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**REQUESTS ADDRESSED TO THE ADVISORY COMMITTEE STEMMING
FROM HUMAN RIGHTS COUNCIL RESOLUTIONS**

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

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Mr. Shigeki Sakamoto, Mr. Dheerujlall Seetulsingh,
Ms. Mona Zulficar: draft recommendation***

**3/... Draft principles and guidelines on the elimination of discrimination
against persons affected by leprosy and their family members**

The Human Rights Council Advisory Committee,

Recalling resolution 8/13 on the elimination of discrimination against persons affected by leprosy and their family members adopted by the Human Rights Council,

Welcoming the open-ended consultation on the elimination of discrimination against persons affected by leprosy and their family members organized by the Office of the High Commissioner for Human Rights on 15 January 2009,

* The present document was not edited before being sent to the United Nations translation services.

Expressing its concern that millions of persons affected by leprosy and their family members suffer as a result of the deep-rooted stigma and discrimination in society,

Expressing also its concern that millions of persons affected by leprosy suffer not only from leprosy as a disease, which is scientifically and medically proven to be curable, but also from political, legal, economic or social discrimination and social exclusion as a result of misunderstanding and indifference, as well as a lack of legislative, judicial, administrative, educative and other appropriate measures to prohibit such discrimination and to protect persons affected by leprosy and their family members,

1. *Welcomes* the study submitted by Shigeki Sakamoto (A/HRC/AC/3/CRP.2), which contains a draft set of principles and guidelines on the elimination of discrimination against persons affected by leprosy and their family members;

2. *Endorses* the draft set of principles and guidelines contained in the annex to the present recommendation, as revised;

3. *Submits* the annexed draft set of principles and guidelines to the twelfth session of the Human Rights Council for its consideration as requested in paragraph 5 of Human Rights Council resolution 8/13;

4. *Recommends* to the Human Rights Council that it request all relevant United Nations bodies, special agencies and programmes, as well as Member States to give due consideration to the principles and guidelines in the formulation and implementation of their policies and measures for persons affected by leprosy and their family members;

5. *Also recommends* that the Human Rights Council should request all actors in society, including hospitals, schools, universities, religious groups and organizations, business companies, newspapers and broadcasting networks and non-governmental organizations, to give due consideration to the principles and guidelines in the course of their activities for the realization of all human rights and fundamental freedoms of persons affected by leprosy and their family members.

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 human rights and fundamental freedoms of persons affected by leprosy and their family members as principles in the first place, and enumerates guidelines for States to respect, ensure and achieve such rights and freedoms in the second place.

I. PRINCIPLES

1. Persons affected by leprosy and their family members should be treated as persons with dignity and are entitled to all the basic human rights and fundamental freedoms proclaimed 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.
2. Persons affected by leprosy and their family members should not be discriminated against or deprived of their basic freedoms on the grounds of having or having had leprosy. Any isolation either before, during or after treatment should be temporary and should be conducted in the context of public health consideration.
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 full citizenship and the right to obtain 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, 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

General

1. States¹ 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. Any isolation either before, during or after treatment should be temporary and should be conducted in the context of public health considerations;

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

2. States should take 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, 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.

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.

Equality and non-discrimination

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.

¹ In the present guidelines, “States” denotes both local and national levels of government.

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.

Women, children and other vulnerable groups affected by leprosy

1. States should recognize that in many societies leprosy has a significantly adverse impact on women, children and other vulnerable groups who are already marginalized.
2. States should pay special attention to the promotion and protection of women, children as well as other vulnerable groups affected by leprosy.
3. States should promote the full development, advancement and empowerment of women, children as well as other vulnerable groups affected by leprosy.

Home and family

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

Living in the community and housing

1. States should promote that persons affected by leprosy and their family members enjoy the same rights as everyone else, allowing their full inclusion and participation in the community.
2. States should identify persons affected by leprosy and their family members living in isolation or segregated from their community owing to their disease, and give them social support.
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.
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 live out their lives in the hospitals/communities that have become their homes. In the event that relocation is unavoidable, the residents of these places should be active participants in decisions concerning their future.

Participation in political life

1. States are encouraged to 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.

Occupation

1. States should encourage opportunities for self-employment, forming cooperatives and vocational training.

Education

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

Discriminatory language

1. States should remove discriminatory language from any governmental publications and revise existing publications containing such language as expeditiously as possible.

Participation in public life, cultural life, and recreation

1. States should promote 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.
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.
3. States should promote equal access to cultural and recreational facilities for persons affected by leprosy and their family members.
4. States should promote equal access to places of worship for persons affected by leprosy and their family members.

Health care

1. States should provide persons affected by leprosy at least with the same range, quality and standard of free or affordable health care as provided for persons with other diseases. In addition, States should provide for early detection programmes to ensure that treatment is provided promptly and that stigmatic consequences are avoided. States are further urged to set national targets to reduce the rate of new leprosy cases.²
2. States should include psychological counselling as standard care offered to persons affected by leprosy who are undergoing diagnosis and treatment, and as needed after the completion of treatment.

² Recently, the WHO is urging Member States to focus on reducing the rate of new leprosy cases with grade 2 disabilities per 100,000 population by at least 35 per cent of the 2010 level by the end of 2015. This reduction would indicate that leprosy is being detected early before nerve damage can develop. Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (Plan period: 2011-2015), WHO, Regional Office for South-East Asia, pp. 11-14.

3. States should guarantee persons affected by leprosy access to free medication for leprosy, as well as appropriate health care.

Standard of living

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.

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.

Awareness-raising

1. 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. To these ends, they should:

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

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

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

(d) 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) Involve artists, poets, musicians and writers, particularly those who have personally faced the challenges of leprosy, in reaching society;

(f) Provide information to social leaders, including religious leaders, on how leprosy in their teachings or written materials may contribute to the discrimination of persons affected by the disease;

(g) 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) 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 each State’s national human rights education programme;

(i) 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) Support grass-roots awareness efforts to reach communities without access to traditional media.

Development, implementation and follow-up to States’ activities

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