**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? **GPDLI: We are aware on that issues and principles and guidelines but not CLEAR yet for Indonesia concern.**

**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? **GPDLI : There is no action until now from the government to do this with their own fund or budget, I do not know why? However GPDLI is MOVE assertively with the government up to date especially President, Social Ministry and Health Ministry, but this is not enough !!**

**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. **GPDLI: YES with Sasakawa only and a little action from Ministry of Health an Social, not significant yet up to date.**

**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? **GPDLI: Just a little action from above two ministries and others, and even the government do not care about this intesively up to date! The other one, even they are feel freedom to choose to live anywhere but the reaction of people still very negative for people affacted by leprosy and their families.**

**This is a story of HERMEN HUTABARAT : I have to go to the hospital when I was in junior high school. At that time my doctor assuming me that I had just has allergies. Then, in short, It turns out I had leprosy. I strongly deplore the doctors do not know me are contracting the disease. Home from the hospital, I became paralyzed. Finally I was taken to the Hospital Sitanala, a leprosy hospital in Tangerang. Because insisted was not a people affected by leprosy, I was rejected even though the end remained in Sitanala.**

**When treated at Sitanala, I am still in a state of total paralysis. Can not do anything - anything. Daily activities - carried the day in bed and had to be assisted by a nurse. Some parts of my body was then almost rot and infestation of ants. It made my condition was desperate. Moreover, many other leprosy patients who died.**

**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. **GPDLI: DISABILITAS KUSTA or Disability – Leprosy/ its meaning still the same, but in Tanah Karo they called GADAMEN or BESAR in Bali, with the story of our team in GPDLI such as below:**

ABSTRACT: This study discusses about the social history of communities in Tanah Karo when the epidemic of leprosy struck in the late 18th century. This topic is chosen because there are not many studies about the study of social history in Tanah Karo society, especially in the aspects of a disease outbreak. The issue in this study is the influence of the epidemic of leprosy control efforts towards social change society in Tanah Karo, 1906-1930's. To answer the point, this study uses the methods of history (historical method) by using three stages, heuristics, source criticism and interpretation (explanation). Written sources are used in the form of literature, archives, documents or secondary sources of books, journals, articles and magazines that obtained from the National Library and National Archives and Jakarta GBKP Karo of North Sumatra and Regional Library. Based on these results, it can be concluded, first, the society's negative attitudes towards the social environment and the natural environment has caused an outbreak of leprosy is endemic and affects people's economic decline and the emergence of new social problems. Second, the condition is then pushed the Colonial government to make efforts to overcome the system of \"separation and isolation\" of established settlements and Lau Simomo leprosy hospital in 1906. Third, prevention efforts have led to outbreaks of leprosy in the field of social change beliefs, education, economy, health as well as changes in the social field of the lepers in the settlement Lau Simomo and society in Tanah Karo, in other words there is no society in Tanah Karo untouched by the social changes resulting from efforts to control outbreaks of leprosy by the Colonial Government. *(Source: Anugerah Dibalik Sebuah Wabah; Sejarah Epidemi Lepra di Tanah Karo (1894 – 1906)*

*By Lister Eva Simangunsong. <http://etd.repository.ugm.ac.id/index.php?mod=penelitian_detail&sub=PenelitianDetail&act=view&typ=html&buku_id=55551>*

**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? **GPDLI: This is not part of the development and even rehabilitation steps yet, but GPDLI would like to be part of this process for the future!**

**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? **GPDLI : Sorry no measurement yet, pretty sad on this matter!!**

**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? **GPDLI : we had already developing a people affected by leprosy – but up to date still struggling for more wide range than before, however people affected by Leprosy, only in several provinces and areas.**

**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. **GPDLI: We must develop local province law and even up to low level (grass root), we are still developing this with DRF Fund and our institution fund.**

**10**. What actions have been taken at the national level with regard to discriminatory, labelling and offensive languages directed at leprosy affected persons? **GPDLI: since 2007 we were developing WORLD LEPROSY DAY in our organisation then we work together with various organisation and even the government !**

**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. **GPDLI: NOT YET – it is a pity.**

**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? **GPDLI: I do not know, but maybe – in the past this is regarding zero budget sum in their budget plan!**

**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? **GPDLI : I think we should go to current President of Indonesia JOKOWI, I think this is more powerful than the others so that is why we would to conduct an event next year !**

**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? **GPDLI: NO ACTION yet**

**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**. GPDLI: We saw a lot of people affected by leprosy abused in their lives everyday, from the traveling people who had leprosy were both in rural and urban areas, nearly all of the story is similar is similar, but it is very painful for those who have and are experiencing. Whereas the health center and the Ministry of Health has done his duty as a professional amid the community, but there are still many who have not been reached! besides it's still a lot of stigma that arises from personal people who have leprosy, as well as civic directly stigmatize the cruel treatment even exceed them in the least though!. The number of children of people who have leprosy slammed in their education because the father or mother have the disease, but the disease is not genetic. Thus create a vicious circle that is getting stronger and poverty and welfare is difficult to accomplish!** [**https://www.change.org/p/hapusstigmadandiskriminasipadakusta-terhadap-komunitas-keluarga-dan-pribadi-orang-yang-mengalami-dan-yang-pernah-mengalami-kusta-mulai-sekarang-hilangkan-lah-stigma-dan-diskriminasi-pada-kusta-berdayakanlah-mereka-dengan-berkesinambungan-bukan-sekeda**](https://www.change.org/p/hapusstigmadandiskriminasipadakusta-terhadap-komunitas-keluarga-dan-pribadi-orang-yang-mengalami-dan-yang-pernah-mengalami-kusta-mulai-sekarang-hilangkan-lah-stigma-dan-diskriminasi-pada-kusta-berdayakanlah-mereka-dengan-berkesinam)

**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**](mailto: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)