry of Social Justice and Empowerment, New Delhi in his presentation inform about the major schemes of the Ministry covering rehabilitation of leprosy cured persons (LCPs) which were- Deendayal Disabled Rehabilitation Scheme (DDRS), Aids and Assistive Devices under the ADIP Scheme and Concessional loans provided by the National Handicapped Finance Development Corporation (NHFDC). He said that a single scheme called the "Scheme to Promote Voluntary Action for Persons with Disabilities", an umbrella Central Sector Scheme was formulated in 1999 by amalgamation of the then existing four schemes. The Scheme was revised (excluding cost norms) and renamed as "Deendayal Disabled Rehabilitation Scheme w.e.f 01.04.2003, and the cost norms prescribed in 1999 were revised w.e.f 1.4.2009. Under DDRS financial assistance is provided to 18 projects including two for rehabilitation. The two projects are Project for Rehabilitation of Leprosy Cured Persons and Half-way Home for LCPs. The project cost varied between Rs. 5 lakh to Rs. 20 lakh per annum.

He mentioned that under revision of cost norms under DDRS, leprosy cured persons (LCPs) who may have residual deformity in any part of the body and if such deformity constitutes minimum 40% disability are generally categorized as orthopedically handicapped and are eligible for: all types of prosthetic and orthotic devices, mobility aids like tricycle, wheelchairs, crutches etc and all types of surgical footwears and MCR footwear. Concessional credit is also being provided by National Handicapped Finance Development Corporation (NHFDC) for the activities such as trading/sales, service sector, agricultural purpose, small businesses, purchase of vehicle and education loans.

Shri Satyabrata Pal, Member, NHRC, said that there are excellent laws in India but the implementation of the laws is where the problem is present. He then brought the session to a close.

Valedictory Session

In his concluding remarks, Justice Shri KG Balakrishnan, Chairperson, NHRC stated that there are good laws, but what is needed is their proper implementation. He said the authorities must ensure that the benefit reaches the needy to enable them to live a fulfilling and dignified life. He stated that the Commission will consider suggestions emanating out of the conference and will finalize its recommendations.

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Important suggestions/recommendations emanating out of the National Conference on leprosy:

- 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 natak, 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 families.
- 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 Karnatka 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.

SUDA

STATE URBAN DEVELOPMENT AGENCY

HEALTH WING
"ILGUS BHAVAN"

H-C BLOCK, SECTOR-III, BIDHANNAGAR, CALCUTTA-700 091
West Bengal

Ref No. **SUDA-Health/65/08/275(127)**

Date **10.12.2012**

From : Director, SUDA

To : The Municipal Commissioner, Kolkata Municipal Corporation

: The Commissioner,

..... Municipal Corporation

: The Chairman / Chairperson,

..... Municipality / NAA



Sub. : Implementation of the suggestion / recommendations emanating out of the National Conference on Leprosy organized by N.H.R.C. at New Delhi on 18.09.2012.

Sir / Madam,

Enclosed kindly find herewith communication of the Special Secretary, to the Govt. of West Bengal, Home Department, Human Rights Branch, vide no. 1904(5)-SL/HRC/Misc.-20/12 dt. 04.12.2012 along with minutes of the National Conference on Leprosy, addressed to the Principal Secretary, Department of Municipal Affairs on the subject mentioned above.

You are requested to take / continue with the activities based on important suggestion / recommendations emanating out of the National Conference on Leprosy.

Thanking you.

Yours faithfully

Encl. : As stated.


Director, SUDA

Contd. to P-2.

SUDA-Health/65/08/275(127)/1(3)

Dt. .. 10.12.2012

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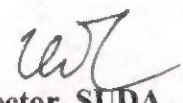

Director, SUDA

SUDA-Health/65/08/275(127)/2(1)

Dt. .. 10.12.2012

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Shri G. Bhattacharya, Special Secretary, Home Department,
Human Rights Branch, Writers' Building, Kolkata – 700 001.


Director, SUDA

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You are requested to take / continue with the measures for Dengue and Chikungunya control in urban areas.

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[Signature]
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Dt. .. 10.12.2012

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[Signature]
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HEALTH WING

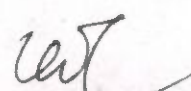


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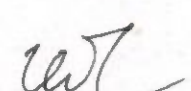

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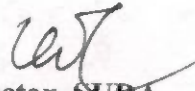
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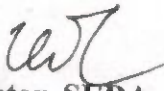

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STATE URBAN DEVELOPMENT AGENCY

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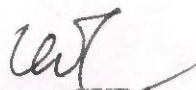
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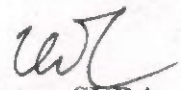

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Shri G. Bhattacharya, Special Secretary, Home Department,
Human Rights Branch, Writers' Building, Kolkata – 700 001.


Director, SUDA

Government of West Bengal
Home Department
Human Rights Branch
Writers' Buildings, Kolkata – 700001.

