

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

by

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**HUMAN RIGHTS COUNCIL
REPORT OF THE ADVISORY COMMITTEE
Elimination of discrimination against persons affected by leprosy and their family
members**

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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 to collect information on the measures that the 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 programmes, non-governmental organizations, scientists, medical experts as well as representatives of persons affected by leprosy and their family members.

2. The Human Rights Council also requests the Advisory Committee to examine the governments and civil society organizations submissions and formulate a draft set of principles and guidelines for the elimination 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 the 15th meeting on 14 August 2008, the Advisory Committee adopted recommendations 1/5 on elimination against persons affected by leprosy and their family members, and designated Mr. Shigeki Sakamoto to formulate the above-mentioned draft set of principles and guidelines. Mr. Sakamoto has been invited to participate in the consultation organized on the issue by OHCHR on 15 January 2009.

4. Since then, the OHCHR has been collecting information about the anti-discrimination measures taken by individual countries. Fortunately, valuable information has already been submitted by 24 countries¹ and many NGOs². Judging from submissions, people affected by leprosy are forcibly quarantined, under the law, in isolated hospitals, sanatoria or colonies in some countries even today. Many submissions demonstrates the fact that stigma against people affected by leprosy is very severe in many countries.

5. There are persons affected by leprosy around the world. The WHO statistics in 2007 show that the number of persons affected by leprosy was 254,525. The number of the newly reported cases exceeds 1000 in 17 countries. In India, Brazil and Indonesia, over

10,000 people are annually affected by this disease. However, leprosy is a chronic, mildly communicable, non-hereditary disease caused by *Mycobacterium leprae*. It is now a curable disease, with MDT (Multiple drug Therapy) medicines, and available free of charge. Despite this, discrimination against them has yet to be eliminated. Many states and NGOs submitted information which demonstrates that such discrimination still exists. Against this background, the medical and public health doctors and nurses should actively contribute to rectify misunderstanding concerning leprosy as a disease.

6. In his Preliminary report on discrimination against leprosy affected persons 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 immediately.³” In many countries, such discriminate treatments still exist.

7. Needless to say, it is necessary to abolish discriminatory legislation against persons affected by leprosy. But that is far from adequate. In the long history of humankind, leprosy has been regarded as highly contagious and incurable. Persons affected by leprosy were consequently despised, isolated, abandoned and even feared. We should eradicate such deep rooted discriminatory practices towards persons affected by leprosy and their family members. They have waited long enough for their rights to be recognized.

I. Government and Civil Society Organizations Submissions

8. It is clear from the information submitted that some countries still hold a segregation policy vis-a-vis person affected by leprosy⁴, or have legislation on their forcible segregation⁵. As a result, the persistence of stigma and of fear of discrimination still exists, despite plenty of evidence that it had decreased in many leprosy-epidemic areas in the last two decades⁶. At present, persons affected by leprosy face great obstacles to their social reintegration after the cure⁷.

9. According to some countries' submissions, there are no specific measures regarding elimination of discrimination against persons affected by leprosy and their family members⁸. It should be noted that some countries do not have any human right related programmes to eliminate discrimination against persons affected by leprosy⁹. Governments and civil society organizations come to the same conclusion that a specific right-based approach is required for addressing stigma and discrimination against persons affected by leprosy.

II. Discussions at the Open-Ended Consultation

Comments of Governments

10. The subject of elimination of discrimination against persons affected by leprosy and their families has attracted not only the attention of non-governmental organizations but also the Governments. Many Governments participated in the open-ended consultation and commented on this issue. For example, Ambassador of Brazil stated that Brazil is in the forefront of efforts to protect the human rights of people affected by leprosy.

Domestically the Brazilian Government has taken several measures, including granting full citizenship to those who were incarcerated in colony hospitals. President Lula of Brazil has granted lifetime pensions to people affected by leprosy. To date the Brazilian Government has granted compensation in 800 out of 1,000 cases.

11. The delegation of Japan elucidated on its past concerning its discriminatory quarantine policy for persons affected by leprosy. Japan's policy began in 1907 with the Leprosy Prevention Law and the establishment of sanatoriums. Finally in 1996, 90 years of forced quarantine came to an end. In 1998, a number of persons affected by leprosy filed for damages. In 2001, the court ruled in favour of the plaintiffs. The prime minister announced compensation. At present, the Japanese Government is carrying out a number of efforts to restore the welfare and honour of people affected by leprosy. Last year, June 28 was designated in Japan as a day to remember victims of leprosy.

12. The delegation of China welcomed the convening of this consultation. The Chinese delegation stated that the right to health and leading a dignified life are very much dependent on the realization of other human rights. China considered this consultation as an opportunity and a window on what concrete actions are needed in realizing some of the basic human rights. The Chinese delegation also reiterated that China is looking

for full and fruitful cooperation with all stakeholders and that it wishes to see an end to discrimination against people affected by leprosy and other vulnerable groups. The delegation of Venezuela explained the measures that the Government had taken to eliminate discrimination against persons affected by leprosy. The Venezuelan Government completely eliminated so-called leprosy colonies. It has constantly run awareness campaigns and elimination campaigns so that the public is aware of the problems and difficulties for the people affected by this disease.

13. The delegation of the Philippines explained that in 2007, the Philippine Declaration to support the Global Appeal to End Stigma and Discrimination against People Affected by Leprosy was endorsed by ministry of health. The delegation of Thailand supported all efforts to tackle health-related discrimination, including leprosy, and also supported incorporating information about this disease into educational materials. Thailand stressed that leprosy is much more than just a health issue. The delegations of Malta illustrated that leprosy patients would be treated together with other patients in a teaching hospital. The delegation of Myanmar explained that the Government of Myanmar abolished its discriminatory leprosy act in 1992.

