**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: Ya kami mengetahui dengan sangat jelas Prinsip dan Guidelines tentang ini dengan baik, oleh karena itu dalam visi misi kami dengan sangat jelas memasukkan ini sebagai salah satu bagian GPDLI, bisa dilihat di** [**http://www.pedulidisabilitas.org/?page\_id=2**](http://www.pedulidisabilitas.org/?page_id=2)

**ENGLISH: GPDLI: Yes we know very clearly the Principles and Guidelines on this well, therefore in the vision of our mission very clearly include this as one part GPDLI, can be seen in http://www.pedulidisabilitas.org/?page\_id= 2**

**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: Kami melihat ini belum maksimal dilaksanakan dengan baik dan inklusif, kami pernah mengirim surat kepada Bapak Presiden RI Bapak SBY dan Bapak Jokowi, selalu memberikan surat itu kembali ke Menkes, dan tanggapan Menkes pada kami tidak ada sama sekali, yang membalas hanya dari Kantor Menteri Sekneg, saat ini kami sedang membuat komunikasi pribadi dengan Kantor Kepresidenan, agar paling tidak ada tanggapan yang serius, apalagi dengan lembaga pemerintahan lain, semuanya belum memiliki pengetahuan yang jelas dan mendalam tentang kusta.KIE hanya dipakai sebagai alat politik belaka, kami sudah melakukan kerja kerja yang konsisten dan persisten untuk hal ini bekerja sama dengan universitas, lembaga social dlsb. Berhasil, namun belum memuaskan, seperti ke Gubernur DKI saat itu dan kini, dari Fauzi Bowo, Jokowi, dan Ahok. Juga beberapa Gubernur daerah lainnya di Indonesia.**

**ENGLISH: GPDLI: We see this not maximized properly implemented and inclusive, we had sent a letter to Mr. President Mr Yudhoyono (Former) and Mr Jokowi, always give the letter back to the Minister of Health, and the response Menkes us nothing at all, the reply only from the Office Minister of State Secretariat, at this time we are making a personal communication with the Office of the President, so that at least no serious response, especially with other government agencies, all of them do not yet have a clear and in-depth knowledge about kusta.KIE (EIC) only used as mere political tool, we've done working consistently and persistently working on this in cooperation with universities, social institutions etc. Successful, but not satisfactory, as the governor of the city then and now, of Fauzi Bowo, Jokowi and Ahok. Governor also some other areas in Indonesia.**

**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: Kami belum melihat sama sekali, peran Kemenkes sebenarnya besar, namun kami tak pernah sekalipun diundang untuk masuk sebagai bagian stakeholders yang mereka bisa pakai, kami melihat masih adanya focus yang tidak merata tentang isu kusta, focus yg berhubungan dengan HUMAN RIGHTS issue, semuanya berfikir ini masalah kesehatan belaka dan isu hanya pada PENYEBAB KUSTA belaka dan bukan AKIBAT KUSTA dan seterusnya. Mereka juga harus mengundang seperti GPDLI, FARHAN dan lain sebagainya. Kami Siap berkolaborasi.**

**ENGLISH: GPDLI: We have not seen at all, the role of the Ministry of Health is actually big, but we never even invited to enter as part of stakeholders that they could use, we see still the focus of uneven on the issue of leprosy, focus on those related to the HUMAN RIGHTS issue, everything the mere thought of health problems and issues only the mere and not CAUSES RESULTING LEPROSY LEPROSY and so on. They should also invite such GPDLI, FARHAN and others. We are ready to collaborate.**

**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: GPDLI dan kelak FARHAN dan lain lain bekerja dengan sangat sistematis, akan tetapi pemerintah belum serius untuk hal ini, disabilitas saja tidak serius apalagi isu kusta, belum banyak yang bisa kita harapkan dari inisiatif mereka, namun kami tidak putus asa utk terus memberikan advokasi, yang sangat high profile, dengan tekanan pada isu isu tertentu, misalnya contoh kecil – Rumah Sakit Sitanala yang justru sering mendiskriminasi pasiennya dan kusta.**

**ENGLISH: GPDI: GPDLI and later FARHAN (INDONESIA HANSEN REINTEGRATION FEDERATION) and others worked very systematic, but the government has not been serious in this case, disability alone is not seriously let alone the issue of leprosy, not much we can expect from their initiative, but we do not despair For continue advocating , a very high profile, with an emphasis on issues of particular issues, such as small sample - Hospital Sitanala INDONESIA in TANGERANG CITY which is often discriminate against patients and leprosy.**

