**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, through alert of TLM network*

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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?

*Currently it is not robust. Government of Myanmar is taking seriously for its obligations to treaty and commitments with the spirit of cooperation as far as I understand but they also do have problems in accepting everything and making real to all what they committed in practice. They usually put in the printed media about their commitments at the UN such as three government’s mouthpiece newspaper, 350,000 total copies in circulation and TV and broadcasting channels but not all are highlighted or making headlines so that recognition widely was not possible.*

**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.

*Apart from the government’s commitment towards elimination of leprosy, running up to WHO targets in 2000, which Myanmar achieved that target by 2003 when they made high intensity advocacy on leprosy awareness raising but since there is not much. It is fair to say the disability movement not necessarily for leprosy but for all gained momentum over the year and raising awareness around disability has gained momentum in country. Recently government passed a bill – disability rights law in accordance with UNCRPD on 5th June 2015.*

**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?

*There is no law that prohibit persons affected by leprosy and their family members regarding freedom to choose where to live but there are difficulties for them at the community level because of stigma and discrimination. With the disability rights law the realization of enjoying people affected by leprosy and persons with disability wouldn’t be a problem but actual implementation and understanding, accepting by public and all stakeholders will take a long time.*

**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.

*“a&m\*gonf” In English “Yawgar The”, it is the terminology used in our place in respect of persons affected by leprosy. It means “a person with disease”.*

*A popular myth about leprosy in our country is leprosy is hereditary. Before MDT was introduced, leprosy affected other family members when there was a leprosy patient in their family as leprosy is contagious in its nature especially when it is left un-treated. People also believe that leprosy could arise if they eat certain things.*

**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?

*I am working in the hospital which works for leprosy and disability people. My answer may not provide full information for the question. So if (0) is minimum and (10) is maximum, I would give my grade as (5) regarding this question. (This is Dr Sar Mu Lar). Again according to the law, there will be a national disability rights committee to be chaired by Vice-President of the country and deputy chair of that committee will be head of central DPOs so in that way and mechanism it would be the case that making decisions which could affect lives of people affected by leprosy and persons with disability will be consulted.*

**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?

*Yes, at state level, there are programs for leprosy affected persons and their family to get their National Registration Card because the leprosy patients around our places are migrants from different parts of Myanmar.*

*The local government provided early voting program for leprosy patient in 2010 and 2015 national election.*

*But according to findings of Myanmar Population and Housing Census in 2014, the following observation found out from the draft disability thematic report!*

*“National identification*

*Among 2,179,389 persons aged 10 or older with mild or higher level of disability who live in conventional households, 500,616 persons or 23.0 percent of them do not have a national identification card. This proportion is lower than that of persons without disabilities (27.6 percent). However, this proportion increases with increasing level of disabilities and the proportion of persons who do not have a national identification card of persons with moderate or severe disabilities is higher than that of persons without disabilities: it is 34.5 percent and 40.9 percent among persons with moderate or higher level of disabilities and severe disabilities respectively. While the GoMM has committed to support persons with disabilities as seen in the National Social Protection Strategic Plan, the capability to support would not be high given the country context of low resource settings. This would imply that only a small proportion of the population with a high level of disability would receive the State support. The high proportion of population with moderate to severe disabilities who do not have a national identification card would be of a concern since this population who have a high need of State support would be unknown or invisible to gain support from the national social protection system.“*

**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?

*Those are included in the recently enacted disability rights law. Practical application will take time.*

**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.

*As above.*

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

*No specific actions apart from the law enacted recently.*

**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.

*There was a national plan of action for persons with disability from 2010 – 12, which was supposed to followed by new round of action plans but it didn’t happen. In those plans because TLMM led to write inclusion of rights of people affected by leprosy were made sure. Instead, GoMM busy with drafting new law which was a great achievement. Meantime the Department of Social Welfare is in its final stage on drafting strategic plan for 10 years about disability in Myanmar. According to the law, the national disability rights committee will be formed and that committee would be chaired by Vice-President of the State and vice chair of the committee will be chair/head of central DPOs formed and elected by PWDs. Not specifically for this Principles and Guidelines.*

**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 government’s thinking would be while they are doing for all the persons with disability they don’t feel there is a separate need for leprosy affected people only.***

**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 must take regular feedback from the people who are working for leprosy patients and this need to be confidential.*

*While there is not much could be done for wider disability movement by the State in Myanmar it will be good continue to encourage government to address the need for the disability issues in country. At the international level, encouragement to include disability more as a cross cutting issue in every development works they push Myanmar to undertake. For the effective implementation of the Principles and Guidelines there need to make cross reference of current movement with the contents of those so that the work can be done inclusively for leprosy cause.*

**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?

*Apart from this new step in putting legislation in place for disability rights, there is no other specific measures.*

**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.

*There continued to be a few places where leprosy colonies continue to exist but even among them intermingling with non-leprosy people coming and staying together is taking place in most places therefore there is very little or almost no existence of disaggregated nature of keeping leprosy affected people only anymore in Myanmar. But unfortunately those places are still remembered by different religious groups and individuals as a place to go and do charitable things, giving away food, clothes and money for their good deeds still continued sadly but compare to the majority of people affected by leprosy versus those who living among such places, those living there are very tiny proportion. For example TLMM is working with partner organization Christian Leprosy Mission Eastern Shan (CLMES) through a community transformation project to transform leprosy villages to become model villages to make more liveable and attract general population.*

**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)