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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**

**“Draft of principles and guidelines on elimination of discrimination
against persons affected by leprosy and their family members”**

**prepared by Mr. Shigeki Sakamoto,
member of the Human Rights Council Advisory Committee**

Summary

The present report on elimination of discrimination against persons affected by leprosy and their family members has been prepared pursuant to the Human Rights Council resolution 8/13 of 12 June 2008, which requests the Human Rights Council Advisory Committee to submit a report to the Council for its consideration by September 2009. The Advisory Committee designated Professor Shigeki Sakamoto, a member of the committee, to formulate a draft set of principles and guidelines on this issue. On the basis of the above resolution, the Office of the United Nations High Commissioner for Human Rights (OHCHR) was requested to collect information about the measures that governments have taken to eliminate discrimination against persons affected by leprosy, 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 programs, non-governmental organizations, scientists, medical experts as well as representatives of persons affected by leprosy and their family members. Professor Sakamoto was invited to participate in an open-ended consultation on the issue organized by the OHCHR on 15 January 2009 in Geneva. This report is based on numerous valuable ideas presented by the participants in this Consultation and on information which the OHCHR has collected on the anti-discrimination measures taken by individual countries. The report recommends the Advisory Committee to adopt, with any necessary changes the draft principles and guidelines and submit them to the Human Rights Council for adoption. In addition, it recommends States to reflect them in their policies for persons affected by leprosy, in order to eliminate discrimination against persons affected by leprosy and their family members. The international community as a whole is responsible for establishing a society in which persons affected by leprosy have their human dignity restored, and do not suffer any inhumane treatment.

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Introduction

1. In its resolution 8/13 entitled “Elimination of discrimination against persons affected by leprosy and their family members”, the Human Rights Council requests the Office of the United Nations High Commissioner for Human Rights (OHCHR) to collect information about the measures that governments have 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 programs, non-governmental organizations, scientists, medical experts as well as representatives of persons affected by leprosy and their family members¹.

2. The Human Rights Council also requests the Human Rights Council Advisory Committee to examine the submissions from governments and civil society organizations and 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.

3. In response to this request, the Advisory Committee conducted a discussion on this matter. At its 15th meeting on 14 August 2008, the Advisory Committee adopted recommendation 1/5 on the elimination of discrimination against persons affected by leprosy and their family members, and designated a committee member, Professor Shigeki Sakamoto, to formulate the above-mentioned draft set of principles and guidelines. Professor Sakamoto was invited to participate in the open-ended consultation on the issue organized by the OHCHR on 15 January 2009 in Geneva. In this consultation, persons affected by leprosy testified about the obstacles they have faced in the enjoyment of their human rights due to discriminatory policies and practices.

4. According to paragraph 4 of resolution 8/13 of the Human Rights Council, the OHCHR has been collecting information about the anti-discrimination measures taken by individual countries. Fortunately, valuable information has already been submitted by 24 countries² and many NGOs³. The submissions demonstrate that in many countries, the stigma against persons affected by leprosy is very severe in many countries.

5. The working paper by Professor Sakamoto, submitted to the second session of the Advisory Committee, focused on the analyses of information submitted by States and NGOs and 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 members⁴.

¹ For the purposes of these principles and guidelines, the term “persons affected by leprosy” is understood to include persons currently under treatment for leprosy and persons cured of leprosy.

² Israel, Oman, Philippines, Costa Rica, Turkey, Japan, Finland, Canada, Netherlands, Egypt, Estonia, Cuba, Mexico, France, Ukraine, Romania, Portugal, Qatar, Ecuador, Spain, Azerbaijan, Greece, Kazakhstan, Armenia and Cyprus (in order of registration).

³ Centre d’Etudes et d’Actions Stratégiques, LEPROA Mozambique, International Federation of Anti-Leprosy Associations, The Leprosy Mission International, German Leprosy and TB Relief Association, International Association for Integration, Dignity and Economic Advancement, and the Nippon Foundation.

⁴ A/HRC/AC/2/CPR.5, 26 January 2009.

6. The Human Rights Council Advisory Committee recommended the Human Rights Council to request Professor 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 2009.⁵ On the basis of this request, the present final report has been prepared and submitted to the Advisory Committee.

I. Leprosy - The nature of the disease

7. Leprosy is a disease caused by a rod-shaped bacillus called *Mycobacterium leprae* (*M. leprae*), which is closely related to the organism causing tuberculosis⁶.

8. More than 85% of leprosy cases are non-infectious and do not spread the disease. Over 99% of people have a natural immunity or resistance to leprosy. *M. leprae* grows slowly, taking 10 to 14 days to multiply, whereas bacteria causing acute infections such as pneumonia can multiply every few seconds. Leprosy affects mainly the skin and peripheral nerves. The first sign is usually the appearance of patches on the skin, which are accompanied by a loss of sensation in the affected areas. If untreated in its early stages, leprosy can result in complications that drastically alter the appearance and cause physical disablement.

9. The mode of transmission of the leprosy bacillus remains uncertain, but most investigators believe that *M. leprae* is spread from person to person, primarily as a nasal droplet infection. The incubation period is unusually long for a bacterial disease, generally five to seven years.

10. Since the beginning of recorded history, there have been numerous references to leprosy in the world. The disease has left behind a terrifying image in history and human memory. Leprosy has struck fear in human beings over the centuries. A cumulative total of the number of individuals who, over the millennia, have suffered its chronic course of physical disabilities and psychological sufferings cannot be calculated.

11. Leprosy is cured by multidrug therapy (MDT), a highly effective treatment that became available in the early 1980s. MDT is a combination of three drugs - dapsone, clofazimine, and rifampicin - administered over a 6- to 12- month period. The first dose of MDT kills 99.9% of the microorganisms in the body that cause leprosy.

12. Timely diagnosis and treatment of cases, before nerve damage has occurred, is the most effective way of preventing disabilities due to leprosy; effective management of leprosy complications, including reactions and neuritis, can prevent or minimize the development of further disabilities. However, if leprosy is detected and treated only after permanent nerve damage has occurred, there will be residual disabilities. Although residual disabilities are not a source of infection, these contribute to the social stigma and discrimination experienced by persons affected by leprosy and their families in many societies.

⁵ Resolution 2/3 adopted by the Advisory Committee, 8th meeting, 30 January 2009, para.3.

⁶ The terms "leprosy" and "Hansen's disease" are synonymous and are used interchangeably in these principles and guidelines.

13. In recent years, the number of people diagnosed with leprosy worldwide has decreased dramatically thanks to the introduction of MDT and concerted efforts of all involved in tackling the disease. According to the World Health Organization (WHO) statistics, 254,525 individuals were diagnosed with leprosy during 2007. During 2007, 17 countries reported over 1,000 new cases each⁷. This compares with 763,262 new cases detected in 2001⁸. The three countries with the highest number of annual new cases, India, Brazil, and Indonesia, alone accounted for 219,562 new cases during 2005⁹.

II. Leprosy - The history of the disease

14. In the Old Testament, there are references to leprosy, although it is thought that the disease did not exist in the Middle East at the time of Moses¹⁰. Around 1500 BC, in the Indian work *Rgveda Samhita*, there are references to *kushtha*, a term covering leprosy as well as some other skin afflictions. Around 1300-1100 BC, there is mention of leprosy under the term *Uchedu* in the *Ebers Papyrus* and *Brugsh Papyrus* of Egypt¹¹.

15. Further, around 600 BC in the Indian text *Sushruta Samhita*, there is a clear description of leprosy. Under the terms *Vat-Rakta* and *Vatasonita* are characterized symptoms and signs such as anesthesia and deformities. In addition to describing other features associated with leprosy, it also cites the use of chaulmoogra oil in the treatment of leprosy¹². These references would appear to confirm the existence of leprosy in India.

16. In the 5th century BC, the Greek historian Herodotus wrote of Persia, "...and whosoever of the men of the city has leprosy or whiteness of the skin, he does not come into a city nor mingle with other Persians." Around 480 BC, leprosy is said to have been introduced to Greece following conquest by Darius and Xerxes. In 97-94 BC, Lucretius wrote in *De Natura Rerum*: "High up the Nile midst Egypt's central plain/Springs the dread leprosy, and there alone."¹³

17. Leprosy also existed in Asia from early times. In 150 AD, the preeminent Chinese surgeon Hua T'o wrote: "The symptoms of leprosy may first appear on the skin but the poison is actually stored in the internal organs." In Japan, it is recorded in the *Nihon Shoki* (The Chronicles of Japan) that in 758 the Empress Komyo founded Japan's first leprosy hospital. It is apparent from these references that leprosy existed in China and Japan. In 150 AD, the Greek Aretaeus gave the first comprehensive clinical description of leprosy in Europe¹⁴. During the 5th and 6th centuries, leprosy was brought to Spain by Roman troops.

