**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?

Yes, I am aware of the Principles and guidelines. I know about these as we are a member of ILEP network.

**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?

I have checked with the Government officials, and though they have not literally translated the Principles and Guidelines but have put the meanings into their National and District level Strategy. The Strategy has been disseminated down into district and community. We as an organisation, have also disseminated these Principles and Guidelines into our Community Based Rehabilitation programmes.

**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.

World Leprosy Day is celebrated from national to federal level. During the celebration the slogans are mainly of “leprosy free society” and “end of discrimination of leprosy affected people” etc. There is also interaction TV programme with the leprosy affected people and their family members regarding the discrimination they face because of leprosy and the ways to end it.

The Government has advocated with other partners for political commitment to eliminate discrimination against persons affected with leprosy and their family members.

**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?

At the initiation of The Leprosy Mission Nepal, with the support of Nepal Government, we led a nation-wide campaign in support of leprosy affected persons to pass the discriminatory Anti-Marriage law, which had created a ground to stop marriage with a person affected with leprosy. We succeeded in stopping the passing of this law in Nepal

**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.

Originally the word “Kodi”, “Maharogi” was the terms used in respect of persons affected by leprosy. The word “kodi” means “leper” in English, while “maharogi” means “person suffering from great disease”. Both of these are derogatory terms.

There are many myths associated with persons affected by leprosy in Nepal, some of which are:

1. Leprosy is hereditary.
2. Leprosy is a curse from Nag Deuta, the snake God.
3. Leprosy is caused by eating bad food.
4. Leprosy is caused by impure blood in your body.

**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?

Yes. In TLM Nepal, we invite persons affected with leprosy in our Annual Country Learning (ACL) meetings. They actively participate in the decision-making processes that deal with matters related to them. They are involved in implementation and evaluation, and planning phase of the project.

**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?

We don’t have problems in regards in obtaining citizenship, obtaining identity documents, the right to vote; the right to stand for elections, and the right to serve the public in any capacity. There is very mild discrimination which doesn’t come to light often.

**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?

The government has not taken any measures except awareness and advocacy programmes. Only persons with severe reaction and visible disability face discrimination in the above mentioned fields. There is no law for or against the people affected by leprosy, and also I have not known about any action taken against the people who discriminate against them.

**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.

I don’t know of any actions taken to promote and protect the human rights. Though from the non-government side (I/NGOs), there is women empowerment programme through CBR intervention for women, for children there is education support and advocacy, and for the elderly there is care and welfare programme to protect their human rights.

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

No actions have been taken against people who discriminate against 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.

No. The Government has developed a Strategy Document which has incorporated the Principles and Guidelines, but they have not directly translated these word by word. Please find below the diagram on what the government has included in its Strategy:

\* GESI stands for Gender Equity and Social Inclusion

This strategy has been translated and elaborated and shared with the concerned government system.

**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?

I think the obstacle is Stigma amongst the educated and bureaucrats. The government needs to be serious on this issue.

**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?

The government needs to take serious initiative on this matter and then they should disseminate them though the government system. With the support of other partners, this mechanism can take place. The government should integrate the human rights issue of leprosy affected people with other human rights campaigns. They should also make a law to protect the leprosy affected people.

We need to create a forum of the Bar Association, Law and Justice Ministry and develop a mechanism. The involvement of other ministries, i.e. Law and Justice Ministry, Women, Children & Social Ministry, Bar Association, is very necessary. Until now we had relied on Health Ministry to tackle these issues, but discrimination is a very pervasive issue and not a health related issue, but a social issue. Therefore we need to involve Law & Justice Ministry in this matter.

**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?

They have prepared the National Strategy document. They are also involved in the World Leprosy Day celebration providing slogans claiming elimination of discrimination against leprosy affected persons and their family. They are involving leprosy affected persons in their case finding activities,

**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.

Mrs Mithu Sanjel, had to leave her home and family when she was diagnosed with leprosy.

A lady named Maisani Tamang came to Anandaban Hospital and stayed there for 38 years until her death couple of years back. Nobody from her family came to visit her during those 38 years.

Just two years back, Gita Chaudhari, 26 years old, was kicked out of her home by her husband and in-laws, after being diagnosed with leprosy. She has also been denied her right to her husband’s property because there is no law to protect her.

Mr Neupane, 42 years old, working in government office, was looked down upon. Nobody drank tea that was prepared by him and also he was not allowed to touch the files in his office.

Aman Gurung, 11 years old, faces discrimination at school. His friends run away from him and are uncooperative.

**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

Attn. Ms. Dina Rossbacher

Office of the United Nations High Commissioner for Human Rights

CH-1211 Geneva 10, Switzerland

Fax: +41 22 917 9011

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)