**ELIMINATION OF DISCRIMINATION AGAINST LEPROSY AFFECTED PERSONS AND THEIR FAMILY MEMBERS**

**Questionnaire for**

 **NON-GOVERNMENTAL ORGANIZATIONS**

**BACKGROUND**

In its resolution A/HRC/29/5, the Human Rights Council requested the Advisory Committee to undertake a study which reviews the implementation of the Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members, together with the obstacles thereto, and to submit a report containing practical suggestions for their wider dissemination and more effective implementation and to submit a report at its thirty-fifth session.

The resolution also requests the Advisory Committee, in its elaboration of the report, to take into account the views of Member States and as appropriate relevant international organizations, including the World Health Organization, the Office of the United Nations High Commissioner for Human Rights and relevant special procedures, national human rights institutions, and non-governmental organizations, as well as the work done on the issue by relevant United Nations bodies, specialized agencies, funds and programmes within their respective mandates.

In this context, the Advisory Committee decided, at its fifteenth session held in August 2015, to establish a drafting group in charge of the preparation of this study.[[1]](#footnote-1) The purpose of this questionnaire is to collect information from non-governmental organizations in order to identify the current state of implementation of the Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members (the Principles and Guidelines); how the Principles and Guidelines apply to different situations in different countries, especially the good practices that may be shared; and the major obstacles to implementation, including views on how best to further strengthen the implementation of the Principles and Guidelines.

**1. Are you aware of the Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members adopted by the United Nations General Assembly in December 2010 (resolution 65/215)? If yes, how did it come to your attention?**

We are aware about the resolution 65/245 through our ILEP members and also from United Nations enable newsletter. The resolution safeguards the human rights and promotes dignity of people we work with.

**2. What mechanism has the Government (Federal or State level) put in place to disseminate the Principles and Guidelines to its citizens? e.g. translation into national and local languages; media; or any other mechanism?**

Currently, the National Human rights commission is taking lead and recommended government to disseminate the principles and guidelines. No formal mechanism is in place, but local NGOs or disabled people organisations are disseminating the information

**3. Have any policies, action plans or any other measures been taken at the national level to promote awareness-raising of the issue of discrimination against leprosy affected persons and their family members? Please provide details on measures taken.**

At national level, Human Rights Commission organised seminars and engaged government officials, peoples organisations, NGOs and state level human rights commission heads emphasised the need to protect the human rights and in ensuring anti stigma and discriminatory provisions, it made recommendations to the government to act and followed up its actions.

Apart from the above, the government has not taken any affirmative steps till now to roll out the plan of action for implementing the UN resolution.

LEPRA Society, Society for Leprosy Affected Persons (now Association of People affected by Leprosy), Nippon foundation organised state level seminar aimed at creating mass awareness by engaging media and politicians for seeking commitment. LEPRA Society in India formally facilitating the CBOs and state level forums of people affected by leprosy in four states in addressing the issues pertaining to discrimination and inclusion.

**4. What measures have been taken (Federal or State level) to modify, repeal or abolish discriminatory laws, policies or practices, including terminating forced segregation, in order to eliminate discrimination against persons affected by leprosy and their family members? Is freedom to choose where to live ensured for persons affected by leprosy and their family members?**

The government of India undertook the task of identifying laws which can either be repealed or need amendment’s and appointed law commission to review. The commission undertook the study and presented report (Government of India, Law Commission of India Report No.256; Eliminating discrimination against persons affected by leprosy). The Law Commission has prepared model draft legislation, titled “Eliminating Discrimination against Persons Affected by Leprosy (EDPAL) Bill, 2015” and it is under review in parliament. In instances of discrimination, the state law commission is acting and responding to the issues with support from leprosy organisations.

**5.** **Which is the terminology originally used in your native language in respect of persons affected by leprosy? Please also provide, aside from the specific terminology in your native language, a translation of it in English. Are there any popular myths associated with persons affected by leprosy? Please provide a short description.**

*Kustharog, Maharog, Kodhi, Badarog, bada bimari* are the common words used locally for persons affected by leprosy which means a big disease. Few are the myths still in practice are

* Leprosy is contagious and dangerous disease and isolate them
* Ramesh Prasad, Deputy Secretary, Samuttan, CBO recently highlighted how people affected by leprosy are stigmatised even in their death. Their families are not allowed to cremate their bodies as per Hindu tradition based on a belief that even the smoke from the cremation might cause leprosy to the general population. So they are forced to bury their dead
* Leprosy is result of a curse

**6. Are those affected by leprosy and their family members being consulted with and/or actively participating in the decision-making processes that deal with matters related to them?**

Persons affected by leprosy and their organisations are raising their voices at district, state and national level and they are being consulted for their views and suggestions pertaining to their entitlements and rights.