⁷ 17 countries: Angola, Bangladesh, Brazil, China, Democratic Republic of Congo, Ivory Coast, India, Ethiopia, Indonesia, Madagascar, Mozambique, Myanmar, Nepal, Nigeria, Philippines, Sri Lanka, and Sudan.

⁸ For details, see the WHO's *Weekly Epidemiological Record*, No.33, 2008, pp.293-300. For steps taken by individual countries for leprosy elimination, see Report of the global forum on elimination of leprosy as a public health problem, Geneva, Switzerland 26 May 2006, WHO/CDS/NTD/2006.4, pp.8-15.

⁹ WHO's *New case detection trends in leprosy*, 2006.

<http://www.who.int/lep/situation/NCDetection2006.pdf>

¹⁰ Tony Gould, *A Disease Apart: Leprosy in the Modern World*, St. Martin's Press, New York, 2005, p.3.

¹¹ Olaf K. Skinsnes, "Notes from the History of Leprosy," *International Journal of Leprosy*, Vol.41, No.2, 1973, p.221. This article serves as a very useful guide to the chronology of leprosy concepts and practices.

¹² R. Dharmendra, "Leprosy in Ancient India Medicine," *International Journal of Leprosy*, Vol.15, No. 4, 1947, pp.424-30.

¹³ Skinsnes, *supra* note 11, p.222.

¹⁴ Francis Adams, *Extant Works of Aretaeus, the Cappadocian*, 1856, pp.368-372.

18. In the Middle Ages, leprosy was regarded as one of the most frightening diseases of all. The physical deformity and functional impairment caused by its effects on the skin and peripheral nerves gave sufferers a wretched appearance. In Shakespeare's *Henry IV, Part 2* is the line: "What, dost thou turn away and hide thy face? I am no loathsome leper. Look on me."¹⁵ Such references provide insights into how the disease was viewed at the time.¹⁶ In *Hamlet*, the ghost of Hamlet's father explains the cause of his death to Hamlet and uses the word "leprous" to mean "evil" or "poisonous."¹⁷

19. In fact, for centuries, leprosy was regarded as incurable. Between the 11th and 13th centuries, leprosaria began to appear in Europe. Unlike leprosaria of later times, where people with the disease were forcibly isolated, these were more akin to religious institutions where persons affected by leprosy were looked upon as *paupers Christi* (Christ's poor). But behind the construction of such facilities was also the fear of contagion.

20. In the 16th to 18th centuries, leprosy spread from Portugal to Brazil; from Spain to Colombia, Ecuador, Cuba and Mexico; from Africa to Santo Domingo, Jamaica, parts of South America and the southern United States; from Norway to Minnesota in the U.S.; and from France to Canada.¹⁸ Thereafter, the disease continued its geographic expansion.

21. In early times, it was thought that leprosy was a hereditary disease that only affected certain households because of its long incubation period and the fact that there were many cases of familial infection that occurred during early childhood when immunity is low. However, in 1873, the Norwegian doctor Gerhard Armauer Hansen discovered *M. leprae*, the bacillus that causes leprosy, clearly establishing that leprosy was an infectious disease¹⁹. By legislation in 1887 and in 1885, Norway adopted a policy of isolating persons with the disease in separate rooms in their houses, or admitting them to hospital²⁰.

22. In 1873, the Belgian priest Father Damien de Veuster went to live in a leprosy settlement on the island of Molokai, Hawaii. Sixteen years later, he died of leprosy. With the death of Father Damien, people at last began to realize that leprosy was indeed an infectious disease, and not a hereditary one. As a hereditary disease, it was not a danger to public health, but as a communicable disease it was seen as posing a risk, and led people to believe that the only option was the forced isolation of anyone with leprosy.

¹⁵ William Shakespeare, *Henry IV, Part 2*. For details, see Olaf K. Skinsnes and Robert M. Elvove, "Leprosy in Occidental Literature," *International Journal of Leprosy*, Vol. 38, No. 3, 1970, pp.294-307.

¹⁶ For a look at how people affected by leprosy are portrayed in literature and art, see K.Grön, "Leprosy in Literature and Art," *International Journal of Leprosy*, Vol.41, No.2, 1973, pp.249-283.

¹⁷ Olaf K. Skinsnes and Robert M. Elvove, "'Leprosy' in Occidental Literature," *International Journal of Leprosy*, Vol.38,1970, pp.297-298.

¹⁸ Skinsnes, *supra* note 11, pp.223-224.

¹⁹ However, this discovery did not soon put an end to the arguments over whether leprosy was a hereditary disease or an infectious disease (spread by contact transmission). In 1914, lecturing at the Royal College of Physicians in London, Charles Mercier said: "The disease of tuberculosis resembles the disease of leprosy in many respects... An hereditary susceptibility is without doubt an important factor in both diseases." See Charles A. Mercier, *Leprosy Houses and Mediaeval Hospitals*, London, 1915, p.21.

²⁰ <http://www.who.int/lep/resources/SWG.pdf>.

23. For much of its long history, there was no effective cure for leprosy. However, in the 1940s, a drug called promin, a derivative of dapsone, a drug used to treat tuberculosis, was found to be effective against leprosy²¹. After further research and testing over the next 40 years, multidrug therapy (MDT) consisting of dapsone, clofazimine and rifampicin was recommended as a standard treatment for leprosy by the World Health Organization (WHO) in 1982. Dapsone is a bacteriostatic drug that halts the progress of the bacillus, clofazimine is an anti-inflammatory drug, and rifampicin is a powerful antibacterial agent.

24. After the WHO announcement, many leprosy experts became convinced that the disease could be controlled globally. In 1991, the WHO initiated a move toward the elimination of leprosy as a public health problem, targeting a prevalence rate of less than 1 case per 10,000 population²². The WHO defined leprosy as a public health problem when the prevalence rate of the disease was more than 1 case in 10,000. In mid-1980s, leprosy was a public health problem in 122 countries²³.

25. In 1995, the WHO started making MDT available throughout the world free of charge. Between 1985 and 2008, more than 15 million people were cured with MDT. The number of persons registered for treatment fell from 5.4 million in 1985 to 250,000 in 2008. Today only three countries have a leprosy prevalence rate of above 1 per 10,000 population (Brazil, Nepal and Timor-Leste²⁴). Global case detection continues to fall every year.²⁵

26. In the not-so-distant future, WHO will be in a position to declare that every country on the world has eliminated leprosy as a public health problem. Nevertheless, although an effective cure is available and treatment is free, people with leprosy continue to hide their symptoms because of the stigma attached to the disease. Stigma and discrimination remain present in both developed and developing nations. Despite medical progress and the availability of information about the disease, a number of countries have regulations limiting access of persons affected by leprosy to work opportunities, to public transport and to international travel, and making leprosy grounds for divorce.

III. Leprosy - The human rights aspect of the disease

27. Despite the fact that there has been a cure for leprosy for more than 60 years, the historical tradition of stigma, discrimination and social exclusion still continues²⁶. In this sense,

²¹ E/CN.4/Sub.2/2005/WP.1,p.4, para.8.

²² *Ibid.*, p.4, para.9.

²³ *Ibid.*, p.4, para.11.

²⁴ The prevalence rate of leprosy in Timor-Leste has been high for some time, but the country did not feature in the statistics until 2009, when its population increased to over 1 million.

²⁵ Presentation by Denis Daumerie titled “Neglected Tropical Diseases—Hidden and Silent: Key Problems” in the open-ended consultation on the elimination of discrimination against persons affected by leprosy and their family members (Geneva, 15 January 2009).

<http://www2.ohchr.org/english/issues/health/discrimination/index.htm>.

²⁶ In India, more than 11 million people have been cured of leprosy in the past 25 years, since the introduction of MDT. However, many of them are living a marginalized life, silently undergoing sufferings. Presentation by P.K. Gopal titled “Elimination of discrimination against persons affected by leprosy and their family members” in the open-ended consultation (Geneva, 15 January 2009). <http://www2.ohchr.org/english/issues/health/discrimination/index.htm>

leprosy is a unique disease that has rendered those affected vulnerable to discrimination around the world, regardless of country, religion or culture²⁷.