**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: LEPRA pernah kita lakukan dan sampai sekarang, tanggapan cukup beragam namun masih belum mengangkat terlalu besar, kami melakukannya sejak 2006-2007, pada saat kami saat itu Pak Nuah Tarigan ikut mempelopori dan menjadi fasilitator dan bahkan pendiri YTLI, dan juga PerMaTa. Kata HANSEN sekarang kami pakai, banyak yang bingung, namun kami akan mencontoh beberapa lembaga di INDIA dan BRAZIL. Yang sangat berhasil.**

**ENGLISH: GPDLI leprosy we've ever done and until now, the responses are quite varied and still not lifting too large, we do since 2006-2007, when we then Mr. Nuah Tarin participate pioneered and became a facilitator and even founder YTLI, and also PerMaTa. HANSEN now we use the word, many are confused, but we will follow the example of some institutions in INDIA and BRAZIL. Which was very successful.**

**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: di JAKARTA dan beberapa daerah di JAWA, SULAWESI, dlsb sudah mulai ok, namun banyak di daerah yang LOW ENDEMIC mereka makin di STIGMA dan DISKRIMINASI, kami ndak setuju dengan turunnya endemic suatu daerah maka stigma dan diskriminasi juga turun, sangat tidak setuju, mereka bahkan disingkirkan. Makanya FARHAN kami bentuk bersama sama lembaga KOMNAS HAM dan lain sebagainya.**

**ENGLISH: GPDLI: in Jakarta and some areas in Java, Sulawesi, etc. have started ok, but many in the region who LOW endemic them increasingly in STIGMA and DISCRIMINATION, we ndak agree with falling endemic region, the stigma and discrimination also fell, strongly disagree, they are even excluded. So FARHAN we form together institutions Human Rights Commission and others.**

**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: GPDLI melihat bahwa belum ada tindakan yang jelas dari lembaga-lembaga sebelumnya yang katanya akan memberikan kontribusi secara nasional maupun kementerian kesehatan yang katanya jadi Patokan dalam isu kusta di Indonesia, PerMaTa hanya berjalan ditempat dan hanya focus pada daerahnya masing-masing yang sangat terbatas. Dan tidak membuka dirinya untuk berkolaborasi dengan siapa saja, semoga FARHAN akan menjadi pioneer disana. Harapan GPDLI. Selama ini GPDLI berkolaborasi dengan ALIANSI DISABILITAS secara nasional dan ikut dalam konteks advokasi disabilitas, sambil kita memasukkan agenda tentang kusta juga didalamnya dan bahkan ikut dalam proses PROLEGNAS RUU DISABILITAS sejak awal. Sehingga masukan CRPD seperti diatas juga sudah masuk isu tentang kusta. Bersyukur tentang hal ini, dan bahkan ikut sampai sekarang kedepan. Bisa dibaca:** [**http://www.dpr.go.id/prolegnas/index/id/26**](http://www.dpr.go.id/prolegnas/index/id/26)

**ENGLISH - GPDLI: GPDLI see that there has been no clear action from previous institutions which he said will contribute nationally and the health ministry which he so benchmark in the issue of leprosy in Indonesia, PerMaTa just running in place and only focus on their respective areas are very limited , And does not open himself to collaborate with anyone, FARHAN hopefully there will be a pioneer. GPDLI expectations. During this GPDLI ALLIANCE DISABILITIES collaborate with national and participate in disability advocacy context, as we enter the agenda of leprosy in it and even participate in the process PROLEGNAS (LEGISLATION PROGRAM of INDONESIA PARLIAMENT) DISABILITIES bill from the beginning. So that the input CRPD as above also have entered the issue of leprosy. Grateful about it, and even come to the fore now. Can be read: http://www.dpr.go.id/prolegnas/index/id/26**

**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: Dengan beberapa pelatihan CRPD yang telah diikuti oleh GPDLI – akan terus dipakai oleh GPDLI untuk masuk ke Arena Leprosy atau Kusta atau Hansen via FARHAN dan GPDLI secara langsung, khusus yang berhubungan dengan hak – hak yang khusus diatas, kami masih melihat masih banyak terjadi tindakan dari luar yang mengalami kusta, keluarga dan komunitasnya, dan bahkan dari diri sendiri yang mengalami kusta! Masih dibutuhkan NGO NGO Internasional memberikan dukungan pada organisasi akar rumput seperti kami di Indonesia.**

**ENGLISH: GPDLI: With some training CRPD which has been followed by GPDLI - will continue to be used by GPDLI to enter the Arena Leprosy or leprosy or Hansen via FARHAN and GPDLI directly, specifically relating to the right - the right specifically above, we still see much happening action from the outside who have leprosy, their families and communities, and even of self leprosy! Still needed NGO International NGO providing support to grassroots organizations like us in Indonesia.**