**7**. **What measures have been taken at the national level to ensure persons affected by leprosy enjoy fully and equally rights with others regarding the rights of citizenship; obtaining identity documents; the right to vote; the right to stand for elections; the right to serve the public in any capacity or other civil and political rights?**

**8. What measures have been taken to ensure persons affected by leprosy enjoy equal rights with others with regard to the rights to work and education; establishing a family; access to public places, including hotels, restaurants; and buses, taxis, trains and other forms of public transport; access to cultural and recreational facilities; access to places of worship or any other economic, social and cultural rights?**

**9. What actions have been taken to promote and protect the human rights of (a) women; (b) children; (c) the elderly; (d) members of other vulnerable groups who have or have had leprosy, as well as their family members? Please provide details.**

**10. What actions have been taken at the national level with regard to discriminatory, labelling and offensive languages directed at leprosy affected persons?**

**11. Have Governments drafted and/or adopted a national action plan to implement the Principles and Guidelines? Please attach a copy. Has a national committee been established? Please provide some details as to its mandate, size and composition of members.**

**For 7-11**

* <http://pib.nic.in/newsite/PrintRelease.aspx?relid=118021>
* <http://lawcommissionofindia.nic.in/reports/Report256.pdf>
* [http://164.100.47.134/lsscommittee/Social%20Justice%20&%20Empowerment/16\_Social\_Justice\_And\_Empowerment\_15.pdf](http://164.100.47.134/lsscommittee/Social%20Justice%20%26%20Empowerment/16_Social_Justice_And_Empowerment_15.pdf);
* <http://164.100.47.192/Loksabha/Committee/CommitteeInformation.aspx?comm_code=47&tab=1>

**12. What major obstacles, if any, have Governments faced in implementing the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members?**

* Lack of staff or manpower in the leprosy programme and the current program focus is more on eliminating the leprosy or reducing the prevalence.
* Government is not adequately addressing the issues of persons affected by leprosy who need care after cure from MDT.
* India achieved elimination goal in 2005 at country level and the false sense of leprosy burden among the government (leprosy is not a problem)
* Delay in parliamentary procedures for passing bills
* Government officials and duty bearers are not aware about principles and guidelines for the elimination of discrimination against persons affected by leprosy and their families
* Self-stigma or perceived stigma among the persons affected by leprosy

**13.**  **In your view, what follow-up mechanisms should be put in place at the national and international levels to effectively implement the Principles and Guidelines?**

* Sensitise the government and other key stakeholders about the UN resolution
* Establish district, state and national level committees with human rights commission, government officials, media, rights based organisations, lawyers forum, people affected by leprosy for reporting and assuring support to eliminate discrimination
* Implement awareness and capacity building activities in Project Implementation plans of leprosy programme at state and national level or in global strategies
* Ensure access to the persons affected by leprosy and their families to Human rights commission members
* Action taken report or measures by the government in ensuring the implementation of the principles and guidelines
* Create awareness or disseminate about free legal services

**14**. **Are there any concrete measures taken by Governments at different levels that you can share with us regarding actions taken to eliminate discrimination against leprosy affected persons and their family members in your country?**

One of the objectives of our National leprosy programme is reduction in the level of stigma associated with leprosy. But the fact is Information, Education and Communication materials target programme aspects or day oriented activities, but not the issues of people affected or human rights. The government is drafting Social Behaviour Change communication strategy and will be rolled out in next year.

As mentioned in the previous section, Indian laws directly or indirectly discriminate the persons affected by leprosy, the need of hour is repeal or amend the laws which , directly and indirectly discriminate against Persons affected by Leprosy and currently the government is reviewing the law commission report.

**15**. Please provide identified cases of discrimination experienced by leprosy affected persons and their family members in your country, disaggregated by its different forms, including de facto discrimination.

**Deadline for submission of responses:**

All parties are encouraged to submit their responses via email or fax as soon as possible but no later than **30 December 2015** to:

**hrcadvisorycommittee@ohchr.org**[Subject: HRCAC Elimination of discrimination against persons affected by leprosy]

or

Secretariat of the Human Rights Council Advisory Committee

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Thank you in advance for your contribution.

For more information about the Advisory Committee, please visit <http://www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/HRCACIndex.aspx>

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1. A/HRC/AC/15/L.3 [↑](#footnote-ref-1)