28. In its resolution 8/13 titled “Elimination of discrimination against persons affected by leprosy and their family members”, the Human Rights Council calls upon governments to take effective measures to eliminate any type of discrimination against persons affected by leprosy and their family members, including awareness-raising. It also requests the OHCHR to collect information on the measures that governments have taken to eliminate discrimination against persons affected by leprosy and their family members²⁸.

29. It is clear from the information submitted that although there were many countries that maintained a segregation policy vis-s-vis person affected by leprosy before, those countries have already abolished such a policy²⁹. In spite of that, the incidence of stigma and discrimination persists and persons affected by leprosy face great obstacles to their social reintegration after the cured³⁰.

30. According to some countries’ submissions, there are no specific measures regarding elimination of discrimination against persons affected by leprosy and their family members³¹. It should be noted that some countries do not have any human right-related programs to eliminate discrimination against persons affected by leprosy³². Governments and civil society organizations come to the same conclusion that a specific, rights-based approach is required for addressing stigma and discrimination against persons affected by leprosy.

31. In his preliminary report on discrimination against persons affected by leprosy and their families, Professor Yozo Yokota, the Special Rapporteur for the Sub-Commission on the Promotion and Protection of Human Rights, emphasized that “the practice of discrimination against leprosy-affected persons, such as discriminatory treatment in the employment, marriage, use of public places, including hotels, restaurants and means of transportation, should be stopped immediately³³.” In many countries, such discriminatory treatments still occurs³⁴.

32. In history, the first appearance of discrimination against persons affected by leprosy relates to marriage. In 880 BC, the Laws of Manu include a proscription against marriage with the offspring of persons having leprosy³⁵. In similar fashion, in 757, King Pepin of France issued

²⁷ *Ibid.*

²⁸ Resolution 8/13 of the Human Rights Council, paras. 2 and 4.

²⁹ Egypt’s submission to Resolution 8/13-Leprosy, registered on 29/09/2008.

³⁰ The International Association for Integration, Dignity and Economic Advancement (IDEA)’s submission to Resolution 8/13-Leprosy, registered on 31/10/2008.

³¹ Portugal’s submission to Resolution 8/13-Leprosy, registered on 22/10/2008.

³² For example, Canada’s submission to Resolution 8/13-Leprosy, registered on 26/09/2008.

³³ Preliminary report of Yozo Yokota on discrimination against leprosy affected persons and their families, A/HRC/Sub.1/58/CRP.7, p.14.

³⁴ In 2009, the Chief of the Andhra Pradesh Human Rights Commission called for legislation to prosecute parents with diseases such as tuberculosis, HIV, leprosy and dyslexia should they, knowing that they have the disease, have children. His comments were sharply criticized by three doctors who said that “the statement is devoid of any substance or rationale”. In many other developing countries, too, ignorance about leprosy and prejudice against the disease remain.

³⁵ Skinsnes, *supra* note 11, p.221.

a decree making marriage of those with leprosy illegal and the disease a reason for divorce. In 1612, Louis XIII of France forbade the marriage of persons with leprosy to anyone³⁶.

33. Discriminatory laws pertaining to marriage are not limited to the Middle Ages. Such laws still exist in a number of countries. For example, in India, there are discriminatory provisions relating to marriage with, and divorce from, persons affected by leprosy in the following laws: the Indian Divorce Act (1869), the Indian Christian Marriage Act (1872) and the Dissolution of Muslim Marriage Act (1939). The Civil Code of Ethiopia used to include leprosy as legal grounds for divorce. This provision was repealed by Special Family Law Proclamation No.1 in 2000. Nepal's Civil Code permits a spouse to seek divorce on the grounds of leprosy. If the wife has leprosy, she is forbidden to ask her husband for subsistence³⁷. States should abolish such discriminatory laws and practices immediately.

34. Down the centuries, persons affected by leprosy were isolated, ostracized and segregated. Leprosy was the first disease to sow divisions among people — resulting in the segregation and isolation of the affected persons from community³⁸. In 1897, the First International Leprosy Congress held in Berlin recommended control by segregation of patients with leprosy. In 1909, the Second International Leprosy Congress held in Bergen reaffirmed the recommendation for control by isolation and segregation and also recommended the removal of children from leprous parents as soon as possible.³⁹

35. South Africa brought in the Leprosy Repression Act in 1891, Australia introduced the Leprosy Act in 1893, India established The Lepers Act in 1898, and, in the same year, Pakistan brought in The Lepers Act No.III in 1898. All these laws sanctioned the compulsory segregation of leprosy patients. In Japan, patients who needed medical treatment and had no one to care for them were placed in leprosaria under the Leprosy Prevention Law of 1907. Under the amended Leprosy Prevention Law of 1931, all persons with leprosy were placed in leprosaria. This policy of compulsory segregation remained in force for 90 years, until the law was scrapped in 1996. In 1907, the Philippines introduced Act 1711 of the Philippine Commission, which gave full responsibility to the director of health for the compulsory segregation of persons affected by leprosy. (It was abolished in 1992) ⁴⁰.

36. Other countries where a policy of compulsory segregation was imposed by law were Malaysia, the Bahamas, the Republic of Korea, Egypt, Singapore and Myanmar. In the Republic of Korea, the compulsory segregation law for persons affected by leprosy was abolished in 1961. In Egypt, the competent Egyptian authorities are currently reviewing Law No.131, passed in 1946, which provides for the segregation of persons affected by leprosy until cure is attained. It

³⁶ *Ibid.*, p.223. Philip IV, King of France, suggested that all persons with leprosy be gathered together and burned, and that the practice continue until the disease was eradicated.

³⁷ According to the presentation by P.K. Gopal, there are about 27 acts, in India, including the Hindu Marriage Act, Muslim Marriage Act and Christian Marriage Act, which make leprosy ground for discrimination. In India, leprosy-affected parents are unable to arrange marriage for their daughters. Gopal, *supra* note 26.

³⁸ *Ibid.*.

³⁹ Skinsnes, *supra* note 11, p.226.

⁴⁰ Compulsory segregation and isolation of leprosy patients was started in 1907. Presentation by Arturo C. Cunanan, Jr. titled "Discrimination against persons affected by leprosy and their family members" in the open-ended consultation on the elimination of discrimination against persons affected by leprosy and their family members (Geneva, 15 January 2009). <http://www2.ohchr.org/english/issues/health/discrimination/index.htm>.

should be stated that Law No.131 has not been enforced since 1984, when the provision of MTD to persons affected by leprosy, recommended by the WHO, began. Any law or policy to forcefully hospitalize, segregate or intern persons affected by leprosy and their family members should be abolished immediately.

37. Persons affected by leprosy encounter stigma and discrimination in their daily life. For example, in the area of public transportation, persons affected by leprosy in India are not infrequently required by the railway authorities to carry a medical certificate stating that their condition is not infectious and that they do not pose a risk to their fellow passengers. This relates to Section 56 of the Indian Railways Act of 1989 pertaining to all infectious diseases, including leprosy⁴¹. According to the Indian Motor Vehicle Act of 1988, persons affected by leprosy cannot obtain a driver's license. In Myanmar, under the Inland Waterways Act, until 1992 a person affected by leprosy needed to report to the captain of a vessel that he or she had leprosy, and request special accommodation. Meanwhile, the Singapore Railways Act of 1906 prohibited persons affected by leprosy from using public transport.

38. In the area of employment, too, persons affected by leprosy have been subjected to discrimination. For example, Thailand's Alien Occupation Law requires all aliens applying for a work permit to submit with their application a recent medical certificate from a physician in Thailand stating that the applicant is not of unsound mind and not suffering from leprosy, acute tuberculosis, elephantiasis, narcotic addiction or habitual alcoholism. Chapter 238 of Statute Law of the Commonwealth of the Bahamas contains provisions discriminating against persons affected by leprosy. Persons affected by leprosy also face discrimination over the use of public facilities. In India, hotels in many places do not allow persons affected by leprosy to stay, and restaurants refuse to serve them⁴². Some countries have provisions in their immigration laws that discriminate against persons affected by leprosy⁴³.

39. Until 1992, Myanmar's Leprosy Act forbade persons affected by leprosy from handling food, medicine, clothing, using public wells and ponds. In Angola, persons affected by leprosy were not issued national identity cards. In China, the children of persons affected by leprosy in one leprosy resettlement village were not allowed to attend public school for many years. Thanks to the efforts of an NGO, seven children were finally accepted by a public primary school in 2002.

