**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, we learnt about the Principles and guidelines at the consultation meeting on elimination of leprosy related discrimination organized by the United Nations Office of the High Commissioner for Human Rights on 15th January 2009, Geneva.**

**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?

**There is Chinese version available on the internet**

**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.

**There is no specific policy or action plan on this at national level. However, each year, government at different level will organize awareness raising activities on World Leprosy Day.**

**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?

**In 2011, government abolished the law --“people who have leprosy disease are not allowed to marry” from the Marriage Law. However, there is not specific approach or promotion to raise the awareness of the change.**

**There was one statement on National Leprosy Control and Leprosy Elimination Plan for 2011-2020 issued by the Ministry of Health, that government should strengthen the public education and eliminate discrimination by means of organizing awareness raising activities. However, there was no detailed actions or measures being written down.**

**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.

**Non-discriminatory terms:**

**麻风康复者：Persons affected by leprosy**

**休养员：Persons staying at nursing home**

**Discriminatory terms:**

**麻风佬：Lepers**

**赖子：Leper**

**发疯老：Persons have mental illness**

**病人：Leprosy patient (refer to the people who have been cured from the disease)**

**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?

**There is no evidence showing that people affected by leprosy are consulted or actively participate in decision making processes in government policy or strategy plan. Only NGOs is trying to engage the people in the decision making processes and promoting their rights.**

**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?

**According to the law and policy, persons affected by leprosy have the equally rights as a citizen to vote and serve the public. However, there is not specific measures to ensure the practise of these rights.**

**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?

**People affected by leprosy were provided with National Medical Insurance System and basic living allowances for people living in rural area by Civil Affair Bureau and were provided with ID cards issued by Public Security Bureau. However, discrimination still exists in many areas which prevent the people to receive public services as any other people in the community.**

**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.

**Beside the subsidy provided by the government to the people affected by leprosy living in leprosy villages/settlement, and medical care in some villages, there is no evidence showing the action taken to promote and protect the human rights of women, children, elderly or other vulnerable groups.**

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

**There is no evidence showing the action taken at national level with regard to discriminatory, labelling an offensive languages directed at persons affected by leprosy**

**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 information available or accessible.**

**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?

**There is not obvious obstacle. If any, then it will be the public understanding and there are many other main issues the government is facing, leprosy discrimination issue won’t be the main topic in government’s agenda.**

**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?

**To speed up the implementation of Principles and Guidelines, more dialogues and communications between international organizations and national government levels are suggested. An evaluation on the implementation of the P & G can be a push to the government and to put it on the urgent agenda.**

**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 the National Leprosy Control and Leprosy Elimination Plan for 2011-2020, there is not any other information available about actions taken to eliminate discrimination against persons affected by leprosy.**

**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.

**On 28th August 2014, although the medical examination reports show that all 30 children of school age from Yiliang leprosy village, Yunnan are healthy, they were still refused by Daqiao Primary School. Some parents of the existing students were against their enrollment because their father or grandfather were once affected by leprosy. An anonymous teacher from Daqiao Primary School said that the school has explained to the parents repeatedly that these children are healthy and would in no way carry the disease, but the parents did not buy it. The school authority has to refuse these children so as to keep the whole school running.**

**On August 29, some parents and their children from Daqiao Leprosy Village held a flag “I want to go to school” and appealed to the Yiliang Government for help, requesting the government to protect their children’s right of education. On September 3, a personnel from Yiliang Government responded them that the government has reached initial decision to establish a school specially for these children. Since the other parents still strongly opposed to this issue, “it takes time to change their attitude”, according to the government. However, in the opinion of the parents from Daqiao Village and the volunteers, it is a waste of resources to establish a special school. Furthermore, such school only suggests that the children are still discriminated and eventually cannot integrate into the society.**

**Immediately HANDA Yunnan staff posted this news on its blog, Weibo and Wechat and has raised many public and media attention. On 6th September, this news was reported on CCTV news channel.**

[**http://v.qq.com/page/e/o/s/e00156bkvos.html**](http://v.qq.com/page/e/o/s/e00156bkvos.html)

**We hope that media exposure would raise the attention of the government and relevant education authority about the education the children from Daqiao Village should have been entitled to. Villagers Mr. Hu said that he is healthy, but his life was ruined simply because his father was affected by leprosy. He has been despised by others since he was born. He could not be admitted to school and became illiterate. Among his four children, two have passed their school age and have never received any education while the other two have reached school age. He claims that he would fight for their right to education whatever it takes. “We are all normal people. Why can’t we go to the local primary school?”**

**HANDA staff will continue to work with villagers, volunteers, media and local government, HANDA will arrange for volunteers to tutor the children after school on regular basis so that the children would not be left behind in school and might catch up with other students in Daqiao Primary School. It is hoped that the media will get the public understand leprosy and get rid of their unnecessary concern about the children’s potential infection of leprosy. Villagers from surrounding villages will change their attitude and get along with people from Daqiao Village without any discrimination or prejudice against them.**

**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 **30December 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)