**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 UN 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?

I am aware of the Principles and guidelines for the elimination of discriminations against persons affected by leprosy and their family members adopted by the United Nations General Assembly in December 2010(resolution 65/215)

I have been attending the United Nations Human Rights Council at Geneva along with The Nippon Foundation, Japan requesting UNHRC to take up the issue of discrimination against persons affected by leprosy and their family members from the year 2004. I also spoke at UNHRC on this issue as a person affected by leprosy.

**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?

No action has been taken by the Governments at the Federal or State level in India to disseminate the Principles and Guidelines to its citizens? e.g. translation into national and local languages; media; or any other mechanism .

**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.

No specific action has been taken at the national level to promote awareness-raising of the issue of discrimination against leprosy affected persons and their family members.

The Government make one time general advertisement in the media on the “Leprosy Day” in January about leprosy and treatment.

**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?

Myself and five other persons have submitted a Petition to the Parliament for amendment of the discriminating laws in 2008. There are 16 laws which have a clause for discrimination of leprosy affected persons. In addition there are many State laws which disqualify a leprosy affected person to contest in Municipal elections. Recently the Indian Law Commission has produced a report for amendment of the discriminating laws but so far no action has been taken on it. This need to be passed in the Parliament.

**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.

Though India has many languages spoken by people in different States, the word “KUSHTAROG” is generally used to mean leprosy. “KUSHTAROGI” is used to mean a person affected by leprosy. This is a very harsh word. The word itself has a stigmatising effect when used. The English media often use the word “LEPER”. Dignified terminology should be used to address a leprosy affected person.

There are many popular myths associated with persons affected by leprosy. They are as follows:

Leprosy is hereditary.

Leprosy is a sexually transmitted disease.

Leprosy is caused by a kind of snake bite.

Leprosy is not curable.

Leprosy spread by contact with the leprosy affected person.

Leprosy affected person should not marry.

Leprosy affected person has not right to claim family assets.

Leprosy affected person can not live with the family.

Leprosy affected persons cannot use the public services, etc.

**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. There is no mechanism to facilitate the persons affected by leprosy and their family members to have consultation with and/or actively participating in the decision-making processes that deal with matters related to them.

**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?

Rights of citizenship is available to all leprosy affected persons;

Obtaining identity documents is not a problem;

The right to vote is possible liken others;

The right to stand for elections is denied in some States especially in the Municipal elections.

The right to serve the public in any capacity or other civil and political rights?

The leprosy affected persons still need to be empowered to reach this level to serve others.

**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 rights to work: The people with visible deformities have problems.

Education: The children of leprosy affected persons have problem in School admission when the give the address of the leprosy colonies where they live.

Establishing a family: It is still a problem;

Access to public places, including hotels, restaurants; In hotels the persons with visible deformities are refused accommodation.

Buses, taxis, trains and other forms of public transport: Not much problem.

 In some places they experience problem in restaurants;

Access to cultural and recreational facilities; Usually they do not go to these places fearing discriminations.

Access to places of worship is generally not a problem.

Any other economic, social and cultural rights: For economic activity they need funding support. Generally social and cultural rights are enjoyed by them in public places.

**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.

The National Human Rights Commission in India conducted two meetings in 2014 and 2015 exclusively on leprosy. The leprosy affected persons and their organisations were invited by the NHRC and gave opportunity to speak. The NHRC also passed many recommendations and sent them to the Government. One among them is on the Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members passed by the UNHRC. But the Governments still need to take action on the recommendations.

The women are more discriminated than the men when they are affected by leprosy. There are no specific places to take care of the aged and invalid individuals affected by leprosy. In consultation with the leprosy colonies the Government can make some special care centres to take care of such persons. It is very much required.

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

So far no action has been taken at the national level with regard to discriminatory, labelling and offensive languages directed at leprosy affected persons. The media can play a major role in educating the public.

**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 National action plan to implement the Principles and Guidelines.

Has a national committee been established? No National Committee has been set up to implement the Principles and Guidelines. In fact such a Committee need to be appointed by the Federal and State Governments involving the persons affected by leprosy and their organisations.

**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?

It is the responsibility of the Governments to take action for implementation of the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members. I think they think that it is not a priority issue for them. Only when they think to implement it they will come across any obstacles. Even if there are any obstacles it should be possible for the Governments to solve them.

**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?

A committee at the National level involving the persons affected by leprosy and their organisations should be nominated by the Government to suggest ways and means to effectively implement the Principles and Guidelines. They should meet and prepare a time bound plan of action for the implementation of the Principles and Guidelines.

At the international level the UNHRC should suggest that it is mandatory for the Governments to nominate such committees and submit periodical / yearly report to the UNHRC for monitoring.

**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?

The Government conduct health education activities in endemic States to educate the people on leprosy for early treatment, etc. Some times in collaboration with the local NGOs. No specific action has been taken to eliminate discriminations against leprosy affected persons and their family members. In India there are 778 leprosy colonies, homes, etc where the segregated / isolated leprosy affected people live with their families. They need help to eliminate stigma and discriminations. Any measure taken on this aspect should deeply involve the persons affected by leprosy and their orgamnisations.

**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.

Discriminations are being experienced by leprosy affected persons and their family members in my country in educational institutions, land ownership, housing, social living with family, etc. The leprosy affected persons are ignorant about their rights. As a result they silently undergo their sufferings. Land ownership is a problem for them. Association of People Affected by Leprosy ( APAL) is a national level organisation having State representatives. This organisation has a Programme to deal with the Human Rights violations with the support of The Nippon Foundation. To collect the information on the discriminations experienced by the leprosy affected persons need to be well organised so that people will report about the discriminations. APAL has got some records on the discriminations experienced by the people affected by leprosy. Last month in a nearby Nursing College a Nursing student was discriminated in the college since she developed early symptoms of leprosy. I went there with the Leprosy Medical doctor to educate the college staff and solve the problem.

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**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 October 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)