No. 1904 (5)-SL/HRC/Misc-20/12

Date : 04/12/2012

From : Shri G. Bhattacharya
Special Secretary

- To : 1. The Principal Secretary,
Health & Family Welfare Department.
2. The Principal Secretary,
Municipal Affairs Department.
3. The Principal Secretary,
Panchayet & Rural Development Department.
4. The Secretary, WCD & Social Welfare Department.
5. The Secretary, School Education Department.



Sub : Implementation of the suggestions/recommendations emanating out of the National Conference on Leprosy organized by N.H.R.C at New Delhi on 18/09/2012.

Sir,

In enclosing hereto a copy of the D.O letter No. 11/3/2012-PRP & P dated 05/11/2012 of Shri J.S. Kochher, Joint Secretary (Training), N.H.R.C alongwith a copy of the minutes of the National conference on above-mentioned subject, I am directed to inform that the implementation of the suggestions/recommendations emanating out of the said conference requires active involvement of the Health & Family Welfare Deptt. as also the WCD & SW Deptt., Panchayet & RD Deptt., the Municipal Affairs Deptt. & the School Education Department.

It has also been decided by the Govt. in the Home Deptt. that the Health & Family Welfare Department will act as the "Nodal Department" in implementation of the suggestions/recommendations of the said Conference organized by N.H.R.C and co-ordinate with the WCD & SW Deptt., Panchayet & RD Deptt. the Municipal Affairs Deptt. & School Education Department In the process of implementation, there may be need to involve some other Departments/organizations.

I am, therefore, directed to request all the departments kindly to examine the suggestions/recommendations and take necessary actions for its proper implementation while the Health & Family Welfare Department is requested to act as the Nodal Department of the issue for its implementation.

Action taken on the suggestions/recommendations emanating out of the said "National Conference" should be intimated by other departments to the Health & Family Welfare Department, who, in turn, will consolidate the same alongwith Health & Family Welfare Deptt's action and send the 'Action Taken Report' directly to Shri J.S. Kochher, Joint Secretary (Training), N.H.R.C under intimation to Home Department. Interim appraisal may also be sent by the Health & Family Welfare Department as the Nodal Department of this Govt. to N.H.R.C directly under intimation to this Department.

Copy of this letter is being endorsed to Shri J. S. Kochher, Joint Secretary (Training), N.H.R.C for his kind information.

The matter may kindly be given its deserving urgency and importance.

Encl: As stated

Dix SUDA.

Yours faithfully,

(G. Bhattacharya)
Special Secretary

जयदीप सिंह कोचर

संयुक्त सचिव (प्रशिक्षण)

Jaideep Singh Kochher

JOINT SECRETARY (TRAINING)



राष्ट्रीय मानव अधिकार आयोग

फरीदकोट हाऊस, कॉपरनिकस मार्ग

नई दिल्ली- 110 001 भारत

National Human Rights CommissionFaridkot House, Copernicus Marg,
New Delhi-110 001 INDIA88-OSD
12.11.12.

D.O. No. 11/3/2012-PRP&P

5 November 2012

Dear Shri Ghosh,

The Commission has been deeply concerned about human rights of people affected by leprosy. The Commission with a view to discuss the issues concerning rights of persons affected by leprosy organized a one-day National Conference on Leprosy on 18 September 2012 at India International Centre (New Building), 40 Max Muller Marg, New Delhi.

In this Conference, representatives of States/UTs dealing with the issue, State Human Rights Commissions, Union Ministries and NGOs working in the leprosy sector participated. The minutes of the meeting are annexed (Annexure-I) for necessary action at your end.

You are requested to issue directions so as to ensure implementation of important suggestions/recommendations emanating out of the National Conference under intimation to the Commission.

With regards,

Yours sincerely,

(J.S. Kochher)

Shri Samar Ghosh
Chief Secretary,
Govt. of West Bengal,
Civil Secretariat,
Kolkata- 700001

HSF	HSL
	30/10/12
	14/11/12

Govt. of West Bengal
Home Department
Special Section

Diary No. 1801 dt. 16-11-12

Minutes of the National Conference on "Leprosy" held on 18 September 2012 at India International Centre (IIC), New Delhi

Inaugural Session

Shri J.S. Kochhar, Joint Secretary (Training), NHRC welcomed the participants of the meeting. He stated that although in India, headway had been made in the eradication of leprosy, many other associated issues require the attention of the stakeholder. He mentioned that persons affected by leprosy still faces stigma and discrimination because of which they are forced to live in colonies, roadsides and religious places, facing financial constraints with no opportunity for education. He also referred to the discriminatory provision in laws on account of which human rights of the persons affected by leprosy are violated. Shri Kochher while referring to the principles and guidelines drafted by Human Rights Council and endorsed by the UN General Assembly, stated that the rights enshrined in the Universal Declaration of Human Rights and international covenants are also available to persons affected by leprosy and their families. He stated that the objective of this conference is to bring out certain specific suggestions to protect the rights of persons affected with leprosy.