**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: Kami tentunya sudah memiliki pengalaman di lapangan untuk hal ini, bahkan dari lingkungan yang sangat sempit seperti Kampung Kusta SITANALA, di Tangerang dan DKI Jakarta dlsb, disamping yang di Sumatera Utara, Surabaya, dlsb. Mengadvokasinya ke Kementerian, dan bahkan dimasukkan dalam rangkaian wawancara baik di media massa seperti koran koran nasional dan TVnya seperti Kompas Gramedia/ Tribun, MetroTV, dlsb bahkan sampai kami bekerja sama dengan beberapa program CSR kampus, perusahaan dalam membangun komunikasi, edukasi dan pengetahuan tentang kusta di Jabodetabek, Banten, Jabar dlsb. Memakai pendekatan above the line, below the line, dan sifatnya high profile dan low profile, termasuk ke Gubernur, Presiden dan Menteri serta masyarakat umum.**

**ENGLISH: GPDLI: We must have had experience in the field for this, even from a very narrow environment such as Kampung Leprosy Sitanala, in Tangerang and Jakarta etc., in addition to that in North Sumatra, Surabaya, etc. Advocating to the Ministry, and even put in a series of interviews both in the mass media such as newspapers national newspapers and TVnya like Kompas Gramedia / Tribune, Metro, etc. even until we cooperate with several CSR programs campus, the company in establishing communication, education and knowledge of leprosy in Greater Jakarta, Banten, West Java etc. Wearing approach above the line, below the line, and its high profile and low profile, including the Governor, the President and the Minister as well as the general public.**

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

**GPDLI: dengan pendekatan advokasi kreatif, menghindari pendekatan yang agresif, namun tetap menjalankan secara ASERTIF dan terbuka, tanpa mengurangi atau menghabisi HAK orang lain untuk membela juga, pendekatan yang sifatnya negosiasi dan edukasi, suatu pemikiran yang sudah kami bawa sejak peristiwa pelecehan terhadap rapat tentang kusta sejak 2007 di Makassar, dimana Pak Nuah Tarigan saat itu mengatakan via telepon bahwa kita tidak boleh membalas dengan kasar mereka yang telah melabel dan bullying di sebuah hotel di Makassar, bahkan akhirnya cerita nya menjadi cerita yang happy ending. Baik bagi komunitas kusta di Sulawesi Selatan, dan bahkan Indonesia secara umum, bayangkan kalau saat itu dibalas dengan kejahatan dan tindakan ofensif juga – akan membawa runyam semuanya, dan akhirnya ada cap di masyarakat secara negative. Bersyukur itu tidak terjadi.**

**ENGLISH: GPDLI: the advocacy approach creatively, avoiding an aggressive approach, but still run Assertive and openly, without reducing or eliminate RIGHTS others to defend well, approaches that are negotiated and education, an idea we've brought since the harassment of the meeting on leprosy since 2007 in Makassar, where Mr. Nuah Tarigan said via telephone at the time that we should not retaliate harshly those who have been labeled and bullying in a hotel in Makassar, even the end of his story into a story a happy ending. Good for leprosy community in South Sulawesi, and even Indonesia in general, imagine that when it met with evil and offensive action as well - will bring everything worse, and finally there is a stamp in the community negatively. Thankful it did not happen.**

**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: Dua tahun yang lalu kami kira bersama KOMNAS HAM dan SASAKAWA dlsb sudah memberikan masukan itu di Hotel Sahid Jaya Jakarta, kami juga ikut disana, dalam acara yang cukup megah, namun sampai sekarang PerMaTa kebanyakan tidak terarah kerjanya sampai ke akar rumput, dan mereka tidak membagikannya kepada CSO CSO yang lain termasuk DPO. GPDLI juga sangat heran atas kejadian itu, makanya KOMNAS HAM akhirnya berpaling.**

**ENGLISH: GPDLI: Two years ago we were celeberating World Leprosy Day together with National Human Rights Commission and the Sasakawa etc. GPDLI already provide such inputs at Hotel Sahid Jaya Jakarta, we were also there, in the event that quite magnificent, but until now PerMaTa mostly directed her to the grass roots, and they do not share it with others, including the CSOs DPO. GPDLI also very surprised at the situation and condition of them, hence the Human Rights Commission finally turned.**

