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Human rights bodies and mechanisms

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

Submitted by the Human Rights Council Advisory Committee

* Late submission.

Introduction

1. In its resolution 8/13, the Human Rights Council 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. The Council also requested the Office of the United Nations High Commissioner for Human Rights (OHCHR) 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, on measures to eliminate discrimination against persons affected by leprosy and their family members.
2. At its first session, the Advisory Committee designated Shigeki Sakamoto to formulate the draft set of principles and guidelines. Mr. Sakamoto was invited to participate in the meeting organized by OHCHR on 15 January 2009.
3. At its third session, the Advisory Committee endorsed the draft set of principles and guidelines prepared by Mr. Sakamoto, taking into account the report of OHCHR on the above-mentioned meeting (A/HRC/10/62), and submitted it to the Council for consideration at its twelfth session.
4. In its resolution 12/7, the Council requested OHCHR to collect the views on the draft set of principles and guidelines of relevant actors, including Governments, observers of the United Nations, relevant United Nations bodies, specialized agencies and programmes, non-governmental organizations, scientists and medical experts, as well as representatives of persons affected by leprosy and their family members, and to make those views available to the Advisory Committee. It also requested the Committee to finalize the draft set of principles and guidelines for submission to the Council by its fifteenth session, taking into full consideration the views of the above-mentioned relevant actors.
5. The revised draft set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members (A/HRC/AC/5/2) was presented by Mr. Sakamoto to the Advisory Committee at its fifth session. At the same session, taking into account the comments received from Committee members and other participants during the debate, the draft set of principles and guidelines was endorsed by the Committee, as orally revised, and annexed to recommendation 5/3. It is submitted to the Council, as an annex to the present document, for consideration by the Council at its fifteenth session.

Annex

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

I. Principles

1. Persons affected by leprosy and their family members should be treated as people with dignity and are entitled, on an equal basis with others, to all the human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights, as well as in other relevant international human rights instruments to which their respective States are parties, including 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 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 a ground 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 the right to serve the public, on an equal basis with others, 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 on an equal basis with others 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 fully 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, and should 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, protect and ensure 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, administrative and other measures to modify, repeal or abolish existing laws, regulations, policies, 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 the Universal Declaration of Human Rights and the international human rights instruments to which they are party, including 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 equal benefit of the law.

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

2.3 Specific measures which are necessary to achieve de facto equality of persons affected by leprosy and their family members shall not be considered as discrimination.

3. Women, children and other vulnerable groups

3.1 In many societies, leprosy has a significantly adverse impact on women, children and other vulnerable groups. States should therefore pay special attention to the promotion and protection of the human rights of women, children and members of other vulnerable groups who have or have had leprosy, as well as their family members.

3.2 States should promote the full development, advancement and empowerment of women, children and members of other vulnerable groups who have or have had leprosy, as well as their family members.

4. Home and family

States should, where possible, support the reunification of families separated in the past as a result of 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 for 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 or segregated from their community because of their disease, and should give them social support.

5.3 States should enable persons affected by leprosy and their family members to choose their place of residence and should 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 in effect at the time to continue to live in the leprosariums and hospitals 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. States should, however, improve living conditions in those leprosariums and hospitals. With due regard to the wishes of the persons affected by leprosy and their family members, and with their full participation, States should also design, promote and implement plans for the gradual integration of the residents of such places in the community and for the gradual phasing out of such leprosariums and hospitals.

6. Participation in political life

States should ensure that persons affected by leprosy, and their family members, enjoy voting rights, the right to stand for election and the right to hold public office at all levels of government, on an equal basis with others. 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, the formation of 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.

9. Discriminatory language

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

10. Participation in public, cultural and recreational activities

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 the Universal Declaration of Human Rights and the international human rights instruments to which they are party, including, 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.

10.2 States should promote access on an equal basis with others 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 access on an equal basis with others to cultural and recreational facilities for persons affected by leprosy and their family members.

10.4 States should promote access on an equal basis with others 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 should 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 are living in poverty by means of scholarships and other programmes sponsored by the Government and/or civil society;

(c) Ensure that persons living in poverty 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 are living in poverty 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 the 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 the following goals:

- (a) To provide information about leprosy at all levels of the education system, beginning with early childhood education affirming, inter alia, that leprosy is curable and should not be used as grounds for discrimination against persons who have or have had leprosy and their families;
- (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, to 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 addressing 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 to develop and implement a “train the trainer” programme and targeted educational materials;
- (h) To promote implementation of the World Programme for Human Rights Education and 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 the human rights field and related fields, and representatives of government.

14.2 States are encouraged to include in their State party reports to the relevant treaty bodies the 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.