⁴¹ Section 56 of the Indian Railways Act prescribes restriction with respect to the carriage of passengers with infectious or contagious diseases:

(1) A person suffering from such infectious or contagious diseases, as may be prescribed, shall not enter or remain in any carriage on a railway or travel in a train without the permission of a railway servant authorized in this behalf.

(2) The railway servant giving permission under sub-section (1), shall arrange for the separation of the person suffering from such disease from other persons in the train and such person shall be carried in the train subject to such other conditions as may be prescribed.

(3) Any person who enters or remains in any carriage or travels in a train without permission as required under sub-section (1) or in contravention of any condition prescribed under sub-section (2), such person and a person accompanying him shall be liable to the forfeiture of their passes or tickets and removal from railway by any railway servant.

⁴² Dr. Gopal's presentation, *supra* note 26.

⁴³ In a Guideline to Chinese Law for Foreigners Coming to, Leaving or Staying in China during the Olympics 2008, it was stated that anyone with leprosy and a number of other listed disease would be prohibited from entering China during the Olympic s. However, in July 2008, the Chinese government lifted the ban. As a matter of course, no persons affected by leprosy should be denied entry into a country on the basis of leprosy.

40. In a number of Indian states, there are laws prohibiting persons affected by leprosy from holding office. For example, the Orissa Municipal Act of 1950 disqualifies a person affected by leprosy from contesting an election or holding the post of councilor or chairperson of a municipality. As recently as September 2008, India's Supreme Court upheld the Orissa law in the case of a man who was disqualified from holding municipal office in Orissa because he once had leprosy⁴⁴. Laws and practices that discriminate against persons affected by leprosy, such as in employment, access to public places including hotels, restaurants and buses, trains and other forms of public transport, should be stopped immediately.

41. The stigma and discrimination against persons affected by leprosy and their family members remain critical issues that must be overcome through legal, societal and empowerment efforts. Needless to say, it is necessary to abolish discriminatory legislation against persons affected by leprosy. But that in itself is far from adequate. Therefore, we must also look at ways to address the deep-rooted stigma attached to leprosy that finds expression in discriminatory social customs and practices that are a legacy of leprosy's long history. Persons affected by leprosy have waited long enough for their rights to be recognized.

IV. Leprosy and the right to health

A. Human rights and public health

42. The WHO defines health as not merely absence of disease or infirmity, but a state of complete physical, mental and social well-being. The preamble to the Constitution of the WHO also provides that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition"⁴⁵.

43. In general, human rights and public health share the common objective to promote and to protect the rights and well-being of all individuals. From the human rights perspective, this can best be accomplished by promoting and protecting the rights and dignity of everyone, with special emphasis on those who are discriminated against or whose rights are otherwise interfered with. Similarly, public health objectives can best be accomplished by promoting health for all, especially for those who are vulnerable to threats to their physical, mental or social well-being⁴⁶. Thus, health and human rights complement and reinforce each other in any context, including our particular context, leprosy.

B. Leprosy as a neglected disease and the right to health

44. The right to health is an inclusive right: It includes a wide range of factors that can help us lead a healthy life. The Committee on Economic, Social and Cultural Rights calls these

⁴⁴ Compilation of submissions in reference to a Note Verbale dated 8 July 2008 sent by the Office of the United Nations High Commissioner for Human Rights pursuant to Human Rights Council Resolution 8/13 of 12 June 2008, p.7.

⁴⁵ Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19 June -22 July 1946.

⁴⁶ Second International Consultation on HIV/AIDS and Human Rights (Geneva, 23-25 September 1996), Report of the Secretary-General, E/CN.4/1997/37, pp.12-13.

factors the “underlying determinants of health⁴⁷”. Furthermore, health services, goods and facilities must be provided to all without discrimination. Non-discrimination is a key principle in human rights and is crucial to the enjoyment of the right to the highest attainable standard of health⁴⁸.

45. Needless to say, the right to health should not be understood merely as a right to be healthy. The right to health has two major dimensions: first, it is a right to access to health services, spelled out without different degrees of concretization in the different instruments; second, it is a right to social order which includes obligations of the State to take specific measures for the purpose of safeguarding public health⁴⁹. The Charter of Fundamental Rights of the European Union provides that “everyone has the right of access to preventive healthcare and the right to benefit from medical treatment under the conditions established by national laws and practices⁵⁰”.

46. At the outset of the open-ended consultation, Mr. Ibrahim Wani of the OHCHR, serving as a chair, expressed his wish to consider the issue of leprosy in the context of neglected diseases, particularly of diseases which are mostly suffered by persons living in the developing world⁵¹. While there are different ways of defining neglected diseases, a WHO publication describes them as those diseases that “affect almost exclusively poor and powerless people living in rural parts of low-income countries⁵²”.

47. Leprosy is one of the 10 diseases within the mandate of Special Programme for Research and Training in Tropical Diseases (TDR). Professor Paul Hunt, the Special Rapporteur on the right of everyone to enjoy the highest attainable standard of physical and mental health, suggested that “it would be instructive to devise a right to health approach to the elimination of leprosy, including the stigma and discrimination associated with the disease. Such an initiative could draw upon the rich experience of human rights and HIV/AIDS, as well as recent work on human rights and tuberculosis⁵³”.

48. The relationship between discrimination against persons affected by leprosy and the right to health has to be elucidated in our context. The crux of the above comment by Mr. Wani is that leprosy-based discrimination must be dealt together with health-related discrimination in the broader context of multiple discrimination i.e. leprosy and race, gender, age and socio-economic status⁵⁴.

49. It is necessary to consider the relationship between HIV/AIDS and leprosy. There is a similarity between the two. Persons affected by HIV/AIDS and those affected by leprosy must

⁴⁷ They includes: Safe drinking water and adequate sanitation; Safe food; Adequate nutrition and housing; Healthy working and environmental conditions; Health-related education and information; Gender equality. The Right to Health, Fact Sheet No.31, p.3.

⁴⁸ *Ibid.*, p.4.

⁴⁹ Janusz Symonides, *Human Rights: Concept and Standard*, UNESCO 2000, p.152.

⁵⁰ Article 35 of Charter of Fundamental Rights of the European Union adopted in Nice, Official Journal of the European Communities, 2000, C 364/16.

⁵¹ Welcome comments by Ibrahim Wani in the open-ended consultation (Geneva, 15 January 2009), p.2.

⁵² *Global Defence against the Infectious Disease Threat*, WHO, 2002, p.96.

⁵³ Interim report of Paul Hunt, Special Rapporteur on the right of everyone to enjoy the highest attainable standard of physical and mental health, Mr. Paul Hunt, A/58/427, p.21, paras.79-80.

⁵⁴ Mr. Wani, *supra* note 51, p.2.

cope both with the disease itself and with stigma and discrimination. Ms. Susan Timberlake of UNAIDS referred to the importance of standard-setting regarding discrimination and health status, based upon various human-right treaties as well as national jurisprudence⁵⁵. This suggests that there is much to be gained from a common approach, i.e. a right to health approach. Such an approach, however, cannot be said to be sufficient. There are some specific issues that characterize discrimination against leprosy: stigma is age-old, deeply ingrained, and closely related to the cultural and religious perspectives of the community concerned. This means that there needs to be another approach clearly focused on leprosy. Therefore, we should take a twin-track approach in combating the stigma and discrimination that persons affected leprosy and their family members have long suffered⁵⁶.

50. The human rights that pertain to persons affected by leprosy should not be seen as relating only to health or disability. Even today, it is estimated that millions of people are unfairly and irrationally treated due to this disease⁵⁷. In fact, persons affected by leprosy have suffered inhumane treatment, including forced isolation, because they were “thought to be infectious” and because the disease “resulted in deformity,” among other reasons. Therefore, discrimination against such people cannot be discussed in the same way as discrimination against persons affected by other diseases. In the case of persons affected by leprosy, they are discriminated against, even after they have recovered. In addition, their families are also discriminated against. In this regard, the problems facing persons affected by leprosy can be seen as particularly serious. Accordingly, efforts to restore their human dignity must be linked to consideration of all their human rights.

51. The lack of accurate understanding among the general public causes prejudice against persons affected by leprosy and other neglected diseases. These diseases primarily affect people living in the poorest parts of the developing world⁵⁸. In his preliminary report, Professor Hunt pointed out “the ‘10/90 disequilibrium’ with regard to the right to health implication of neglected diseases—only 10 percent of health-research and development spending being directed at the health problems of 90 percent of the world’s population⁵⁹”. In formulating a set of principles and guidelines, there is a need to focus on the distinctiveness of leprosy, while taking into account the situation in the poorest developing countries.

