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

Revised principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members*

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* Late submission.

1. The Human Rights Council, in its resolution 8/13, requested the Advisory Committee to formulate a draft set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, and to submit it to the Council for its consideration by September 2009. In response to that request, the Advisory Committee conducted a discussion on the issue. At its first session, the Advisory Committee designated Shigeki Sakamoto, member of the Committee, to formulate a draft set of principles and guidelines on this subject.
2. Pursuant to Council resolution 8/13, the Office of the United Nations High Commissioner for Human Rights (OHCHR) was requested to collect information about the measures that Governments had taken to eliminate discrimination against persons affected by leprosy and their family members, and to hold a meeting to exchange views among relevant actors, including Governments, observers of the United Nations, relevant United Nations bodies, specialized agencies and programmes, non-governmental organizations, scientists, medical experts, as well as representatives of persons affected by leprosy and their family members.
3. In accordance with paragraph 4 of resolution 8/13, OHCHR collected information about the anti-discrimination measures taken by individual countries. Valuable information had already been submitted by 24 countries^a and 7 non-governmental organizations.^b The submissions demonstrated that the stigma suffered by persons affected by leprosy is very severe in many countries. Mr. Sakamoto was invited to participate in an open-ended consultation on the issue organized by OHCHR on 15 January 2009, in Geneva. At that consultation, persons affected by leprosy testified about the obstacles they faced in the enjoyment of their human rights because of discriminatory policies and practices.
4. The working paper by Mr. Sakamoto, submitted to the Advisory Committee at its second session (A/HRC/AC/2/CRP.5), focused on an analysis of information submitted by States and non-governmental organizations and the discussions at the open-ended consultation, for the purpose of obtaining more comprehensive knowledge on legislative, judicial, administrative and educational measures concerning discrimination against persons affected by leprosy and their family members.
5. In its recommendation 2/3, the Advisory Committee recommended that the Human Rights Council request Mr. Sakamoto to formulate a draft set of principles and guidelines on the elimination of discrimination against persons affected by leprosy and their family members, for review by the Advisory Committee at its third session and for consideration by the Council by September 2009. In accordance with that request, a draft set of principles and guidelines, on the elimination of discrimination against persons affected by leprosy and their family members, was submitted by Mr. Sakamoto to the Advisory Committee at its third session (A/HRC/AC/3/CRP.2).
6. The Advisory Committee adopted the draft set of principles and guidelines at its third session (A/HRC/AC/3/2) and submitted it to the Council at its twelfth session for consideration, as requested by the Council in paragraph 5 of resolution 8/13. At its twelfth session, the Council adopted resolution 12/7 on elimination of discrimination against persons affected by leprosy and their family members. In its resolution, the Council

^a In order of registration, Israel, Oman, the Philippines, Costa Rica, Turkey, Japan, Finland, Canada, the Netherlands, Egypt, Estonia, Cuba, Mexico, France, Ukraine, Romania, Portugal, Qatar, Ecuador, Spain, Azerbaijan, Greece, Kazakhstan, Armenia and Cyprus.

^b Centre d'études et d'actions stratégiques, LEPROA Mozambique, the International Federation of Anti-Leprosy Associations, Leprosy Mission International, the German Leprosy and TB Relief Association, the International Association for Integration, Dignity and Economic Advancement and the Nippon Foundation.

requested OHCHR to collect the views of relevant actors on the draft set of principles and guidelines and to make those views available to the Advisory Committee, and requested the Advisory Committee to finalize the draft set of principles and guidelines taking into full consideration the views of relevant actors.

7. Pursuant to resolution 12/7, OHCHR requested relevant actors to submit their views on the draft set of principles and guidelines by 30 November 2009. Many relevant actors, including 12 Governments,^c 1 specialized agency, the World Health Organization (WHO) and 9 non-governmental organizations,^d submitted their comments. Many comments focused on the issue of isolation raised in article 1.2 of the principles and article 2.1 (a) of the guidelines. The crux of the comments was that the isolation of leprosy patients had never been regarded as a useful public measure and had no relevance in the modern treatment of leprosy.^e In addition, many non-governmental organizations^f asked to specifically mention their objection to the use of the term “leper”, since the current paragraph on discriminatory language was considered too vague.