Justice Shri KG Balakrishnan, Chairperson, National Human Rights Commission (NHRC) in his inaugural address stated that leprosy affected persons suffered human rights violations on various counts including their rights to life of dignity and equality. Jobs are denied to them, which affects their right to dignity. He stated that although leprosy is curable, the physical deformity caused by it coupled with certain myths about the disease result in discrimination. Although, leprosy is the least infectious of all the communicable diseases, yet social prejudice, and discrimination that stems from it, remains deep-rooted. He stated that persons affected by leprosy are routinely denied their basic rights including food, housing, education, health, employment opportunities and full participation. As a consequence, they suffer from poverty and lack of resources. Some of the most insidious of discrimination come with the stigma and social barriers they face – a root cause of their exclusion and marginalization. He stated that leprosy should not be a ground for divorce and that those affected by leprosy should enjoy rights like right to marry, right to hold office, right to work on an equal basis with others.

He expressed his concern about the living conditions in colonies where the persons affected by leprosy and their children are forced to live due to the stigma and discrimination. Chairperson, NHRC further stated that the Commission has collected information from State Governments regarding the financial assistance being provided by them to the persons affected by leprosy. A few States are providing financial assistance in the form of pension, but most of the State Governments do not have such a scheme. Besides, there is no uniformity in the amount of pension being given. He observed that in the light of the fact that stigma and discrimination faced by the people affected by leprosy result in lack of economic capacity. Coupled with high cost of living and inflation, it results in pushing these people below poverty. As such, there is a need to provide decent level of financial support to the persons affected by leprosy. He also stated that there is need to consider if an appropriate pension scheme to enable the persons affected by leprosy to live their life with dignity is required to be put in place uniformly across the

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country. He stated that there is a need to change public attitude by awareness campaigns, education etc. He hoped that the conference would help in bringing out suggestions towards this objective. He also stated that the NHRC would collaborate with any organization to help those affected with leprosy.

Dr. Savita Bhakry, Deputy Secretary (Research), NHRC gave the Vote of Thanks for this session. She thanked the Hon'ble Chairperson, NHRC for enumerating issues of human rights faced by people affected with leprosy and their families. She also thanked all the Members of the NHRC and Joint Secretary (Training), NHRC for giving the overall background of this Conference. She expressed her thanks to representatives of State Governments, Special Rapporteurs of the NHRC, NGOs and the media for participating in the Conference.

Session- II Rights of Persons Affected by Leprosy: Sharing of Best Practices

This session was chaired by Justice Shri GP Mathur, Member, NHRC. He stated that leprosy was also called Hansen's disease. It is caused by Mycobacterium leprae and Mycobacterium lepromatosis and 95% of people are naturally immune to them. He also stated that the progress of leprosy is slow and may take years to develop. He mentioned that the United National General Assembly vide its resolution No.65/215 dated 25.3.11 reaffirms that the persons affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and laws.

He also stated that, as per statistics till April, 2011, the Prevalence Rate (PR) of leprosy is 0.69 per 10,000 populations. As such our country has made good progress in terms of eradication of the disease but lot more needs to be done. He prescribed that by education and employment, it is possible to break the barriers and curb the violations of human rights of those affected by leprosy. He stated that there are two provisions of the Hindu Marriage Act, 1955 that are causing ambiguity. Under section 13 (iv) of the said Act, if one party had been suffering from virulent and incurable form of leprosy, it is a ground for divorce. He said that the meaning of the word "virulent" is strong, poisonous and extremely infectious. The second is section 18 (2) of the same Act which states that if a person is suffering from a virulent form of leprosy, the wife became entitled to live separately from him without forfeiting her claim to maintenance. These provisions, however, did not become grounds for automatic dissolution of marriage. Before 1956, there were no such provisions, but after 1956, society underwent a sea change.

Justice Mathur then explained about the Deendayal Disabled Rehabilitation Scheme of the Government of India. He stated that it provides aid to voluntary organizations to give a wide range of services for rehabilitation of persons with disabilities. The project dealing with persons with leprosy is the project for Rehabilitation of Leprosy Cured Persons. He said that despite leprosy being easily curable, persons with leprosy and their families faced widespread discriminations. They found it difficult to get education, find employment and marry. Even medical professionals discriminate them because of the stigma attached to it. As such they are forced to settle in separate

colonies. Section 2 (t) of the PWD Act, 1995, states that a person with disability meant a person suffering from not less than 40% of any disability certified by a medical authority. As per Section 2 (i) of the Act, persons with disability includes leprosy cured. But, gaps still remained regarding the issue of disability certificates to persons affected with leprosy, preventing a person affected by the disease from taking advantage of the facilities being provided. This needed to be rectified so that there is no harassment caused to the people affected by leprosy.