V. A human rights approach to elimination of discrimination

52. In its resolution 8/13 entitled “Elimination of discrimination against persons affected by leprosy and their family members”, the Human Rights Council affirms that persons affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all basic human rights and fundamental freedoms under customary international law, relevant

⁵⁵ Presentation by Susan Timberlake titled “Reducing HIV Stigma and Discrimination: lessons for leprosy” in the open-ended consultation (Geneva, 15 January 2009).

⁵⁶ Comments by Dr. Wim van Brakel, Royal Tropical Institute/NLR in the open-ended consultation (Geneva, 15 January 2009).

⁵⁷ Presentation by Yohei Sasakawa, WHO Special Ambassador for the Elimination of Leprosy titled “Leprosy and human rights” during the fifty-fifth session of the Sub-Commission on the Promotion and Protection of Human Rights, 4 August 2003.

⁵⁸ Regarding the neglected diseases, see Report of Paul Hunt, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt, Addendum Mission to Uganda, E/CN.4/2006/48/Add.2, 19 January 2006, pp.6-7.

⁵⁹ Interim report by Prof. Hunt, *supra* note 53, p.20, para.76.

conventions and national constitutions and laws and requests the OHCHR to include the issue of discrimination against persons affected by leprosy and their family members as an important matter in its human rights education and awareness-raising activities⁶⁰. We need a human-rights approach in eliminating discrimination against persons affected by leprosy.

A. Universal Declaration of Human Rights

53. The Universal Declaration of Human Rights recognizes the inherent dignity and the equal and inalienable rights of all members of the human family as the foundation for freedom, justice and peace in the world. Article 1 of the Universal Declaration provides that “all human beings are born free and equal in dignity and rights.” Notwithstanding, persons affected by leprosy have had their dignity, which is protected under this article, taken away from them. Furthermore, Article 2 provides that “everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind.”

54. However, persons affected by leprosy and their family members do not enjoy many rights and freedoms stipulated in the Universal Declaration. These include: “the right to life, liberty and security of person”(Article 3); the right not to “be subjected to ...cruel, inhuman or degrading treatment”(Article 5); “the right to recognition everywhere as a person before the law”(Article 6); “the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by constitution or by law”(Article 8); the right not to “be subjected to arbitrary arrest, detention or exile”(Article 9); the right not to “be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation”(Article 12); “the right to freedom of movement and residence within the borders of each State”(Article 13, Paragraph 1); “the right to marry and to found a family”(Article 16, Paragraph 1); “the right to own property”(Article 17, Paragraph 1); “the right to social security”(Article 22); “the right to work”(Article 23, Paragraph 1); “the right to a standard of living adequate for the health and well-being of himself and his family”(Article 25, Paragraph 1); and “the right to education”(Article 26). Many persons affected by leprosy are subjected to various types of discrimination without effective protection⁶¹.

55. People affected by leprosy have been the subject of deep-rooted prejudice and misunderstanding, and legislative and administrative measures alone are not enough to prohibit discrimination against them, or to protect them. As a result, millions of persons affected by leprosy still suffer political, legal, economic or social discrimination and live on the margins of society as a result. The Sub-Commission on the Promotion and Protection of Human Rights, in its resolution 2005/24 dated 11 August 2005, expressed grave concern about their circumstances.

B. International Covenant on Economic, Social and Cultural Rights

56. International Covenant on Economic, Social and Cultural Rights (ICESCR), adopted on 16 December 1966, addresses the right to health. Article 12, paragraph 1 provides that “the State Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard for physical and mental health” and Paragraph 2 provides that “the steps to be taken by the State Parties to the present Covenant to achieve the full realization of this right shall

⁶⁰ Resolution 8/13 of the Human Rights Council, paras.1 and 3.

⁶¹ E/CN.4/Sub.2/2005/WP.1, p.5, paras.14-15.

include those necessary for : ... (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases; (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness” (Paragraph 2).

57. The Committee on Economic, Social and Cultural Rights, in its General Comment 14, affirms that “Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity⁶²” (Paragraph 1). The right to health is linked indivisibly to other human rights and includes certain components that are legally enforceable, e.g. the principle of non-discrimination.

58. The full enjoyment of the right to health still remains a distant goal for millions of people throughout the world, among them, for persons affected by leprosy and their family members. In the words of General Comment 14, the obligations of states include “ensuring equal access to health care and health services.” Such access is vital, especially where the weakest numbers of society are concerned, and must be provided in a timely manner. As General Comment 14 has rightly pointed out, “States have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health-care facilities, and to prevent any discrimination on internationally prohibited grounds in the provision of health care and health services, especially with respect to the core obligations of the right to health⁶³”.

59. What is noteworthy is that General Comment 14 shows the three categories of obligations imposed on State parties with respect to the right to health: “The right to health, like all human rights, imposes three types or levels of obligations on State parties: the obligations to respect, protect and fulfil. In turn, the obligation to fulfil contains obligations to facilitate, provide and promote. The obligation to respect requires States to refrain from interfering directly or indirectly with the enjoyment of the right to health. The obligation to protect requires States to take measures that prevent third parties from interfering with Article 12 guarantees. Finally, the obligation to fulfil requires States to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realization of the right to health”. These categories of obligations may be applicable to these principles and guidelines for what States should do for the elimination of discrimination against persons affected by leprosy. For now it can be said that the provisions of this article remain almost entirely unfulfilled for persons affected by leprosy.

C. International Covenant on Civil and Political Rights

60. Under the International Covenant on Civil and Political Rights (ICCPR) adopted in 1966, “Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention” (Article 9, Paragraph 1). The Human Rights Committee confirms in General Comment 8, Paragraph 1, that “paragraph 1 is applicable to all deprivations of liberty, whether in criminal cases or in other cases such as, for example, mental illness, vagrancy, drug addiction, educational purposes, immigration control, etc.⁶⁴” (Paragraph 1). Therefore, this article applies to persons affected by leprosy and their family members deprived of their liberty by detention

⁶² General Comment No.14 (2000), E/C.12/2000/4 11 August 2000, p.1, para.1.

⁶³ *Ibid.*, p.6, para.19. For the core obligations, see paras.43 and 44 of General Comment No.14 (2000).

⁶⁴ CCPR General Comment No.8 (Right to liberty and security of persons), para.1.

based on the policy of forced segregation or isolation. Even if the detention was conducted by law, there is a possibility of breach of this article. The reason for this is that the term “arbitrariness” is not a synonym of “lawfulness”. In the Committee’s view, “the introduction of the concept of arbitrariness is intended to guarantee that even interference provided for by law should be in accordance with the provisions, aims and objectives of the Covenant and should be, in any event, reasonable in the particular circumstances.⁶⁵” In other words, laws must not be arbitrary⁶⁶.

61. The Covenant also provides that “All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person” (Article 10, Paragraph 1). While Article 9 regulates the reason for which persons may be detained, Article 10 provides for the conditions of such detention. Paragraph 1 of this article guarantee that States treat persons in detention with humanity and dignity. According to the Committee, this paragraph “applies to anyone deprived of liberty under the laws and authority of the State who is held in prisons, hospitals - particularly psychiatric hospitals - detention camps or correctional institutions or elsewhere. State parties should ensure that the principle stipulated therein is observed in all institutions and establishments within their jurisdiction where persons are being held⁶⁷” (Paragraph 2 of General Comment 21).

62. Article 12 of the ICCPR protects the freedom of movement of persons, including the right to move freely and to choose freely where to live. Any restrictions must be in conformity with Paragraph 3. This paragraph provides for exceptional circumstances in which rights under paragraphs 1 and 2 may be restricted. The Committee, in General Comment No. 27, “authorizes the State to restrict these rights only to protect national security, public order, public health or morals and the rights and freedoms of others. To be permissible, restrictions must be provided by law, must be necessary in a democratic society for the protection of these purposes and must be consistent with all other rights recognized in the Covenant⁶⁸”. “Thus, it would be a clear violation of the Covenant if the rights enshrined in Article 12, paragraphs 1 and 2, were restricted by making distinctions of any kind, such as on the basis of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or *other status*⁶⁹” (Emphasis added). It is presumed that the term “other status” includes health status, such as leprosy. Therefore, if people were deprived of their freedom of movement only because of leprosy, this would constitute a violation of Article 12.

63. It is important to remember that under the pretext of “protection of public health”, many governments have applied their own laws to forcibly isolate persons affected by leprosy . Such segregation policies must be corrected as soon as possible, because this disease is not highly contagious.