8. The Advisory Committee held a discussion on the above subject at its fourth session. It requested Mr. Sakamoto to take into consideration the comments and views of relevant actors on the draft set of principles and guidelines. In accordance with the Council’s request in its resolution 12/7, the Advisory Committee had the task of finalizing a draft set of principles and guidelines and submitting it within the time limit. The present document contains the revised draft set of principles and guidelines reflecting the comments and views from the relevant actors and members of the Advisory Committee (see annex). The text is submitted to the Advisory Committee for adoption and for further submission to the Council at its fifteenth session.

^c In order of registration, Japan, Paraguay, Thailand, the United Kingdom of Great Britain and Northern Ireland, Greece, Serbia, Oman, Qatar, Spain, Columbia, Guatemala and Jamaica.

^d The International Federation of Anti-Leprosy Associations, the International Leprosy Association, Guangdong HANDA Rehabilitation & Welfare, the Memorial Health Foundation, Movimento de Reintegracao das Pessoas Atingidas pela Hanseníase, the International Disability Alliance, Culion Sanitarium and General Hospital, the International Association for Integration, Dignity and Economic Advancement and the Ethiopian National Association of Persons Affected by Leprosy.

^e According to WHO, “Isolation of leprosy patients has never been considered as a useful public measure. Isolation before, during and after treatment has no relevance in the modern treatment of leprosy and may in fact work against current efforts to eliminate the disease”. In fact, the Technical Advisory Group on Leprosy, at its last meeting on 23 April 2009, stated that “in public health terms, it is reasonable to conclude that a leprosy patient’s infectiousness becomes negligible after starting multidrug therapy”.

^f For example, the International Federation of Anti-Leprosy Associations, the International Leprosy Association, Guangdong HANDA Rehabilitation & Welfare and the International Association for Integration, Dignity and Economic Advancement.

Annex

Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members

In formulating a draft set of principles and guidelines on the elimination of discrimination against persons affected by leprosy and their family members, the Rapporteur enumerates firstly the human rights and fundamental freedoms of persons affected by leprosy and their family members as principles, then guidelines for States to respect, ensure and achieve such rights and freedoms.

I. Principles

1. Persons affected by leprosy, and their family members, should be treated as people, with dignity, and are entitled to all the human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights and, in accordance with State's obligations, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the Convention on the Rights of Persons with Disabilities and other relevant human rights treaties apply equally to them as to others.
2. Persons affected by leprosy and their family members should not be discriminated against or deprived of their human rights on the grounds of having or having had leprosy.
3. Persons affected by leprosy and their family members should have the same rights as everyone else with respect to marriage, family and parenthood. To this end:
 - (a) No one should be denied the right to marry on the grounds of leprosy;
 - (b) Leprosy should not constitute grounds for divorce;
 - (c) A child should not be separated from his or her parents on the grounds of leprosy.
4. Persons affected by leprosy and their family members should have the same rights as everyone else in relation to full citizenship and obtaining identity documents.
5. Persons affected by leprosy and their family members should have an equal right to serve the public, including the right to stand for elections and to hold office at all levels of government.
6. Persons affected by leprosy and their family members should have the right to work in an environment that is inclusive and to be treated equally in all policies and processes related to recruitment, hiring, promotion, salary, continuance of employment and career advancement.
7. Persons affected by leprosy and their family members should not be denied admission to or be expelled from schools or training programmes on the grounds of leprosy.
8. Persons affected by leprosy and their family members are entitled to develop their human potential to the fullest extent, and to realize their dignity and self-worth. Persons affected by leprosy and their family members, who have been empowered and who have had the opportunity to develop their abilities, can be powerful agents of social change.