Thereafter the representatives of States/Union Territories made presentations focusing on welfare schemes for persons affected by leprosy in their respective States/Union Territories.

Andhra Pradesh

Dr. Ranganath Rao, representative from Andhra Pradesh, gave a presentation on Welfare Schemes on Persons Affected by Leprosy- Health and Social Justice on behalf of Dr. T. Tarachand, State Leprosy Officer, Andhra Pradesh. He said that the Leprosy Programme had been integrated into general health care system in Andhra Pradesh and that the Prevalence Rate in the state is 0.63/10,000. He said that there were 99 leprosy colonies in the state.

He stated that the Government of Andhra Pradesh is providing services such as Multi Drug Therapy, Supportive Drugs, Dressing Materials, Self-Care Services and Management of Ulcers through weekly clinics. Micro Cellular Footwear (MCR) is also being provided to protect anesthetic feet. All the families living in the colonies are covered under the Antyodaya scheme. Pension is also given @ Rs.200 per month and disability persons is given @ Rs. 700/- month. Besides, NGOs are also giving support by setting up Vocational Training Centres. Other projects like LEPROA Chetana Project-SLAP, Scholarships to the children of Persons Affected with Leprosy are also there. Besides there are various RCS Centres also set up. Dr. Rao stated that some of the challenges that lay ahead are increase in disability pension, extension of Indiramma Houses allotted to BPL families to be extended to people affected by leprosy. Besides, there is persistence of stigma attached to these people resulting in discrimination at schools, workplace and hospitals. He stated that the way forward is by sensitizing the Department of Social Justice and Social Welfare on Leprosy, inter-sector coordination, inclusion of leprosy affected persons in consultation and monitoring of Services.

Arunachal Pradesh

Dr. Hage Tabyo, Joint Director Health Services (DHS) cum State Leprosy Officer, Arunachal Pradesh in his presentation stated that in the state of Arunachal Pradesh, there are 38 Leprosy Affected Persons and 58 persons are residing within 4 Leprosy Colonies of Tawang, Aalo, Pasighat and Senua (Tirap District). He also said that free ration and medicines were being provided to the inhabitants of the colonies. Medical and para-medical officers are visiting these colonies on weekly basis.

Bihar

Dr. Yantreshwar Jha, Deputy Director Health Services- cum- State Programme Officer gave a presentation on the National Leprosy Eradication Programme (NLEP) in Bihar. He stated that the Multi Drug Therapy (MDT) came into wide use from 1982 and

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was started in Bihar in a phased manner. It was launched in the whole state in 1996-97. He also said that at present, the NLEP is fully integrated into the General Health Care System from sub centres to district hospitals/ medical colleges. He said that the Prevalence Rate in the state was 1.12 as on 31/03/2011, 0.89 as on 31/03/2012 and 1.07 as on 31/07/2012.

He enumerated that some of the major highlights of NLEP in Bihar are that there is involvement of ASHA for referring suspected cases followed by confirmation of cases at all General Health Care Services (GHCS) centers. All confirmed cases get MDT free of cost and there is provision of treatment of intercurrent illnesses and provision of MCR shoes for patients having insensitive feet and ulcers and also an incentive of Rs.5000 to each leprosy cured patient undergoing reconstructive surgery (RCS) for wage loss. As far as the role of supporting agencies was concerned, he said that in addition to providing technical support to the state, associations and organizations like International Federation of Anti Leprosy Association, DFIT, NLR and LEPRO India also provided aid like provision of hand pumps and conducting public awareness programmes by audio visual methods to make people aware of leprosy and its causes.

Gujarat

Dr. K.R. Pujara, State Leprosy Officer in his presentation stated that there are several facilities that are being made available to Leprosy patients under the Social Welfare Scheme. These include distributors of MCR shoes to patients free of cost, Reconstructive surgery is being done free of cost, patients under leprosy treatment and persons with leprosy related disability being rehabilitated free of cost with the help of NGOs. He mentioned about Antyodya scheme for Weak and Old persons under which Rs.200 per month was given to those above 60 years has been extended to persons affected by leprosy. Besides, they are being provided free medical aid and free bus pass. He also stated that needy leprosy patients are being provided economic rehabilitation with the help of NGOs and other donor agencies on voluntary basis. He mentioned that approximately 1490 leprosy patients were staying in 17 leprosy colonies and were being provided free medical and Disability prevention and Medical rehabilitation (DPMR) services.

Haryana

Dr. Rakesh Shel, State Leprosy Officer, Haryana made a presentation on behalf of Government of Haryana. He stated that the Prevalence Rate of leprosy in the state is 0.22. The total number of colonies of leprosy affected persons was 21, out of which 5 are government aided. MDT are distributed free of cost to all persons and Self care kits are also being provided. Besides, free Reconstructive Surgeries are being done along with the provision of Rs. 30,000 to each patient and Rs. 5,000 to the institution.