⁶⁵ CCPR General Comment No.16 (The right to respect of privacy, family, home and correspondence, and protection of honour and reputation), para.4.

⁶⁶ Sarah Joseph, Jenny Schultz, and Melissa Castan, *The International Covenant on Civil and Political Rights Cases, Materials, and Commentary*, 2nd ed., Oxford University Press, 2004, p.484, n.15.

⁶⁷ CCPR General Comment No.21 (Replaces General Comment No.9 concerning humane treatment of persons deprived of liberty), para.2.

⁶⁸ CCPR/C/21/rev.1/Add.9, General Comment No.27 (Freedom of Movement), para. 11.

⁶⁹ *Ibid.*, para.18.

64. It should be remembered that ICCPR provides that “Everyone shall have the right to recognition everywhere as a person before the law” (Article 16). Persons affected by leprosy and their family members should be treated in such a way that their human dignity is respected, whenever and wherever they are.

65. Article 23, Paragraph 2 provides that “the right of men and women of marriageable age to marry and to found a family shall be recognized.” Under this paragraph, the right to found a family implies, in principle, the possibility to procreate and live together. It is clear that persons affected by leprosy can enjoy the right provided for in this paragraph. In many countries, however, there are still marriage laws and practices that discriminate against persons affected by leprosy. It is clear that those laws and practices violate Article 23.

66. As provided in Article 25 of the Covenant, “Every citizen shall have the right and the opportunity, without any of the distinctions mentioned in article 2 and without unreasonable restrictions: ... (c) To have access, on general terms of equality, to public service in his country.” Article 25(c) thus guarantees a fair opportunity to serve the public. According to General Comment 25 adopted by the Human Rights Committee in 1996, it is established that “no person should suffer discrimination or disadvantage of any kind because of that person's candidacy. State parties should indicate and explain the legislative provisions which exclude any group or category of persons from elective office⁷⁰”. As in the above-mentioned case of an Indian state, when an individual is hindered from working in public service, this would be in violation of the universal standard.

67. The Covenant clearly provides that “all persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status” (Article 26). Persons affected by leprosy can also enjoy any rights provided for in this article.

D. UN Convention on the Rights of Persons with Disabilities

68. We should take a close look at the UN Convention on the Rights of Persons with Disabilities as it contains some very important elements. In its preamble, the Convention reaffirms “the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination⁷¹.” Parties to this Convention shall undertake to take all measures to eliminate “discrimination on the basis of disability”.

69. According to Article 2, the term “discrimination on the basis disability” means “any discrimination, exclusion or restriction on the basis of disability which has any purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.” In the context of leprosy, this definition is applicable to persons who have had a disability or are perceived as having a disability due to a delay in medical treatment.

⁷⁰ CCPR/C/21/Rev.1/Add.7, General Comment No.25, para.15.

⁷¹ Vienna Declaration and Programme of Action (A/CONF.157/23), adopted by the World Conference on Human Rights, held in Vienna, 14-25 June 1993 admitted that human rights are interdependent, indivisible and interrelated.

70. Another relevant element of the Convention is that it tries to ensure a life within the community for persons with disabilities. Shutting people away is now outlawed by the Convention, which tries to ensure that states put in place alternative options, so that persons with disabilities have a chance to live outside institutions. The key word is “inclusion”. In this regard, it is noteworthy that the Convention introduces a new concept of “reasonable accommodation”. In Article 2, this is defined as “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”. The lack of reasonable accommodation amounts to discrimination.

71. This concept could be applied to persons affected by leprosy⁷². On many points, there is no difference between persons affected by leprosy and persons with disabilities as a legal subject enjoying all human rights and fundamental freedoms. Therefore, these principles and guidelines could be formulated through the same approach as in this Convention.

VI. Principles and Guidelines

Part 1: Purpose

72. An open-ended consultation was held on 15 January 2009 under the auspices of OHCHR. On that occasion, many NGOs and many persons affected by leprosy expressed strong support for drafting a set of principles and guidelines to eliminate discrimination against persons affected by leprosy and their family members.

73. The purpose of the principles and guidelines is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms of all persons affected by leprosy, and to promote respect for their inherent dignity.

Part 2: Approach to Principles and Guidelines

A. Terminology

74. There is a range of positions concerning this issue. For example, some people prefer “leprosy”, while others prefer “Hansen’s disease”⁷³. The English word “leprosy” comes from the Latin word *lepra* and is widely used as a medical and legal term. However, some consider it inappropriate because the word is often associated with a disease thought to be incurable, contagious and even dangerous. For this reason, in Japan, the use of the word *rai* or *raibyō*, a direct translation of “leprosy”, is now discouraged and “Hansen’s disease” is commonly used⁷⁴. In Brazil and the Republic of Korea, the term “Hansen’s disease” is preferred and widely used⁷⁵.

⁷² Comments by Stephan Tromel, International Disability Alliance, during discussions at the open-ended consultation (15 January 2009).

⁷³ Comments by Anwei Law, International Association for Integration, Dignity and Economic Advancement (IDEA), during discussions at the open-ended consultation (15 January 2009).

⁷⁴ Discrimination against leprosy victims and their families, Note by the Secretariat, E/CN.4/Sub.2/2005/29, 15 July 2005, pp.5-6.

⁷⁵ In Brazil, the National Sanitary Dermatology Division adopted by decree on 14 May 1976 the term “hansenise”, or “Hansen’s disease” as it is known in English, in place of “leprosy”. See submissions by International Federation of Anti-Leprosy Associations (ILEP) to resolution 8/13-Jeprosy, registered on 24/10/2008.

In formulating a set of Principles and Guidelines, both “leprosy” and “Hansen’s disease” will be used interchangeably⁷⁶.

75. In this regard, it should be emphasized that we possibly perpetuate stigma and discrimination by using certain words. For that reason, terms such as “victims” and “sufferers” should be avoided. Furthermore, in order to change the traditional social image of leprosy, it is important to use terminology that promotes the dignity of affected persons, and that recognizes a person as an individual separate from the disease⁷⁷. In particular, the use of the pejorative term “leper” and its equivalent in other languages, especially its use in the media, should be banned⁷⁸. The language and images used to describe the lives of persons affected by leprosy are required to reflect their dignity.

B. Adoption of a social approach

76. In the past, the emphasis was on the medical aspect of leprosy rather than its social aspect, such as stigma and discrimination against persons affected by the disease and even their family members. Thus the Human Rights Council affirms that persons affected by leprosy and their family members should be treated as individuals with dignity and are entitled to all basic human rights and fundamental freedoms. This is the same approach as that taken by the UN Convention on the Rights of Persons with Disabilities.

77. For addressing the issues of people who have been excluded from their communities because of their disabilities, the UN Convention on the Rights of Persons with Disabilities recognizes the need for a social approach. The social approach, in contrast to the medical approach, treats disability as a social problem, and tries to realize the rights of persons with disabilities and prohibit discrimination against them. As has already been made apparent, persons affected by leprosy are still subject to discrimination. This means that putting the emphasis on a medical approach is not enough. Accordingly, societal rehabilitation is important to restoring their self-worth and status in the society. The concepts of non-discrimination, full and effective participation and inclusion in society, equality of opportunity and accessibility will be included in formulating the principles and guidelines.

C. Human dignity

78. Human dignity is inviolable. It must be respected and protected⁷⁹. Moreover, the concept of human dignity is a central one not only in international human rights instruments but also in many modern constitutions. Thus Article 1 of the German Basic Law provides that “the dignity of man is inviolable⁸⁰. To respect and protect it shall be the duty of all state authority”. We can find the same approach in the new constitution of South Africa. Article 1 declares that the

⁷⁶ Needless to say, States should remove discriminatory language from any governmental publications and revise existing publications containing such language.

⁷⁷ See submission by IDEA to resolution 8/13-Leprosy, registered on 31/10/2008.

⁷⁸ In the Fifth International Leprosy Congress held in Havana(3-11 April 1948), it was agreed that “the use of the term ‘leper’ in designation of the patient with leprosy be abandoned.”

⁷⁹ We can find the same expression in Article 1 of Charter of Fundamental Rights of the European Union in 2000.

⁸⁰ See also Article 10 of the International Covenant on Civil and Political Rights and Article 13 of the International Covenant on Economic, Social and Cultural Rights.

Republic of South Africa is founded on certain values, the first mentioned of which are “human dignity, the achievement of equality and the advancement of human rights and freedom”⁸¹.

