**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?

No

**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?

The Government has not taken any steps to disseminate the Principles & Guidelines. But the Ministry of Health, Anti Leprosy Campaign (ALC) has taken many steps to conduct Prevention & Control of activities in the country. FAIRMED FOUNDATION (FM) in Sri Lanka has been assisting the ALC to conduct these activities in the districts they work with since 1991.

**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.

In addition to the answer provided in question 2, the following work undertaken by the Ministry of Health and FM needs to be considered.

The National Action plan developed by the Ministry of Health for the years 2014 – 2016 has activities targeting the awareness raising on issues of discrimination as well as workshops on stigma for community members and health workers.

The Annual Report of ALC for 2014 mentions –‘To fight all forms of stigma associated with Leprosy’ as one of their specific objectives.

Leprosy was made a notifiable disease in the country in 2013 but no proper measures have been taken to repeal the leper’s ordinance (1901).

**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?

No measures have been taken to repeal the leper’s ordinance. There have been no issues pertaining to segregation in the country and the people affected live in the same community as well as the others. But some of them who do not want to reveal themselves live in distress as they do not want the rest of the community to know about the infection.

**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.

In Sinhala – ‘Laduru’

In Tamil – ‘ Thola noi’

The awareness regarding the disease seems to be still poor and as a result there are some people who still believe that it is due to a curse by the God. In addition, there are various misconceptions regarding the mode of transmission, as they believe that they could get infected by touching a person resulting in stigma & Discrimination in certain circumstances.

**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?

No

**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?

In spite of the above-mentioned issues, the persons affected by leprosy enjoy their right as any other person in the country.

**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?

No specific measures have been taken by the country to ensure equal rights of the persons affected by leprosy. But the persons with disabilities are protected and cared for to a certain extent by the Act No 28 of 1996 - ‘Protection of Rights of Persons with Disabilities’. Therefore, the rights of persons with deformities such as claw hands, foot drops etc are provided under this Act.

**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.

No specific action for these groups has been taken as yet.

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

None

**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

**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?

Cannot comment, as the government has not initiated any activities.

**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?

At National Level, mechanisms could be initiated to repeal the leprosy ordinance and to enact laws to protect the fundamental rights of the affected persons.

International support provided for the Government to initiate the above 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?

A social media campaign was conducted in 1989, which was instrumental in detecting many hidden cases. In addition, Leprosy has been integrated in to the general health services since 2001 and the national Action plan of 2014 – 2016 has identified some activities that would be carried out in the country.

As, FAIRMED FOUNDATION in Sri Lanka, we have been supporting the Ministry of Health and has been working in 5 districts since 2014 to carryout the activities of the National Action Plan. We have supported the Government to train health staff such as Medical officers, Public Health Inspectors and Physiotherapists to carry out the field level activities and establishing District Leprosy Teams. Conducting Awareness programmes, Advocacy programmes as well as counselling training for public health staff are some of the other activities supported by FM.

**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.

The most commonest discrimination found is that the Person loosing the job due to various reasons. There have been instances where factory workers have lost the job as the co-workers refuse to work with them.

In some rare instances it has been brought to our notice that when a female is infected the husband is forced to divorce her due to the pressure of his family members mainly.

**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**](mailto: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)