**ELIMINATION OF DISCRIMINATION AGAINST LEPROSY AFFECTED PERSONS AND THEIR FAMILY MEMBERS**

**Questionnaire for**

**NON-GOVERNMENTAL ORGANIZATIONS**

**(The Leprosy Mission International Bangladesh –TLMIB)**

**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 PersonsAffected 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?

Answer: Very recently we come to know the resolution 65/215 via TLMI and website of UN Human Rights.

**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?

Answer: Don’t know. We are not aware about this.

However, we talked with Project Manager of National Leprosy Elimination Programme (the Bangladesh Government main authority working with Leprosy) about the Principles and Guidelines. But she does not know about the Principles and Guidelines.

**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.

Answer: Government of Bangladesh in cooperation with eight NGOS is implementing National Leprosy Elimination Program (NLEP). Different policies, action plans and measures been taken at the national level to promote awareness-raising of the issue of discrimination against leprosy affected persons and their family members. These are given in below –

* Repealed “Lepers Act 1895” (advocacy by TLMIB)
* Celebrate World Leprosy Day (NGOs lead these celebration, GoB official join the program)
* Awareness raising through electronic and print media (TLMIB is doing this campaign)
* Organised conference, workshop, seminar at national level
* Different courtyard session at local level by different NGOs

**4.** What measureshave 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?

Answer: Parliament of Bangladesh repealed a British colonial law “The Lepers Act 1898”on 24 November 2011; which has so far permitted public servants to violate human rights of people suffering from leprosy.The Lepers Act 1898 was passed in order to isolate persons affected by leprosy from the society and even from their own families.

Thus, by repealing the act, it is established the human rights of leprosy patients and ensured freedom of persons affected by leprosy and their family membersto choose where to live.

**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.

Answer:The following terminology is used-

* “Leprosy” or “Hansen’s Disease” in Bangali language is “Kustharog”
* “Leprosy patients” in Bangali language is “Kustharogi”
* Leper asylum in Bangali language is Kostha Ashroykenro”
* Leper/ pauper leper

The following myths associated with persons affected by leprosy –

* Leprosy is not curable
* Leprosy is the result of past sins or immoral behaviour
* You can catch leprosy from touching someone who is affected.
* Someone who has leprosy needs to be isolated
* Leprosy only affects older people
* Leprosy causes your fingers, toes and limbs simply to fall off.
* Everyone who has leprosy will become disfigured.
* Those affected by leprosy cannot work or participate in community life.
* People affected by Leprosy are not allowed in religious activities; prayer in mosque, in ethnic area (CHT) their body will barred (not burned according the religious rules)

However, all these myths are changing day by day; nowadays we have heard very few incidents to people with leprosy

**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?

Answer: Different NGOs including The Leprosy Mission International Bangladesh are trying to involve and active participation of people affected by leprosy and their family members in the decision making processes. People affected by leprosy and their family members are supported to form/run Self-Help groups or CBOs, self-help microfinance, self-advocacy to get different government services and social safety net.

People affected by leprosy and their family members are improved enough to take their decisions by own that deal with matters related to them.

However, few representatives of people affected by leprosy are participating in Leprosy and TB Coordination Committee (LTCC) meeting. Yet about 10 organization lead by people with leprosy obtained GoB registration and a Central Committee formed with the representatives of 1300 SHGs (Self-help groups - organizations of people affected by leprosy) to advocate for 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?

Answer: There are no separate acts, legislations or measures taken for persons affected by leprosy. But according to the Constitution of Bangladesh, every citizen are enjoy fully and equally rights with others regarding the rights of citizenship including human rights, the right to vote, the right to stand for elections etc. Recently, there are no laws, legislations or policies in Bangladesh that restricted the rights of people affected by leprosy.

**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?

Answer: There are no separate acts, legislations or measures taken by Government for persons affected by leprosy. But according to the Constitution of Bangladesh, every Bangladeshi are enjoy equal rights. However, the NGOs working with leprosy are taking different advocacy initiatives, community based approaches 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.

**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.

Answer:

* The GoB does not introduce any special rules/laws/initiatives/actions to promote and protect human rights except repealed “Lepers Act 1895” in 2011. and recently recruited GoB staff for leprosy service.
* Mainly NGOs are working for rehabilitation and livelihood development and forming CBOs with people affected by leprosy and their family members to promote and protect their own rights.

Different actions have been taken from both Governments and NGOs 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. Such as –

* Repealed “Lepers Act 1895”
* Free medicine and treatment provision
* Rehabilitation provision by both government and NGOs
* Free education support
* Different livelihood support including IGA support
* Capacity building support
* Financial accessibility/ Microfinance support
* Celebrate World Leprosy Day
* Awareness raising through electronic and print media
* Organised conference, workshop, seminar at national level
* Different courtyard session at local level by different NGOs

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

Answer: By repealing “Lepers Act 1895” on 24 November, 2011 the discriminatory labelling, definition and offensive languages directed at leprosy affected persons are prohibited.

