**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)?

Yes we are aware about it.

If yes, how did it come to your attention?

Through Sasakawa Memorial Health Foundation (SMHF), email from INFOLEP and also thru LML

1. 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?

Since we are dealing with Ministry of health, we are not fully aware as to what actions have been initiated by Ministry of Social Justice and Empowerment in it’s dissemination. To our knowledge Govt. have not been very active in this regard. Printed booklets in English were distributed in various meetings thru WHO and SMHF.

1. 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.

Campaigns and routine IEC activities include dissemination of messages through print media, face to face discussions during meetings at grass root level and it remained part of yearly Project Implementation Plan (PIP) in all the states/provinces and union territories. ILEP members in India are part of movement to amend discriminatory laws related to leprosy. National Human Right Commission (NHRC) in India played a vital role by organizing national workshops and monitoring related activities in different states/provinces.

**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?

Central Leprosy Division (CLD), Ministry of Health & Family Welfare took the initiative and organised interdepartmental meetings to discuss the issues related to amendment of discriminatory laws and rights of persons affected by leprosy. A Rajya Sabha (Pariamentary) Committee was constituted to examine the matters related to rights of persons affected & discrimination, current situation and steps to be taken. Rajya Sabha (Pariamentary) Committee report 131 and its subsequent reports (available on web site) played a vital role in promoting change in derogatory laws. Recently Law Commission of India has submitted a bill to Parliament, in favour of repealing the laws and protecting the rights of persons affected by leprosy. ILEP agencies are playing a major role in it.

1. 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.

Persons Affected by Leprosy were traditionally called “Kodhi” in native language, now they are called as “Kusth Rogi or Kusth Peedit” in Hindi meaning suffering from leprosy in English. Certain myths e.g. leprosy is due to past sins, wrath of God, incurable and highly infectious were prevailing in the community but are gradually decreasing. Self-stigma and fear of contracting the disease still exists but is less now.

1. 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?

Representatives of persons affected by leprosy / Association of persons affected by leprosy (APAL) are invited in meetings at national & state level and they participate actively e.g. State leprosy Officers’ meeting, during discussion on ILEP in India strategy, WHO global strategy etc. Self-Care Groups of P.A.L. are formed in India where peer group discussions are held and local committees decide about support required to their dependants.

1. 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?

All persons affected by leprosy have equal rights e.g. voter ID cards, ration cards. They have right to vote but do not have right to contest elections due to existing law which is under process of repealing. Persons with disability due to leprosy (PWDL) are given disability certificates and other entitlements such as pension, travel concessions etc. A separate category of “Leprosy Cured Persons” has been added in Persons with Disability (PWD) and schemes for them have been added. Related bill will be submitted by Law Commission before Parliament.

**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?

To our knowledge there are no special measures taken by the Govt, however there is no ban or prohibition for people affected by leprosy to travel or participate in society.

**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.

There are provisions and government schemes for women, children and elderly vulnerable groups / family members of persons affected by leprosy. ILEP agencies, missionaries and other civil societies take care of these vulnerable groups in their areas.

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

Word ‘Leper’ has been banned and is not used in any communication by government and is highlighted during meetings also. Persons affected are not abused.

**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.

We are not aware about such steps.

**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?

Not known.

**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?

Ministry of social Justice and human rights commission should be approached to first for acceptance of guidelines by them then it’s dissemination in print and in series of meetings/activities.

**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?

These points are covered in reply to number 6 to 10.

**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.

Case studies are not readily available

**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>

Behaviour Change Communication (BCC) strategies to remove perceived fear of infection are needed to end discrimination and change the image of of leprosy in the minds of people. Central Leprosy Division together with ILEP in India organized an IEC strategy workshop to evolve operational aspects of BCC strategy. Some NGOs are trying to implement stigma removal strategies through studies funded by Leprosy Research Initiatives (LRI)

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