**Elimination of discrimination against persons affected by leprosy and their family members**

**Questionnaire**

**Non-governmental organizations**

In its resolution A / HRC / 29/5, the Commission on Human Rights requested the Advisory Committee to lead a study that reviews the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, as well as the obstacles which oppose it , and to submit it at its thirty-fifth session, a report which would include practical proposals to further disseminate and apply more effectively the principal and the directives to eliminate discrimination and stigma associated with leprosy and to promote, protect and respect the rights of the people affected by leprosy and their family members.

The resolution encourages the Committee to consider, during the elaboration of the above report, the views of Member States, as appropriate, and those of International and regional organizations, including the World Health Organization, the UN High Commissioner for Human Rights and the mandate holders of special procedures, national institutions for human rights and non-governmental organizations, as well as the works led on the question by the organs , specialized institutions, funds and programs of the United Nations, within the framework of their respective mandates.

It is in this context that the Advisory Committee decided, at its fifteenth session held in August 2015, to establish a drafting group to conduct this study. The group developed the following survey to obtain the views of NGOs. The objective is to gather information 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 (principles and guidelines): How the Principles and Guidelines are applied to different situations in different countries, in particular what are the best practices that can be shared; as well as the main obstacles to their accomplishment, including views on how best to strengthen their implementation.

**1.** Do you know the principles and guidelines for the elimination of discrimination against persons affected by leprosy and family members, adopted by the UN General Assembly in December 2010 (resolution 65/215 )? If so, how did you know it ?

Yohanna Abdou

**1.1** As TLM Niger’s Program Manager , I make reference to the principles and guidelines as part of capacity building of organizations of persons affected by leprosy (IDEA Niger, FSNA FNPH).

1.2 Yes, as a representative of IDEA Niger Association, I attended the consultation meeting of organizations of persons affected by leprosy in Manila in June 2010.

Issa Harouna

As a National Association of IDEA Niger President, I have participated in "Africa Regional Symposium on Leprosy and Human Rights" in September 2013.

On this occasion, I had the opportunity to learn a lot about this.

. How the government (federal or centralized level) has disseminated the principles and guidelines to bring them to the attention of citizens? For example, by translating them in various national and local languages; through the media; or via any other mechanism?

As TLM Niger, we have not seen an effort by the Nigerian government in this direction. We are tempted to assert that these principles and guidelines are unknown to the people of Niger.

**3.** Policies or action plan were developed or other measures taken at the national level to promote the raising awareness to the question of the discrimination against the people affected by the leprosy and the members of their family? Please supply details of such measures.

There is no national policy or national plan of awareness promotion activities to the issue of discrimination against persons affected by leprosy in Niger. However, in the action of the National Program of Fight against the Leprosy ( PNLL), the discrimination is evoked with raising awareness made in the state radio. However, TLM Niger in its program supports awareness promotion activities to the issue of discrimination against them. This is done through partnerships with local private and state structures.

**4.**What measures (federal or centralized level) have been taken to amend or abolish discriminatory laws, policies or practices, including the abolition of forced segregation, to eliminate discrimination against persons affected by leprosy and their family members? Is the freedom to choose their residence or place to live ensuredfor people affected by leprosy and their family members?

- The Nigerian Federation of Disabled People has made a plea to amend articles in the constitution (be capable physically to be candidate in certain post)

- The order of 93-012 March 2, 1993, on the minimum rules for the protection of rights of disabled people in Niger, was modified to take into account the inclusion of disabled people including people affected by leprosy and thanks to the advocacy;

- Support of International NGOs (CBM, TLM, HI) and local remains the most significant;

- The People affected by leprosy have the freedom to choose where to live especially for those who have their own home. However, in the Zinder region (cases of people in the city of Magariya) some affected people are victims of isolation on the periphery.

**5.** What is the terminology used initially in your native language against people affected by leprosy? Please also provide a translation thereof in English. Are there popular myths associated with people affected by leprosy? Please provide a brief description.

Hausa: kuturu (leper); Dan Kuturu; Manya; Diyan Manya; Unguwar Manya; Larabawa (Dan Issa); Fama da masu ciwon Gangu, Albaras, Pakistan, Jagejage (Garin Dogo May Dashe) Gajaja in connection with disability and poor hygiene; Karakara; Unguwar masakai;

Popular Myths: A person with leprosy is a victim of a spell cast, a divine punishment for sins (theft, adultery, breach of trust), hereditary etc.

**6.** Persons affected by leprosy and their family members are they consulted and / or do they participate actively in the processes of decision-making which handle questions that concern them directly ?