79. As in the resolution 8/13 of the Human Rights Council, persons affected by leprosy and their family members should be treated as individuals with dignity and entitled to all basic human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and laws. Human dignity should be affirmed also in formulating a set of principles and guidelines.

D. Non-discrimination

80. In a draft set of principles and guidelines, the principle of non-discrimination stipulated in the international human rights instruments should be adopted. The term “or other status” in non-discrimination provisions in international human rights texts can be interpreted to cover health status, including leprosy, as well as HIV/AIDS⁸².

81. In formulating guidelines, we should enumerate the anti-discrimination measures to be taken by States. In addition, participation in public affairs must be highlighted, because some countries still have regulations that prevent people with leprosy from holding public office⁸³. The guidelines should also cover issues such as access to means of transportation and access to public places including hotels, opportunities for employment, housing, health care, personal property and inheritance.

E. Women and children affected by leprosy

82. Women and children affected by leprosy should be afforded special treatment and protection. Women are a particularly vulnerable group of persons affected by leprosy⁸⁴. Once a mother contracts leprosy, the health and well-being of the whole family can suffer⁸⁵. States

⁸¹ David Kretzmer and Eckart Klein (eds.), *The Concept of Human Dignity in Human Rights Discourse*, Kluwer Law International, 2002, v.

⁸² The Resolution of the Commission on Human Rights, 53rd meeting, 3 March 1995— 995/44. The protection of human rights in the context of human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS), para.1. In this Resolution, the Commission on Human Rights confirms that discrimination on the basis of AIDS or HIV status, actual or presumed, is prohibited by existing international human rights standards. The same could be said of leprosy.

⁸³ The Orissa Municipal Act of 1950 in India disqualifies a person affected by leprosy from contesting an election or holding the post of councillor or chairperson of a municipality. The Supreme Court upheld this law in 19 September 2008, when a man who had been disqualified from holding a post because he once had had leprosy, brought his case before the Court. Supreme Court judges CK Thakker and DK Jain said in their ruling : “It is true that now with aggressive medication a patient may be fully cured of the disease, yet the Legislature in its wisdom has thought it fit to retain such provisions in the statute in order to eliminate the danger of the disease being transmitted to other people from the persons affected by the disease.” See Reportable in the Supreme Court of India Civil Appellate Jurisdiction, Civil Appeal No.5743 of 2008, p.22, para.21.

⁸⁴ From the medical point of view, a unique danger to women is that even after release from treatment they may be vulnerable to reactivation of persisting bacilli due to depression of cell-mediated immunity (CMI) during pregnancy. Matthew John Hunter Shale, “Women with leprosy A woman with leprosy is in double jeopardy,” *Leprosy Review*, Vol.71, 2000, p.7. According to Dr. Le Grand, “Gender inequalities may play an even larger role, because of their effect on physical appearance and the social stigma associated with them”. Amanda Le Grand, “Women and leprosy: a review,” *Leprosy Review*, Vol.68, 1997, p.203.

⁸⁵ Joy Rafferty, “Curing the stigma of leprosy,” *Leprosy Review*, Vol.76, 2005, p.120.

should recognize that women affected by leprosy are subject to multiple-discrimination as observed in numerous, deplorable examples.

83. Leprosy affects people of all ages, except children under the age of 2 years who are spared presumably because the incubation period for the disease is 2 years or more and there is no known transplacental (intrauterine) transmission of the disease. In a population in which leprosy is endemic, approximately 20 percent of the people with leprosy are between the ages of 2 and 15 years. Since childhood leprosy is most often detected in the relatively early stage, before disabling anesthesia or paralysis, successful treatment means prevention of deformity, thereby improving the quality of the individual's entire adult life⁸⁶. The problem is, however, that there are many children with leprosy whose conditions have worsened due to inadequate treatment. They often face social discrimination, as, for example, with regard to educational access.

84. For the improvement of such a situation, it is absolutely important for States to ensure that children affected by leprosy are provided with adequate access to education and ample opportunities to develop their skills. Furthermore, States should take appropriate steps to make such an education accessible to them. It shall be unlawful for any educational institution to deny the admission of children affected by leprosy to any of its courses by reason of having or having had leprosy and/or with secondary disability due to leprosy.

F. Human rights education

85. Ignorance, misunderstanding, indifference and fear on the part of the general public, often reinforced by the legacy of past discriminatory laws, result in the fact that millions of persons cured of leprosy and their family members still face stigma and discrimination. For example, although a country may have abolished its forced segregation law against persons affected by leprosy, they are still excluded from their families and communities, discriminated against in the job market, and forced to beg on the streets. Likewise, people tell their children not to play with children affected by leprosy, do not eat with persons affected by leprosy, and do not even greet them. To eradicate such practices, human rights education is required. Human rights education raises awareness of stigma and discrimination against persons affected by leprosy and their families. Therefore, in drafting a set of principles and guidelines, the need for human rights education should be included in order to provide the public with accurate information about leprosy as a disease.

86. Education is the key to overcoming misconceptions and misunderstandings about this disease. For this very reason, the General Assembly of the United Nations launched the World Programme for Human Rights Education on 1 January 2005. This programme encourages States to include education to provide accurate information about leprosy as a disease in their relevant action plans. In addition, the United Nations should designate January 29 as World Leprosy Day and organize seminars, meetings and other awareness campaigns using a wide range of media such as television, radio, newspapers and magazines to provide accurate information regarding leprosy, its treatment and curability, in order to eliminate discrimination against persons affected by leprosy and their families.

⁸⁶ Janet M. Berreman, "Childhood Leprosy and Social Response in South India," *Social Science & Medicine*, Vol.19. 1984, p.854.

G. Good practices

87. In Japan, the discriminatory quarantine policy regarding leprosy was implemented in 1907 in accordance with the enactment of the “Leprosy Prevention Law” and the establishment of sanatoria. In 1996, this 90-year history of forced segregation came to end with the “Act to Abolish the Leprosy Prevention Law”. In 1998, persons affected by leprosy who had been placed in sanatoria filed a complaint with the Kumamoto District Court, citing the government’s failure to reverse its leprosy policy in a timely manner. In 2001, the Court ruled in favor of the plaintiffs. After this judgment, Japan’s prime minister at that time issued a statement on the government’s intention to resolve the leprosy issue in a prompt and thorough manner.

88. Japan decided to designate June 22 as the “Day to Commemorate Victims of Leprosy Prevention and Restore Their Honor”, because “Law for the Provision of Compensation for Former Leprosy Patients Placed in Leprosaria” came into force on that day in 2001. In order to promote the welfare and restore the honor of persons affected by leprosy and resolve the issues surrounding the disease, Japan enacted “Law for the Promotion of the Resolution of the Leprosy Issue” in 2008⁸⁷. The law states as guiding principles that: (1) Measures directed toward the leprosy issue must, to the fullest extent possible, redress the damage committed against persons cured from leprosy, whether physical, financial, or social, (2) When measures related to the leprosy issue are taken, it must be kept in mind that persons currently under treatment for leprosy in national sanatoria should be afforded a reassuring and comfortable lifestyle not in isolation from the local social environment⁸⁸, and (3) No one shall discriminate against or infringe upon the rights of persons affected by leprosy, including those who have recovered from leprosy⁸⁹.

89. In Estonia, people are fully compensated for the cost of leprosy treatment following the enactment of Government Regulation No.308 of 26 September 2002. In 2007, Brazil enacted Law No.11520 to guarantee the amount of B\$750 (approximately US\$300) per month in compensation to all the people who were compulsorily interned in leprosy colony hospitals until 31 December, 1986. Greece enacted Law No.1137/1981 on Treatment and Social Protection of Patients suffering from Hansen disease, which prohibits discrimination against persons affected by leprosy and provides them with a monthly income.

90. In addition, the Government of the Republic of Korea enacted the law concerning subsistence for persons affected by leprosy in 2007. In 2008 for the first time, a person affected by leprosy was elected to the National Assembly of the Republic of Korea. Many countries are addressing the issue of leprosy-related discrimination and are taking the initiative in eliminating human right violations against persons affected by leprosy and their family members.

91. In China, Chapter IV, Article 16 of the Regulation on the Prevention and Control of Leprosy, enacted in 1988, states that there shall be no discrimination against persons affected by leprosy and their family members in terms of education, employment, army service and marriage. Ukraine enacted Law No.1645-III in 2000 and made medical assistance and treatment available to all persons affected by leprosy.

⁸⁷ Statement by the Government of Japan in the open-ended consultation (Geneva, 15 January 2009).