Jharkhand

Dr. H.B. Barwar, State Leprosy Officer, Jharkhand in his presentation stated that in the state of Jharkhand the prevalence rate is 0.68. Free diagnosis and treatment of leprosy is available on all working days in government health care facilities (195 CHCs, District Hospital & Skin Department of Medical College). MCR footwears are being provided to persons having anesthetic sole. Facilities for reconstructive surgeries are being provided through four tertiary health care facilities. Besides, in order to reduce

stigma and discrimination, awareness in the community is created through gram goshtis, stalls in health melas, publicity during village hat, folk dances, wall writings, hoarding, banner, posters and also through public meetings on special occasions. He also stated that some NGOs are providing educational support to children of persons affected by leprosy. Antoyadaya card are given to 1556 persons and pension card have been given to 1490 persons affected by leprosy

Karnataka

Dr. Shivaram, State Leprosy Office, Karnataka stated that 3718 new cases of leprosy were detected in year 2011-2012. He also mentioned that the state is focusing on early detection and treatment by involving all government health care institutions, ASHAs, nursing homes, private hospitals and NGOs. He stated that there are 20 leprosy colonies in the state having a population of 2401. He also informed about the welfare measures taken by the state government, namely a leprosy hospital with 120 beds in Bangalore having OPD, IPD, physiotherapy and ulcer care services. The state is providing pension of Rs.400 to the persons affected by leprosy with less than 40% disability and Rs. 1000 having more than 70% disability

Kerala

Dr. B Sreelatha, Deputy Director (PH) and State Leprosy Officer, Government of Kerala in her presentation stated that efforts are being made in the state to reduce stigma attached to leprosy by broadcasting short messages and talks through radio, television and other means of mass media, folk shows, magic shows in all districts, health education classes in schools and community by the health staff, counseling for patients to avoid self stigmatization and for family members to accept the patients. She stated that during 2011-2012, efforts for early detection were made through out reach camps. As a result, in 504 outreach camps 138 cases were detected.

Madhya Pradesh

Dr. K.L. Sahu, Director, Health Services, Government of Madhya Pradesh in his presentation stated that confidentiality and privacy of patients affected by leprosy are preserved. He stated that in the state there are 28 leprosy colonies having 3311 inhabitants. He stated the state government is training one member of each colony in self care and first aid procedure to make the colony self dependent. Besides, sub health centre have been established in the colonies. Skill development of colony dwellers have been done in collaboration with the Nippon Foundation, Anganwadi centres have been established in the colonies and amount of pension has been raised.

Maharashtra

Shri T.C. Benjamin, Secretary, Public Health and Dr. B.D. Nanaware, State Leprosy Officer, Government of Maharashtra made presentations. In their presentation, it was stated that the prevalence rate in the state is 1.06 and the annual new case detection rate is 15.96/lakh compared to national average of 10.35. The figures are high probably due to active screening and large scale migration. During the year 2011-12, 17892 new cases of leprosy were detected in the state. There are 32 self settled colonies having 10,798 inhabitants. The state government last year has announced two schemes. As per it an identified dressor of the colony is paid an amount of Rs. 1000 to 3000/ month depending upon the number of patients. Besides, the grant being given to ngo has been

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increased from 480/patient/month to Rs. 2200/patient/month. It was also informed that the steps taken by the state government has reduced stigma and discrimination in terms of isolation and rejection of persons affected with leprosy from community. But it still existed in rural areas as is evident from the fact that 2674 leprosy cured persons residing in leprosy colonies never went home because of stigma. Besides, the persons affected by leprosy have been given direct benefits under Sanjay Gandhi Niradhar Yojna and Antyodya Anna Yojna. He also stated that full pay leave of two years is given to the State Govt. Employees in case he/she is affected with leprosy.

Odisha

Smt. Kasturi Mahapatra, State Commissioner for Persons with Disabilities, attended the conference on behalf of the government of Odisha. She stated that the prevalence rate in Orissa is 0.99. She further stated that Odisha was the first State in the country to achieve leprosy elimination target on 31st July 2006. All the leprosy cases are being diagnosed and treated by General Health Care system. Over 11 lakhs cases of leprosy have been cured with Multi Drug Therapy (MDT) in Odisha so far since 1983. Leprosy is considered as one of the categories of disability. Those affected by Leprosy are provided disability certificate by the District Disability Board. On the basis of certificate, a leprosy cured person is given the same benefit as other PWDs. There are nearly 30000 leprosy cured persons with disabilities in Odisha. All these cases were provided services under Disability Prevention & Medical Rehabilitation Programme (DPMR). 4,500 Leprosy deformities had been corrected with reconstructive surgery (RCS). After each surgery Rs.5,000/- is being paid to each patient. More than 35000 pairs of Micro Cellular Rubber (MCR) foot wear were distributed to the leprosy persons during last 5 years. The Health & Family Welfare Department, Odisha is providing MDT as well as other medicines free of cost and is available in all Government Hospitals. The State Government is also providing free foods to the indoor patients @ Rs50/- per day per patient. Old Age Pension @ Rs.300/- per month under Madhubabu Pension Yojana is being provided to those who were above 60 years of age and Rs.500/- per month to those who were above 80 years of age. Most of the leprosy patients were covered under BPL category and are availing different facilities meant for the BPL. The leprosy cured persons were getting Traveling Concession @50%. The leprosy patients who were staying at in the colonies are provided street lights, water, road etc. by the concerned Municipality. In places like Balasore and Mayurbhanj people affected with leprosy living in slums had been provided land patta and their houses had been constructed under Indira Awas Yojana. Besides, the children of leprosy affected persons were given assistance as follows-