Before it was difficult, but today with the support of partners in the field of health, capacity building, actions of social and economic integration , of IDEA Niger effort in educating, these people can regain their dignity, they are consulted, actively involved in decision-making processes, on everything concerning them (nothing for us without us)

**7.** What measures have been taken at national level to ensure that people affected by leprosy can exercise fully and equally with others of their rights, particularly regarding the rights of citizenship; obtaining identity documents; the right to vote; the right to stand for election; the right to serve the public in any capacity, and any other civil and political rights?

Shares of Advocacy Partners (CBM, HI, TLM) PNLL, FNPH, Promotion of National Committee of Disability Rights. In this sense, HI has designed a project that ended in 2013.

The FNPH takes over in the awareness of its members. IDEA is a member of the FNPH.

**8.** What steps have been taken to ensure that people affected by leprosy have the same rights as other regarding rights to work and education; the right to form a family; access to public places, including hotels, restaurants; and buses, taxis, trains and other means of public transport; access to cultural and recreational facilities; access to places of worship or other economic, social and cultural rights?

Not much, but IDEA FNPH and NGOs ODI Niger are tirelessly working on this directive with the support of partners (TLM and CBM).

**9.** What steps have been taken to promote and protect the rights (a) women; (B) children; (C) the elderly; (D) other vulnerable members who are or have been affected by leprosy and their family members? (Please provide details).

The state work on this directive through Justice and the National Commission for Human Rights (CNDH). There is a division of disabled and elderly people in the Ministry of Population of the Promotion of Women and Child Protection. A very limited number of disabled persons began to receive aid from social welfare in urban councils from 2014. Some private organizations of human rights (ANDDH etc.) bring them to the building but TLM, FNPH, IDEA continue promoting the texts of the Convention on the rights of persons with disabilities (CRPD), the rights of children and women with disabilities.

**10.** What measures have been taken at national level in terms of discriminatory language, or offensive stereotype against people affected by leprosy?

None really, but the IDEA organization tries to see a change in behavior in this direction. TLM Niger seeks to understand through a study on stigma, discriminatory language to do better things in a future advocacy .

**11**. Is the Government prepared and / or adopted a national action plan to implement the Principles and Guidelines? Please attach a copy. Have you established a national committee? Please give some details about its mandate, size and composition.

NO nothing is done in this directive.

**12.** What are the main obstacles, if any, faced by the Government in implementing the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members?

Priority level, in a poor country like Niger, disinterest in the fate of vulnerable group, unwillingness, few PNLL initiatives in this area.

13. In your opinion, what are the monitoring mechanisms should be put in place at national and international levels to effectively implement the principles and guidelines?

Make sure it has a policy, an action plan, an annual meeting; substantial support to leprosy coordinators of regions, local and state structures. It would have to be one in the curricula of health and social work education programs.

**13**. In your opinion, what are the monitoring mechanisms that should be put in place at national and international levels to implement effectively the principles and guidelines?

Make sure there is a policy, a plan, an annual meeting; substantial support for leprosy coordinators of regions, local and state structures. It would have to be one in the curricula of health and social work education programs.

**14.** Can you give examples of concrete measures taken by the government at various levels to eliminate discrimination against persons affected by leprosy and their family members in your country?

The ministry supports the World Day population in Niger leprosy awareness sessions in national radio, training of health workers, even if limited.

**15.** Please provide specific cases of discrimination experienced by people affected by leprosy and their family members in your country, followed by various forms of discrimination, including discrimination in fact.

- Social rejection; rejection friends; neighbourhood; (using objects, square, place, greetings, people disperse,);

- Family rejection;

- They have never returned home; to leave the family

- PAL marriage problems (abandonment of a partner, engagement)

- Dropout (headquarters);

- Abandonment of a workstation;

- Refusal to purchase food;

- Type of property;

- The behavior of patients and accompanying persons visiting the Centre for Health and Leprology (CSL Danja SIM);

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| **Deadline of submission of responses to the questionnaire:**  All parties are encouraged to submit their replies by email or fax as soon as possible and no later than December 30, 2015 at:  **hrcadvisorycommittee@ohchr.org**  [Message Subject: HRCAC Elimination of discrimination against persons affected by leprosy]  OR  Secretariat of the Advisory Committee of the Council of Human Rights  c / o Ms. Dina Rossbacher  Office of the High Commissioner of the United Nations for Human Rights,  Palais Wilson, United Nations Office at Geneva  CH-1211 Geneva 10, Switzerland  **Fax: +41 22 917 9011** |

Thank you in advance for your contribution.

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