**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, we only became aware of it recently through one of our advocacy partners.**

**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 bring awareness on the principals drafted by the UN advisory committee. In consultation with Anti-Leprosy Campaign a government founded committee in 1954, the Alliance Development Trust (NGO) also received information that programs have only been implemented to address the medical needs of the patients affected by leprosy. Majority of these activities included training medical officers, pharmacists and dispensers of the country on leprosy and their new role. Health institutions being provided adequate stock of Multi Drug Therapy (MDT) etc.**

**A Social Marketing Campaign in 1990 was conducted to educate the general public about early signs of leprosy and to dispel misconceptions surrounding the disease.**

**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.

**Most of the programs and action plans implemented by the government have been on awareness raising concerning the cure for leprosy. Please refer answer to question no. 2.**

**The ministry of health annual report on performance and progress (2012-2013, [[2]](#footnote-2)most recent report) under the objectives of the Anti-Leprosy Campaign mention the below as their future objectives;**

* ***To fight all forms of stigma associated with leprosy***
* ***Ensuring the rights of persons affected with leprosy***

**However, no concrete measures have been taken to repeal the Leper’s Ordinance 1901[[3]](#footnote-3) or cancel discriminatory circulars presently in effect (A circular dated 09th October 2013 [[4]](#footnote-4)was issued by the ministry of health instructing that leprosy should be a notifiable disease, Circular titled as establishment code issued in 1985** **deals with all matters governing the public servants such as payment of salary, transfers and leave. The E-Code provides for a 22 months compulsory full paid leave to be granted to patients suffering from leprosy under Section 1(1.3) of Chapter 23.)**

**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 effective measures have been taken to repeal or cancel discriminatory circulars.**

**The leper’s ordinance 1901 and discriminatory circulars (dated 09th October 2013 and 1985- please refer answer in question 3) are presently in effect in the country. The government together with the Ministry of Health, have made several undertakings that discriminatory laws concerning persons affected by leprosy will be repealed, however, no concrete action has been taken up to date.**

**Notably, even though the discriminatory law and circular concerning public services officers are not repealed or cancelled, they are not used by the state against persons affected by leprosy. Therefore, in the present context, persons affected by leprosy have no restrictions concerning segregation. Nevertheless, a sense of stigmatisation and fear exists among those affected by leprosy since these restrictive laws could be used against them at any given time.**

**Also circular dated 09th October 2013 was issued by the Ministry of Health, instructing leprosy to be a notifiable disease.**

**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.

**Terminology used - Laduru’ in Sinhala and ‘Thola Noi’ in Tamil. “Dreadful disease” is one such response.**

**Yes there are popular myths, example-**

* **It is a curse by the Gods**
* **Can get infected with Leprosy by touching**

**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 general, persons affected by leprosy enjoy their citizenship rights. However, at the same time specific laws / circulars protecting their citizenship rights have not been introduced.**

**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?

**There are no specific measures taken to ensure the above mentioned rights to persons affected by leprosy. However, *Protection of the Rights of Persons with Disabilities Act, No. 28 of 1996* provides some basic rights for those who are affected by deformity or disability. This law could be used for those suffering from leprosy who are subject to other physical disabilities such as shortening of their fingers and toes as the cartilage gets wasted.**

**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.

**None**

**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 specific national action plan has been implemented to address the principals and guidelines of the advisory committee.**

**A Health Master Plan was prepared by Sri Lanka in November 2003 aimed at improving the Health conditions in the country. The prevention and control of leprosy has been mentioned as one of the functions of the Divisional Health Organization directed by the Divisional Director for Health Services.**

**The government strategic plan for 2014- 2016 mentions leprosy and the eradication of the disease.**

**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?

**In conversation with government institutions such as the Anti-Leprosy Campaign which is part of the Health Ministry, the main obstacle is the lack of awareness on the principals and guidelines.**

**Government institutions only deal with the curative health services aimed at treating the patients, however the public health role is yet to be strengthened due to many reasons.**

**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?

**National level**

* **Take immediate steps to repeal the leprosy ordinance 1901**
* **Enact specific laws to protect the fundamental and other rights of persons affected by Leprosy**
* **Involve stake holders such as NGO’s participation in drafting laws to protect the right of persons affected by Leprosy**
* **Cancel discriminatory circulars (circular dated 09th October 2013 [[5]](#footnote-5)was issued by the ministry of health instructing that leprosy should be a notifiable disease, Circular titled as establishment code issued in 1985 deals with all matters governing the public servants such as payment of salary, transfers and leave. The E-Code provides for a 22 months compulsory full paid leave to be granted to patients suffering from leprosy under Section 1(1.3) of Chapter 23.)**
* **Conduct campaigns dealing with discrimination and rights violations of persons affected by Leprosy**

**International level**

* **Exert pressure on the Sri Lankan government to repeal the leprosy ordinance, enact laws to protect the rights of persons affected by leprosy**
* **Encourage the government to follow its obligations on signing the resolution passed by the Human Rights Council, addressing discrimination in relation to Leprosy in 2008 (Resolution 8/13). The resolution calls upon Governments to eliminate any type of discrimination.**

**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?

* **Integrated leprosy service**
* **Anti-Leprosy Campaign conducted a social marketing campaign in 1989**

The government of Sri Lanka has taken many positive steps towards curative health measures and creating awareness on the fact that Leprosy can be healed. However, bare minimum measures have been taken to address discrimination.

**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.

1. **A young boy aged 14 years, living in Kirishthavakulam village in the Chettikulam division of Vavuniya district (name not mentioned due to confidentiality) was affected by leprosy in 2013. This was subsequent to his sister the disease in 2012. The young boy also lost his father during the ethnic war in the country. He was studying Grade 06 and studying at the Vavuniya Arivuthotam Sivanantha vithiyalayam. One day his class teacher observed his skin patch and told him ‘please don’t come to School with this disease’. However, he went to school the next day. The following day teacher strongly said to him ‘don’t come to school with this disease’. Therefore, due to the stigmatisation he did not go to school from 2013 to 2015 October. Due to this he also failed to complete his MDT within six-months. He lost 2 years of his school years due to this stigmatisation. Presently, he is taking medication, however his face is badly affected. Also, he has only now returned to school.**
2. **A wife of a person affected by leprosy filed a divorce case against the patient based on the fact that he has leprosy. Similar cases like this portray the fear among family members concerning leprosy and myth that is a highly infectious disease.**

**Note- there are many incidents of discrimination and stigmatisation against persons affected by leprosy. However, most patients affected by leprosy are afraid to come forward with their experiences due to fear of further stigmatisation. A culture of fear and shame exists among those affected by leprosy.**

**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)
2. <http://www.health.gov.lk/en/publication/P-PReport2012.pdf/PerformanceReport2012-E.pdf> [↑](#footnote-ref-2)
3. <http://www.lawnet.lk/process.php?st=1956Y8V228C&hword=%27%27&path=3> [↑](#footnote-ref-3)
4. <http://203.94.76.60/cms/upload/english/02-139-2013-eng.pdf> [↑](#footnote-ref-4)
5. <http://203.94.76.60/cms/upload/english/02-139-2013-eng.pdf> [↑](#footnote-ref-5)