- Upto Class-V Rs.200/- per month
- Upto Class-VIII Rs.250/- per month
- Upto Class-X Rs.300/- per month
- +2 and +3 Rs.350/- per month
- Technical Rs.350/- per month

Punjab

Dr. Balbir Singh, State Leprosy Officer, Punjab informed the Commission that the prevalence rate in the state is 0.26. Most of the affected persons are the migrants from the Eastern States He further stated that there were 33 colonies in the state in which 2298

inmates are residing. District Magistrates visit these colonies at least once in a year. The colonies are visited by a medical officer once in a week.

Uttarakhand

The representative from Uttarakhand stated that the state has achieved the target of elimination of leprosy in March 2005. The annual new case detection rate is 5.10 per 1,00,000 of population and the prevalence rate is 0.38 as on August 2012. It was mentioned that there were 29 Kushth Ashrams in the state where a total of 726 persons affected by leprosy are residing. The welfare measures undertaken in these Ashrams are dressing materials and supportive medicines for ulcer cases and minor ailments, MCR footwear for people having anaesthetic feet, aids and appliances like crèches and sun protective glasses. All persons affected by leprosy are being given training for self care. For stigma reduction and to increase awareness in the community, services of health workers and ASHAs have been taken. Disability certificates are issued to the disabled persons as per norms and pension is being given to the disabled, widows and old aged persons affected by leprosy.

Discriminatory Laws: Need for Amendment

In this session, Dr. P.K. Gopal, President, International Association of Integration Dignity and Economic Advancement (IDEA) made a presentation. In his presentation he stated that leprosy has two faces, one is medical and the other is social. Cure has no meaning unless the leprosy cured person returned to the community and led a normal life. The fight against leprosy, as a disease, had been successful with the availability of the effective Multi-Drug Therapy. He further stated that Leprosy, the second most disabling disease, has been the first in the world to divide the affected people from family and community. The social fabric of the leprosy affected individuals had been ruined by the disease- thus creating another face to the disease. He explained that the disease attacked the nerves, causing loss of sensation in the affected body parts. The feeling of pain is a great protection from injuries to the body parts. But the leprosy affected persons did not have the benefit of pain. The deformities in leprosy made people to be afraid of leprosy. There are many wrong notions about the disease. The unscientific beliefs among the people became the very basis of stigma in leprosy. The persons lose their social and economic positions and are driven away to the streets and forced to beg for their living. They started to live together in places away from the community and these places were called as leprosy colonies or leprosy villages.

He thanked the efforts of Nippon Foundation, Japan for providing the drugs free of cost worldwide which was followed later by the Novartis Foundation. He also informed that, with the support of Nippon Foundation, IDEA India, in the year 2005, conducted a survey to know the number of leprosy colonies in different States of India. The study revealed that there are about 850 leprosy colonies, leprosy homes and leprosy hospitals in India. The number of leprosy affected persons in India has always been the highest in the world. More than 12 million patients had been cured from leprosy in the last three decades since introduction of Multi Drug Therapy. Many among them are still living a marginalized life, silently undergoing the sufferings. He stated that in India, though there is no law to segregate them, the family and community abandoned the affected persons or forced them to leave. These persons had to resort to begging for their

living. When there is a leprosy affected person in a family, the entire family is socially and economically affected. People refuse to marry a girl from these families. When the person had visible deformities, it was very difficult for the family to find a house for rent to live. Leprosy affected person's still face problems to find an alliance for marriage of their sons and daughters.

He stated that many laws have been enacted to segregate the leprosy affected persons from the community. The provisions of the laws are discriminatory and unscientific in the light of modern concepts of science. He named various laws that have discriminating provisions for the leprosy affected persons:

1. Indian Railways Act 1989, Sec.56.
2. Maharashtra State Road Transport Corporation Act 1980
3. Life Insurance Corporation Act as amended in Nov.1987
4. Hindu Marriage Act 1955.Sec13 (IV)
5. Hindu Special Marriage Act 1954, Sec.27 (1) (g)
6. Dissolution of Muslim Marriage Act 1939
7. Indian Christian Marriage Act, 1872
8. Indian Divorce Act,1869
9. Prevention of Begging Act 1959 (Maharashtra, Gujarat, Karnataka)
10. Persons with Disabilities Act, 1995
11. Industrial Disputes Act, 1947
12. Bombay Municipal Corporation Act ; Sec.419
13. Juvenile Justice, Care & Protection Act 2000; Sec.48
(This Act has been amended.)
14. Motor Vehicles Act 1988
15. Hindu Adoption & Maintenance Act, Sec.18
16. Rehabilitation Council of India Act 1992.

