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

**Questionnaire for**

 **NON-GOVERNMENTAL ORGANIZATIONS**

Gerakan Peduli Disabilitas dan Lepra (GPDLI)

Disability and Leprosy Care Movement - Jakarta

**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?

**GPDLI: Yes we know, and we have to say in our statement to the public both in the general publication of information on the internet and brochures and writing and in public discussions related to the person who had leprosy but also their families and even their communities.**

1. 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?

**GPDLI: We see that this statement is not so considered by the government and all its components, it is still very sad, in a national context is still good, but after coming down increasingly vague.**

1. 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.

**GPDLI: We are expecting the government many times soon hold a meeting with the community of leprosy, GPDLI and even now we have FARHAN (Federation reintegration Hansen Indonesia) but has not been successful, but we did not despair for an advocate.**

1. 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?

**GPDLI: Not clear what the creative solutions and the impact of the Indonesian government, it remains unclear what action will be implemented clearly and consistently, the paradigm of thinking still focuses on charity is not yet at empowerement consequently. Even people who had leprosy has not been given the chance to choose the best for themselves and their families.**

1. 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.

**GPDLI: Many local language associated with the word leprosy, in Tanah Karo, North Sumatra, said gadamen, a term that is very discriminatory and highly stigmatized, even very insulting, is what happens to people who had leprosy and even family is not considered good and weird. So they do not have friends who are sincere and willing to accept what the people affected by leprosy and their families. There are many other areas that have suffered extreme and reduction of stigma and discrimination need to be careful, GPDLI very concerned about this situation.**

1. 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?

**GPDLI: Very rare, and they are placed in the position of a backward and marginalized in every area of people's lives. GPDLI provide a time and place to help a community like that, but it is not perfect because of limited funds, we hope that the future will bring about transformation in our community facilitation.**

1. 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?

**GPDLI: Needed for a law that can accommodate the above, our experience in facilitating the Bill disabilities in the context of the CRPD be a good experience and very important to build a special community in particular, there needs to be a turning point that is agreed by all the people of Indonesia to occur wide impact!**

1. 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?

**GPDLI: We associate with the condition to Law disability newly incorporated, things that are associated with sensory disabilities have been included in the verses of the legislation, but there are still many who have not accommodated properly. There needs to be more repairs due to Law of the disability community are still not satisfied, only the social ministries are becoming the main players, but must go in also other ministries, including the ministry of health.**

1. 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.

**GPDLI: We expect all of this is no longer the domain of the ministry of health or social, but it must involve many ministries and especially the President and higher institutions of others, because this issue is the issue of cross-cutting, which greatly involves many people and the employment component of the ruling government, if no results will not be impacted, eg the problem of women and children should be the relevant ministry also parents or elderly and so forth, so synergic action could happening and will have a positive impact.**

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

**GPDLI: Only words alone, but not in the form of tangible and realistic, is still very depressing.**

1. 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.

**GPDLI: GPDLI expected to contribute either through the Commission, and last year had stood FARHAN, currently being developed properly and consistently, this organization is an umbrella organization, but lack of attention, so just GPDLI and colleagues were seriously slowly build it, hopefully be real and more apparent in the coming years, all organizations leprosy be included simultaneously.**

1. 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?

**GPDLI: The absence of a strong legal basis to establish principles and guidelines for the elimination of leprosy discrimination and families, advocacy needed continuous, strong and supported by many members of shareholders and stakeholders.**

1. 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?

**GPDLI: Built a strong MOMENTUM where all are committed to the well and consistently, GPDLI expected to be carried out early in 2017 that will come.**

1. 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?

**GPDLI: You can imagine people who have leprosy are very in discrimination on all fronts, and experiencing double even triple discrimination, so sad, so the approach should be high profile, we already have FARHAN, hopefully some venture fund that we are developing in FARHAN can fulfilled in the future, and could become a national organization like HANDA in China and MORHAN in Brazil as well as IDEA in India.**

1. 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.

**GPDLI: Many people who have leprosy do not receive basic health services should be, considered the lowly and outcast, even in cities that exist around Jakarta as though they had thrown away, even though the hospital was once home leper, GPDLI thought that the word leprosy that being said the word free of leprosy, so there should be no lepers there because it would be very disturbing, this being a situation where stigma and discrimination will continue to grow and will be even greater.**

**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>

1. A/HRC/AC/15/L.3 [↑](#footnote-ref-1)