**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.

Answer: Don’t know. We are not aware about this. However, we talked with Project Manager of National Leprosy Elimination Programme (the Bangladesh Government main authority working with Leprosy) about the Principles and Guidelines. But she does not know about the Principles and Guidelines.

However, Leprosy and TB Coordination Committee (LTCC) formed to working collaborate away for people affected by leprosy and TB. The committee composed of Government line department personnel, NGOs and leaders form CBOs working with/for people affected by leprosy and TB.

**12.** What major obstacles, if any, have Governments faced in implementing the Principles and Guidelines for theelimination ofdiscrimination against persons affected by leprosy and their family members?

Answer: Major obstacles-

* Lack of fund and resources
* Lack of awareness about leprosy among community
* Stigma still found etc.
* People with leprosy aware not aware about their rights. However, ifsomeone know, than they are not able capacitated to raise their voice (as they are poor and less educated).

**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?

Answer: following mechanisms should be put in place

* Sufficient budget and staffs allocation
* Wider dissemination of Principles and Guidelines
* Mass awareness raining initiatives for leprosy awareness and stigma reduction including involvement of electronic and print media
* Strong monitoring system should put in place

**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?

Answer: Different actions have been taken from both Governments and NGOs at different level to eliminate discrimination against leprosy affected persons and their family members. Such as –

* Repealed “Lepers Act 1895”

**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.

**Awareness the best medicine to eliminate leprosy**

Helena, 25, wife of a bus driver, hailing from Gabtali of Bogra district, used to reside at Kuril slum in the capital. Small sores developed on her skin. She went to a local medical centre and physician gave him medicine of skin disease.

After taking the medicines, she became more weak, as she was prescribed without proper diagnosis of the disease. She felt pain and other symptoms were developed on her body. She went to Shaheed Suhrawardy Medical College and Hospital. A physician of the hospital diagnosed leprosy positive on her body.

Helena said, "I was infected with the disease due to curse of people. I got result of my sin. Firstly, I kept it secret and then informed my husband of the matter. Finally, he divorced me and married another girl. Now, I am staying with my parents. My parents are poor and they do not know about my disease. They will kick me out if they know it and now I am taking treatment secretly."

She said, "It happened to me at the will of Allah and only the almighty can save me from the curse. I prefer death to live with the disease. Now, I realize that no one will give shelter to the leprosy patients in the society."

Like Helena, many women of the country think that leprosy is the outcome of sin as they have no proper idea about it.

Deputy Program Manager, Dr Shafir Uddin of National Leprosy Eradication Programme (NELP), said, "Leprosy is considered as public health problem and around 4,000 leprosy patients are under the regular treatment in our country." He said, "Bangladesh has achieved the target of controlling leprosy in 1998. Despite the fact, a significant number of patients have been diagnosed positive for leprosy every year."

According to Dr Shafir, creating awareness with the participation of the government and non-government organizations could play a vital role in eradicating leprosy from the society.

To create awareness, Leprosy Day is now being observed across the globe on second Sunday of the month of January every year, he added.

"Leprosy is an old disease. There are superstitions about the disease. Many people think it is a result of sin, contagious and a hereditary disease," said, Beauty Gosh, Facilitator of Leprosy Mission Community Health. The organization is working at Shaheed Suhrawardy Medical College and Hospital with a view to eradicating leprosy. Beauty stressed the need for counseling of the leprosy patients and requested all to come forward in helping the patients to ensure their normal life.

Leprosy, also known as Hansen's Disease (HD), is a chronic infection caused by the bacteria Mycobacterium that causes severe, disfiguring skin sores and nerve damage in the arms and legs.

In general, symptoms of leprosy are developed three to five years later after being infected. In some cases, it will take 15 to 20 years. The disease cannot enter the human body in case of high level of antibody. Filthy and soggy environment is appropriate to spread the disease.

Newly affected leprosy patients are now being diagnosed at different hospitals including Leprosy Hospital, Mohakhali in the capital and the level of its infection is not similar across the country, according to some studies.

National Leprosy Eradication Programme (NELP), International Leprosy Elimination Programme and Leprosy Mission International conducted the researches.

The number of patients is over one among 10,000 people in Gaibandha, Nilphamari, Khagrachhari, Rangpur, Dinajpur, Sylhet, Dhaka and Chittagong, the study said.

It is learnt that around 30,000 people became physically challenged and have been living inhuman life across the country after being infected with the disease.

In a private research, it was found that a total of 1.90 lakh people had been diagnosed leprosy positive from 1985 to 2009 and 1.85 lakh people of them became well after taking multi drug therapy (MDT). There are 35,000 leprosy patients as they are not taking medicine regularly while there is lack of awareness.

The effect of leprosy has declined by 90 percent across the globe in 15 years from 1985 to 2000 for using MDT.

Experts recommend necessity of creating awareness about the superstitions and effect of the age old disease and make people understand that leprosy is not the outcome of sin and it is curable if diagnosed at right time.

Source: http://www.bssnews.net/newsDetails.php?cat=0&id=450273&date=2014-11-22

**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)