Dr Gopal suggested that all the discriminating provision in the above laws need to be changed. During the presentation, he stated that IDEA, India is conducting Socio-Economic Empowerment Workshops for persons affected by leprosy in different states. In some cities it was difficult to get a venue and accommodation facilities to conduct such workshops. People refused to give their places when they came to know that the place would be used by persons affected by leprosy. He further added that the Swaminathan Committee of Government of India, 1982 had recommended that all derogatory Acts adversely affecting the fundamental rights of a leprosy affected person, should be repealed or amended where needed, without any delay. He informed that with the efforts of Mr.Yohei Sasakawa, Chairman, Nippon Foundation, Japan, the UNHRC passed a resolution to end stigma and discriminations which had been adopted by the UN General Assembly in March 2011. He suggested that the Government should take measures involving NGOs and persons affected by leprosy to implement the resolution. This would also help the leprosy affected persons to know their rights. He said that the fight against discriminations experienced by the people affected by leprosy, the fight against stigma in leprosy needed to start now on a large scale.

Session III Economic and Social Rights : Current Scenario and Challenges

This session was chaired by Justice Shri BC Patel, Member, NHRC. Justice Patel Patel in his introductory remark stated that the persons affected by Leprosy could be helped by the medical professionals and NGOs. He also said that the persons affected by leprosy faced a lot of discrimination in their daily lives. Justice Patel then asked Shri Sunil Anand, Director, Leprosy Mission Trust of India to make his presentation.

In his presentation, Shri Anand enumerated the rights of persons affected by leprosy. He stated that the Right to Health included good quality, affordable care close to place of stay. He said that the denial of this right is often a result of discrimination in access, self stigma and non-availability or lack of expertise. He mentioned that the right to education includes appropriate opportunities for low income leprosy families where discrimination still existed. State must take affirmative action to ensure children have access to education. Under the right to housing and sanitation, the focus should be on the leprosy colonies where they are forced to live resulting in marginalization and segregation. He said that the right to food and livelihood are inherently related to other rights as they have a persistent pattern of discrimination. He suggested that the Government schemes should be formulated to ensure food security.

During his presentation Shri Anand suggested that using of the word 'leper' should be stopped, Elimination, according to him, does not mean end of the problem. As such intensive awareness campaigns should be organized. Funding should be ensured for leprosy services/research and further studies/research on discriminatory laws should be facilitated. In addition, full access to rights should be ensured to build an inclusive society; Greater involvement of persons affected by leprosy should be encouraged. Greater emphasis should be put on right to education and regional public hearings should be held involving civil society organizations. Shri Sunil Anand, also highlighted that in some cases, doctors were even refusing to touch the leprosy patients.

Dr. R.C. Gupta, Vice Chairperson, Hind Kusht Nivaran Sangh in his presentation stated that the symptoms of leprosy were first seen in 1400 BC in Egypt and there is also a mention of this disease in Indian literature of that period. He stated that in India, the most affected states are Tamil Nadu, Orissa, Andhra Pradesh and Maharashtra. He further stated that in past, almost in all societies, the people affected by leprosy were segregated and were sent outside the community. But now, owing to availability of MDT, they can live their life normally during and after treatment. He mentioned that as per NLEP report for the year 2010-2011, 32 states and union territories have eliminated leprosy. In Delhi, the prevalence rate is 0.68. He stated that doctors and NGOs working in the field need to be congratulated for their efforts. He referred to recent media report about the rise in cases of leprosy and stated that after its eradication in 2005, owing to lack of monitoring, the disease seems to be rising its head again. He also stated that efforts must be made to economically and socially rehabilitate the persons affected by leprosy. Although, efforts have been made to rehabilitate persons with other disabilities but very little efforts have been made for rehabilitation of leprosy affected persons. The policy makers and NGOs must work towards it. He suggested that there should not be separate colonies for leprosy affected person, they should be provided land or housing, the products prepared by them should be sold through exhibitions and fairs, a chapter in

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the school textbooks on leprosy be added to tackle the myth and remove stigma about the disease and awareness be created through seminar and conferences about the issue.