**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: Menurut kami kesadaran inklusif tentang disabilitas belum jalan, apalagi yang berhubungan dengan isu kusta, kementerian social yang cukup perhatian dan kami sangat menghargainya, namun kemenkes makin lama kami melihat makin tak jelas arahnya dalam kasus kasus kusta yang ada, keterkaitan yang berhubungan dengan BPJS atau Asuransi kesehatan saja, sangat mendiskriminasi kusta itu sendiri, bahkan lebih terasa stigma dan diskriminasi di Rumah sakit yang dulu adalah rumah sakit kusta bila dibandingkan dengan rumah sakit umum biasa! Sungguh sangat menyedihkan. Kelihatanya tidak cukup hanya kata kata manis belaka, harus ada tindakan yang jelas dan terbuka infonya. Kami sudah mencatat ini dan mengadvokasinya berkali kali.**

**ENGLISH: GPDLI: According to our realization inclusive of disability is not the way, let alone dealing with the issue of leprosy, the ministry of social considerable attention, and we appreciate it very much, but the Ministry of Health the longer we see less and less clear directions in the case of leprosy cases that exist, linkages associated with BPJS or health insurance only, very discriminating leprosy itself, even more pronounced stigma and discrimination at the hospital which was once the leprosy hospital when compared with regular public hospitals! It is very sad. Not enough just seems pretty sweet mere words, there must be a clear action and open the information. We have noted this and advocating repeatedly.**

**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: Perlu ada KELOMPOK KERJA kecil saja dahulu yang di fasilitas oleh Kemenkes dan Kemensos, dan yang paling bagus juag BAPPENAS, karena ini menyangkut banyak hal, kami akan memberika secara detail jika GPDLI diundang untuk masuk didalam WORKING GROUPS itu jangan hanya dengan pendekatan dokter pasien yang masih saja terus dikembangkan oleh Kemenkes.**

**ENGLISH: GPDLI: There needs to be WORKING GROUP small advance which at the facility by the Ministry of Health and Ministry of Social Affairs, and the most good juag BAPPENAS, because it involves a lot of things, we will give employees in detail if GPDLI invited to enter inside WORKING GROUPS it not only with the approach of the patient's physician which is still being developed by the Ministry of Health.**

**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: Program RAN seperti yang di Kemensos, masih sangat minim dan bahkan makin hancur, setelah program Leprosy Control tidak ada lagi, bahkan dana itu juga ndak seperti 10 tahun yang lalu, pertemuan pertemuan koordinasi ANEK dan ADEK yang luas juga sudah makin menghilang, tidak tahu apakah karena dana dari luar tidak ada lagi, atau tak jelas lagi motivasinya. Kami mengira bahwa mungkin tentang Human Rights based saat ini pada kusta sudah tidak jelas lagi di agenda Kemenkes, sedangkan di Kemensos masih relevan, mungkin pendekatan CBR yang dilakukan saat ini harus dengan pendekatan social approach bukan lagi dengan pendekatan dokter-pasien, memang secara statement sudah ada, namun dari tindakannya masih belum berubah.**

**ENGLISH: GPDLI: Program RAN (NATIONAL ACTION PLAN) as in the Ministry of Social Affairs, is still very minimal and even more destroyed, after the program Leprosy Control does not exist anymore, even funds also ndak like 10 years ago, meeting coordination meeting ANEK and adek wide has also been increasingly disappear, not know whether because of outside funding no longer exists, or is not clear anymore motivation. We thought that perhaps on Human Rights based this time on leprosy is no longer clear in the agenda of the Ministry of Health, while the Ministry of Social Affairs is still relevant, may approach CBR done today should approach social approach is no longer with the approach of the doctor-patient, it is a statement already No, but of action have not changed.**

**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: kasus diskriminasi pelayanan kesehata d RS KUSTA termasuk SITANALA, juga beberapa kampong kampong kusta di Sumatera yang sangat didiskriminasi oleh masyarakat sekitarnya, bahkan Pak Samsul yang notabene anaknya sekolah disekitar kampong kusta, tidak diterima bersekolah di lokasi itu, mereka harus jauh bersekolah dan tidak dapat berjalan kaki, mereka semua sangat tertekan perasaan, dan minta bantuan. Dan masih banyak lagi yang lainnya, bahkan didaerah yang tingkat eliminasi yang sudah ok menurut WHO, namun malah kasus stigma dan diskriminasi nya sangat besar !!!**

**ENGLISH: GPDLI: discrimination cases health care in previous LEPROSY hospital including Sitanala, also some kampongs leprosy in Sumatra are highly discriminated against by the surrounding community, even Mr. Samsul (a people affected by leprosy from Aceh) who incidentally his childeren’s school around the village leprosy, was not accepted in school at that location, they should be attended school quite far from his current place, they were all very depressed feelings, and ask for help. And still many others, even in regions where the level of elimination is ok according to the WHO, but even cases of stigma and discrimination is very strong !!!**

**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)