9. Persons affected by leprosy and their family members, have the right to be actively involved in decision-making processes regarding policies and programmes that directly concern their lives.

II. Guidelines

1. General

1.1 States[§] should promote the full realization of all human rights and fundamental freedoms for all persons affected by leprosy and their family members without discrimination on the grounds of leprosy. To this end, States should:

(a) Take all appropriate legislative and administrative measures to modify, repeal or abolish existing laws, rules, policies, regulations, customs and practices that discriminate directly or indirectly against persons affected by leprosy and their family members, or that forcefully or compulsorily segregate and isolate persons on the grounds of leprosy in the context of such discrimination;

(b) Ensure that all authorities and institutions take measures to eliminate discrimination on the grounds of leprosy by any person, organization or private enterprise.

1.2 States should take all appropriate measures to achieve for persons affected by leprosy and their family members the full realization of all the rights enshrined in international human rights instruments to which they are party, including the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities.

1.3 In the development and implementation of legislation and policies and in other decision-making processes concerning issues relating to persons affected by leprosy and their family members, States should consult closely with and actively involve persons affected by leprosy and their family members, individually or through their respective local and national organizations.

2. Equality and non-discrimination

2.1 States should recognize that all persons are equal before and under the law and are entitled, without any discrimination, to the equal protection and benefit of the law.

2.2 States should prohibit all discrimination on the grounds of a person having or having had leprosy, and guarantee to persons affected by leprosy and their family members equal and effective legal protection.

3. Women, children and the vulnerable

3.1 In many societies, leprosy has a significantly adverse impact on women, children and the vulnerable. States should therefore pay special attention to the promotion and protection of women, children and the vulnerable.

[§] In the present guidelines, "States" denotes both local and national levels of government.

3.2 States should promote the full development, advancement and empowerment of women, children and the vulnerable.

4. Home and family

States should, where possible, support the reunification of families separated in past decades owing to policies and practices relating to persons diagnosed with leprosy.

5. Living in the community and housing

5.1 States should promote the enjoyment of the same rights for persons affected by leprosy and their family members, as everyone else, allowing their full inclusion and participation in the community.

5.2 States should identify persons affected by leprosy and their family members living in isolation^h or segregated from their community owing to their disease, and give them social support.

5.3 States should enable persons affected by leprosy and their family members to choose their place of residence and ensure that they are not obliged to accept a particular living arrangement because of their disease.

5.4 States should allow any persons affected by leprosy and their family members, who were once forcibly isolated by State policies then in effect, to continue to live in the hospitals/communities that have become their homes, if they so desire. In the event that relocation is unavoidable, the residents of these places should be active participants in decisions concerning their future.

6. Participation in political life

States should ensure that persons affected by leprosy, and their family members, enjoy equal voting rights. Voting procedures must be accessible, easy to use and adapted to accommodate any individuals physically affected by leprosy.

7. Occupation

States should encourage and support opportunities for self-employment, forming cooperatives and vocational training for persons affected by leprosy and their family members, as well as their employment in regular labour markets.

8. Education

States should promote equal access to education for persons affected by leprosy and their family members as for everyone else.

^h In its comments on Advisory Committee recommendation 3/1, the World Health Organization stated that “leprosy is a chronic infectious disease, and one of the leading causes of permanent physical disabilities in the world. The disease and its visible complications still contribute to intense social stigma resulting in discrimination of patients and their family members. Isolation can never be justified in the case of leprosy”.

9. Discriminatory language

States should remove discriminatory language, including the term “leper” or the equivalent in any language or dialect, from governmental publications and revise existing publications containing such language as expeditiously as possible.

10. Participation in public life, cultural life and recreation

10.1 States should promote the equal enjoyment of the rights and freedoms of persons affected by leprosy and their family members, as enshrined in international human rights instruments, including the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities, indispensable for their dignity.