It was followed by the presentation by Dr. Vineeta Shankar, Director, Sasakawa – India Leprosy Foundation. She stated that the major challenge in eliminating the leprosy is the lack of efforts put in to eliminate it. Besides, leprosy has a social and medical impact and all efforts must be made to help persons affected with leprosy take their rightful place in society. One of the ways of doing it is through the economic empowerment and by providing them with educational opportunities. She said that if proper opportunities are provided, they could even be persuaded to give up begging. But this is not easy. She stated that persons affected by leprosy must be trained in technical skills to ensure they have sustainable livelihoods. The aim must be not to supplement begging, but to end its practice altogether. She said that the youth could also help in building the confidence and self assertiveness of persons with leprosy and support in their transition to a normal life after being cured.

Session IV Review of Implementation of Central Schemes for Persons Affected by Leprosy

This session was chaired by Shri Satyabrata Pal, Member, NHRC. The first presentation was made by Dr. A.K. Puri, Assistant Director General (Leprosy), Union Ministry of Health and Family Welfare. Dr Puri highlighted the work done by the Ministry in regard to Leprosy. He explained about the strategy under National Leprosy Eradication Programme which is early detection of cases by increasing voluntary reporting through intensive IEC, treatment with full course of MDT within a specified period, prompt treatment and medical rehabilitation.

He stated that the Disability prevention and medical rehabilitation programme was introduced in the year 2007-2008. Services are being provided to persons affected with Leprosy through General Health Care Service Centres. 51 hospitals/medical colleges and 41 leprosy institutions run by NGOs are providing RCS services. An amount of Rs. 5000/- is provided as incentive to leprosy affected persons from BPL family for undergoing major reconstructive surgery to compensate loss of wages. Support is also provided to Institutions in the form of Rs. 500/- per RCS conducted, for procurement and supply & material and other ancillary expenditure required for the surgery. For prevention of disability among persons with insensitive hands and feet, dressing material, supportive medicines and MCR footwear are being provided.

According to him, 43016 leprosy affected persons were provided with self care kit during 2011-2012. During the same period, 2548 reconstructive surgeries have been conducted and MCR footwear were provided to 55126 persons.

Guidelines to reduce stigma and discriminations against the persons affected by leprosy were issued in March 2012. The Ministry is also coordinating with other Ministries and Departments for the welfare of the persons affected by leprosy and for amendment of discriminating laws and Acts. IEC campaigns through print and electronic media have been intensified. IEC activities are now being integrated with NRHM for

wider dissemination. State Health Secretaries are directed to ensure weekly visit by medical and para-medical personnel to leprosy colonies for providing free medical services. Dr. Puri further informed that the Ministry is coordinating with other ministries and departments to take appropriate action for the amendment of Persons with Disabilities (Equal Opportunity, Protection of Right and Full Participation) Act, 1995 and make a provision for uniform sustenance allowance for persons affected by leprosy.

Shri O.P. Dogra, Deputy Secretary, Ministry of Social Justice and Empowerment, New Delhi in his presentation inform about the major schemes of the Ministry covering rehabilitation of leprosy cured persons (LCPs) which were- Deendayal Disabled Rehabilitation Scheme (DDRS), Aids and Assistive Devices under the ADIP Scheme and Concessional loans provided by the National Handicapped Finance Development Corporation (NHFDC). He said that a single scheme called the "Scheme to Promote Voluntary Action for Persons with Disabilities", an umbrella Central Sector Scheme was formulated in 1999 by amalgamation of the then existing four schemes. The Scheme was revised (excluding cost norms) and renamed as "Deendayal Disabled Rehabilitation Scheme w.e.f 01.04.2003, and the cost norms prescribed in 1999 were revised w.e.f 1.4.2009. Under DDRS financial assistance is provided to 18 projects including two for rehabilitation. The two projects are Project for Rehabilitation of Leprosy Cured Persons and Half-way Home for LCPs. The project cost varied between Rs. 5 lakh to Rs. 20 lakh per annum.

He mentioned that under revision of cost norms under DDRS, leprosy cured persons (LCPs) who may have residual deformity in any part of the body and if such deformity constitutes minimum 40% disability are generally categorized as orthopedically handicapped and are eligible for: all types of prosthetic and orthotic devices, mobility aids like tricycle, wheelchairs, crutches etc and all types of surgical footwears and MCR footwear. Concessional credit is also being provided by National Handicapped Finance Development Corporation (NHFDC) for the activities such as trading/sales, service sector, agricultural purpose, small businesses, purchase of vehicle and education loans.

Shri Satyabrata Pal, Member, NHRC, said that there are excellent laws in India but the implementation of the laws is where the problem is present. He then brought the session to a close.

Valedictory Session

In his concluding remarks, Justice Shri KG Balakrishnan, Chairperson, NHRC stated that there are good laws, but what is needed is their proper implementation. He said the authorities must ensure that the benefit reaches the needy to enable them to live a fulfilling and dignified life. He stated that the Commission will consider suggestions emanating out of the conference and will finalize its recommendations.

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Important suggestions/recommendations emanating out of the National Conference on leprosy:

- 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 families.
- 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.
- There 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.