⁸⁸ There are 15 leprosy sanatoria in Japan. 2,717 persons live in 13 national sanatoria, and 16 persons in 2 private sanatoria. Their average age is 80.

⁸⁹ Statement by the Government of Japan in the open-ended consultation (Geneva, 15 January 2009).

Part 3: Principles and Guidelines

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

92. In formulating a draft set of principles and guidelines on 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.

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 on the grounds of having or having had leprosy.
3. Persons affected by leprosy and their family members should not to be segregated or deprived of basic freedoms against their will or by force.
4. 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 marriage 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.
5. Persons affected by leprosy and their family members should have full citizenship and the right to obtain identity documents.
6. 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.
7. 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.
8. 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.

9. 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.

10. 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.

Guidelines

General

1. States⁹⁰ should promote the full realization of all human rights and fundamental freedoms for all persons affected by leprosy and their family members without discrimination of any kind 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;
- 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 using the maximum available resources to progressively 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 of 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.

⁹⁰ 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 and children affected by leprosy

1. States should recognize that in many societies leprosy has a significantly adverse impact on women and children who are already marginalized.
2. States should pay special attention to the promotion and protection of women and children affected by leprosy.
3. States should promote the full development, advancement and empowerment of women and children 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 older generations of 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 publication 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 of Economic, Social and Cultural Rights, the International Covenant of 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.
2. States should include psychological counseling as standard care offered to persons affected by leprosy who are undergoing diagnosis and treatment, and as needed after the completion of treatment.
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 government departments, educational organizations and civil society, 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.

VII. Conclusions and Recommendation

Conclusions

93. States shall adopt legislative, judicial, administrative, educative and other appropriate measures in order to follow these guidelines. It is important to raise awareness of the principles and guidelines not only among public officials and State agents but also among the public.

94. Leprosy is a curable disease that is rendered non-infectious after the first dose of treatment. It is neither highly infectious nor hereditary. Individuals who are diagnosed at an early phase and begin treatment promptly will not face long-term physical effects of the disease⁹¹.

⁹¹ 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 % of the 2010 level by the end of 2015. This reduction would

However, prolonged incarceration increases a person affected by leprosy's dependency on their isolated institution where they lead their daily lives, fostering social stigma and making it even harder to repeal such a policy⁹². A new series of measures must be implemented that take account of current scientific knowledge of leprosy.

Recommendations

95. To eliminate stigma and discrimination against persons affected by leprosy, various steps must be taken, including examining existing legislation for discriminatory provisions with a view to revising them, prohibiting segregation policies, encouraging respect for human rights, monitoring the status quo and establishing a program of assessment⁹³, promoting community involvement in overcoming stigma, ensuring an integrated healthcare system, and fostering cooperation between the public and private sectors. At the same time, residents of existing as well as former leprosy hospitals, sanatoria and colonies should be entitled to continue to live, if they so wish.

96. Human rights education is required to combat the stigma and discrimination deeply rooted in society. Legal literacy is also essential for persons affected by leprosy to recognize their own rights.

97. The Rapporteur recommends that these draft principles and guidelines will be adopted by the Advisory Committee at its third session to be held in August 2009, and by the Human Rights Council at its 12th session to be held the following month. The Rapporteur also recommends that States will reflect these principles and guidelines in their policies toward persons affected by leprosy and that they eliminate the discrimination to which persons affected by leprosy and their family members have long been subjected. We must reaffirm that the international community as a whole is responsible for establishing a society in which persons affected by leprosy can restore their human dignity, and not suffer any inhumane treatment, including segregation. States are required to cooperate with each other toward eradication of leprosy and elimination of human rights abuses against persons affected by leprosy.

98. Leprosy is no longer a public health problem in most countries of the world but there is still much work to be done to further reduce the burden of the disease.

99. International, regional and sub-regional bodies should provide support for the elimination of discrimination against persons affected by leprosy and their family members, through medical, financial, technical and legal assistance. International and regional human rights institutions, as well as international civil society, should monitor and support such efforts to eliminate discrimination against such persons.

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.

⁹² Hajime Sato and Minoru Narita, "Politics of leprosy segregation in Japan: the emergence, transformation and abolition of the patient segregation policy," *Social Science & Medicine*, Vol.56, 2003, p.2537. In fact, many countries that once gave special emphasis to the isolation of persons affected by leprosy experienced serious difficulties in reintegrating these persons into the community. Cf. P. Feenstra, "Leprosy control through general health service and/or combined programmes," *Leprosy Review*, Vol.64, 1993, pp.89-96.

⁹³ The need to evaluate and monitor existing programmes to improve effectiveness was pointed out by Ms. Timberlake. Ms. Timberlake, *supra* note 55.

100. All international organizations, including relevant United Nations bodies, specialized agencies and programs, should devote a particular attention to discrimination against persons affected by leprosy and seek to prevent and address the multiple forms of human rights violations resulting from stigma and discrimination.

101. In order to eliminate deep-rooted stigma and discrimination from society, it is essential that States take all possible measures at the central as well as local level. All actors in society, including hospitals, schools, universities, religious groups and organizations, business companies, newspapers and broadcasting networks and non-governmental organizations, should take steps immediately and effectively to eliminate all discriminatory acts..

102. Every human being is guaranteed the right to pursue happiness. We should not condone a society in which persons are forced to give up everything just because they contracted leprosy. Persons affected by leprosy have long been subject to stigma and discrimination and treated inhumanely. The international community must not forget this history of discrimination and must act to correct this injustice.

103. On the basis of the foregoing observations and conclusions, the Rapporteur makes the following recommendations:

- a. The Advisory Committee should adopt the draft principles and guidelines on elimination of discrimination against persons affected by leprosy and their family members, with necessary amendments and improvements, and submit the revised principles and guidelines to the Human Rights Council for adoption;
- b. The Human Rights Council should consider the draft of principles and guidelines and request all relevant United Nations bodies, special agencies and programs, as well as Member States of the United Nations 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;
- c. The Human Rights Council should also request all actors in society, including hospitals, schools, universities, religious groups and organizations, business enterprises, 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

Supporting Laws for Elimination of Discrimination against Persons affected by Leprosy

- Law No.1137/1981 on Treatment and Social Protection of Patients Suffering from Hansen's Disease ,Greece⁹⁴
- The Regulation on the Prevention and Control of Leprosy, Chapter IV, Article 16,1988, China⁹⁵
- The Constitution of the Federal Democratic Republic of Ethiopia,1995⁹⁶
- Royal Decree No.101/96, Oman⁹⁷
- Article No.27 of Law No. 1645-III 2000, Ukraine⁹⁸
- Government Regulation No 308 of 26 Sep 2002, Estonia⁹⁹
- Constitution Article 32 and 50, Ecuador¹⁰⁰
- Law for the Provision of Compensation for Former Leprosy Patients Placed in Leprosaria, 2001, Japan
- Revision of the Law for the Provision of Compensation for Former Leprosy Patients Placed in Leprosaria, 2006, the Republic of Korea
- Law No.11520, 2007, Brazil¹⁰¹
- Law regarding the investigation of the case in which persons affected by leprosy were victimized and subsistence for those victims, 2007, the Republic of Korea
- Law for the Promotion of the Resolution of the Leprosy Issue, 2008, Japan
- Policy/Regulations on services for rehabilitation of persons with disabilities, Tanzania¹⁰²

⁹⁴ This law prohibits discrimination against persons affected by leprosy and provides for a monthly income, among other measures.

⁹⁵ This regulation stated that there shall be no discrimination against persons affected by leprosy and their families in terms of education, employment, army service and marriage.

⁹⁶ Article 41, Paragraph 5 of the Ethiopian Constitution provides that “the State shall, within available means, allocate resources to provide rehabilitation and assistance to the physically and mentally disabled [persons]”, not only for persons affected by leprosy.

⁹⁷ This decree ensured material and medical assistance to Omani citizens and their families in case of sickness, incapacity or old age.

⁹⁸ Medical assistance and treatment have been made available to all persons affected by leprosy.

⁹⁹ The treatment of leprosy is compensated 100%.

¹⁰⁰ Preferential and specialized treatment for persons suffering from catastrophic diseases are guaranteed.

¹⁰¹ To guarantee the amount of B\$750 (approximately US\$300) per month in compensation to all persons who were compulsory interned in leprosy colony hospitals until 31 December 1986. In addition, they are guaranteed priority access to outhouses, prostheses, surgeries and all medical needs under the national healthcare system.

¹⁰² Includes persons affected by leprosy.