10.2 States should promote equal access to public places, including hotels, restaurants and buses, trains and other forms of public transport for persons affected by leprosy and their family members.

10.3 States should promote equal access to cultural and recreational facilities for persons affected by leprosy and their family members.

10.4 States should promote equal access to places of worship for persons affected by leprosy and their family members.

11. Health care

11.1 States should provide persons affected by leprosy at least with the same range, quality and standard of free or affordable health care as that provided for persons with other diseases. In addition, States should provide for early detection programmes and ensure prompt treatment of leprosy, including treatment for any reactions and nerve damage that may occur, in order to prevent the development of stigmatic consequences.

11.2 States should include psychological and social counselling as standard care offered to persons affected by leprosy who are undergoing diagnosis and treatment, and as needed after the completion of treatment.

11.3 States should ensure that persons affected by leprosy have access to free medication for leprosy, as well as appropriate health care.

12. Standard of living

12.1 States should recognize the right of persons affected by leprosy and their family members to an adequate standard of living, and take appropriate steps to safeguard and promote that right, without discrimination on the grounds of leprosy, with regard to food, clothing, housing, drinking water, sewage systems and other living conditions. States should:

(a) Promote collaborative programmes involving the Government, civil society and private institutions to raise funds and develop programmes to improve the standard of living;

(b) Provide or ensure the provision of education to children whose families fall below the poverty line by means of scholarships and other programmes sponsored by the Government and/or civil society;

(c) Ensure that persons below the poverty line have access to vocational training programmes, microcredit and other means to improve their standard of living.

12.2 States should promote the realization of this right through financial measures, such as the following:

(a) Persons affected by leprosy and their family members who are not able to work because of their age, illness or disability should be provided with a government pension;

(b) Persons affected by leprosy and their family members who fall below the poverty line should be provided with financial assistance for housing and health care.

13. Awareness-raising

States, working with human rights institutions, non-governmental organizations, civil society and media, should formulate policies and plans of action to raise awareness throughout society and to foster respect for the rights and dignity of persons affected by leprosy and their family members. These policies and plans of action may include:

(a) To provide information about leprosy at all levels of the education system, beginning with early childhood education;

(b) To promote the production and dissemination of “know your rights” material to give to all persons recently diagnosed with leprosy;

(c) To encourage the media to portray persons affected by leprosy and their family members with dignified images and terminology;

(d) To recognize the skills, merits and abilities of persons affected by leprosy and their contribution to society and, where possible, support exhibitions of their artistic, cultural and scientific talents;

(e) To encourage creative persons, including artists, poets, musicians and writers, particularly those who have personally faced the challenges of leprosy, to make a contribution to awareness-raising through their specific talents;

(f) To provide information to social leaders, including religious leaders, on how leprosy in their teachings or written materials may contribute to the elimination of discrimination against persons affected by the disease and their family members;

(g) To encourage higher education institutions, including medical schools and nursing schools, to include information about leprosy in their curricula, and develop and implement a “train the trainer” programme and targeted educational materials;

(h) To promote collaboration with the World Programme for Human Rights Education to incorporate the human rights of persons affected by leprosy and their family members into the national human rights education programme of each State;

(i) To identify ways to recognize, honour and learn from the lives of individuals forcibly isolated by their Governments for having been diagnosed with leprosy, including oral history programmes, museums, monuments and publications;

(j) To support grass-roots awareness efforts to reach communities without access to traditional media.

14. Development, implementation and follow-up to States' activities

14.1 States should consider creating or designating a committee to address activities relating to the human rights of persons affected by leprosy and their family members. The committee should ideally include individuals affected by leprosy and their family members, representatives of organizations of persons affected by leprosy, human rights experts, representatives from human rights and related fields, and representatives of government.

14.2 States are encouraged to include in their State party reports to be submitted to the relevant treaty bodies policies and measures that they have adopted and/or implemented with regard to the elimination of discrimination against persons affected by leprosy and their family members.