Leprosy and the Right to Health

14. In our discussion, the relationship between discrimination against persons affected by leprosy and the right to health was raised. At the outset of the consultation, Mr. Ibrahim Wani of OHCHR as a chair expressed his wish to highlight the importance of universal access to health without discrimination. According to him, this is vital, especially where the weakest members of society are concerned, and must be provided in a timely manner. Universal access to health, however, does not suffice. It is linked indivisibly to human rights. We must ensure that health status does not infringe other human rights. We must also make the utmost efforts to address multiple discrimination (e.g. due to sex, age, economic condition). We need to frame today's debate in the context of health-related discrimination, of which leprosy-based discrimination is but one concern among them.

15. Dr. P.K. Gopal, National Forum, India/IDEA, registered his disagreement with the position that considers leprosy-related stigma and discrimination under the right to health. He said that this would dilute the efforts to reduce stigma and discrimination. In his opinion, leprosy-related discrimination should not be linked to the right to health. In consideration of this issue, the statement of Dr. Wim Ban Brakel, Royal Tropical

Institute/NLR, is worth listening to. He proposed that there was a need for a twin-track approach in combating stigma. There is a similarity between the stigma and discrimination, on one hand, faced by people with other diseases, and on the other, people with leprosy. That suggests that there is much to be gained from a common approach. At the same time, the second track needs to be clearly focused on leprosy. There are some specific issues that characterize discrimination against leprosy: stigma is age-old, ingrained very strongly, and closely related to cultural and religious perspectives of the community concerned. We need to give leprosy and leprosy-affected person the focus they are due.

The UN Convention on the Rights of Persons with Disabilities

16. Mr. Stephan Tromel, International Disability Alliance, urged all participants to have a close look at the UN Convention on the Rights of Persons with Disabilities as it contains some very important elements. Parties to this Convention undertake to take all measures to eliminate “discrimination on the basis of disability”¹⁰. In the leprosy context, this includes discrimination toward families, persons who might have had a disability in the past, and those perceived as having a disability. The definition used by the Convention covers all these situations. In addition, he pointed out a rather new element – the lack of reasonable accommodation as a form of discrimination. Another relevant element of the Convention is that it tries to ensure that persons with disability can lead lives in the community. 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. Another emphasis by Mr Tromel was that our campaigns must not confirm the stigma that exists. For example, road safety campaigns in Spain have used the image of persons with disabilities. The message of implied disability in such a campaign, [i.e. that a traffic accident results in disability] in his view, was inappropriate. Similarly, the use of the word “suffer” in this context is inappropriate. Through the use of such words, we perpetrate stigma.

17. Mr. Doug Soutar, ILEP, concurred with Mr. Tromel on this point about the use of certain terminologies. It is very important, especially in circles like this, that we look inwards at our sometimes-stigmatizing language. Mr. Soutar also stressed that terms such as “victims” and “sufferers” should be avoided. Apart from the language, another important element of the Convention is that it tries to ensure a life within community for persons with disability . 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 Convention defines the concept of “reasonable accommodation” as follows; “Reasonable accommodation” means 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. This concept could be applied to persons affected by leprosy.

Informal consultation

18. For the purpose of hearing the views and suggestions from leprosy affected persons regarding their past experiences, present conditions and future aspiration, the informal consultation on elimination of discrimination against persons affected by leprosy and their family members organized by the Nippon Foundation was held on 16 January 2009. All the stakeholders present, particularly the representatives of the persons affected by leprosy, coming from Ethiopia, the Philippines, China, India and Brazil, told their own stories of sufferance in the past and expressed their strong expectation to end discrimination against them.

III. Principles and Guidelines

Use of words

19. In a discussion in the open-ended consultation, the issue of terminology was raised. There was a range of positions concerning this issue. For example, some people prefer leprosy, while some prefer Hansen’s disease¹¹. The English word “leprosy”, which comes from a Latin word *lepra*, is widely used as a medical and legal terminology. However, some consider this expression inappropriate because the word is used to describe the disease as “incurable”, “easily transmitted” 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 used¹². In Brazil, the term “Hansen’s Disease” is preferred and widely used¹³. In formulating a set of principles and guidelines, both “leprosy” and “Hansen’s Disease” will be used interchangeably¹⁴. In order to change the traditional social image of leprosy, it is important to use the term that promotes the dignity of the affected persons, and that recognizes a person as an individual separate from the disease¹⁵.

Adoption of Social approach

20. In the past, the emphasis was on a medical approach to the issue of leprosy. This approach treats leprosy as an individual problem and assists people affected by leprosy and their family voluntarily. In this approach, its social aspect, such as prejudice and discrimination against people affected by the disease and even their family members has not been adequately addressed. 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 of the UN Convention on the Rights of Persons with Disabilities which recognizes the need for a social approach to address the ways in which people with disabilities have been excluded from society.

The social approach, differs from the medical approach. It treats disability as a social problem, and tries to realize the rights of disabled people and prohibit discrimination against them. As it has already been made apparent, persons affected by leprosy are still subject to discrimination. It means that putting the emphasis on a medical approach is not enough. Thus, we should adopt a social approach to eliminate discrimination against persons affected by leprosy and their families. The concepts of non-discrimination, full and effective participation and inclusion in society, equality of opportunity and accessibility are included in formulating the principles and guidelines.

Dignity of the Human Person

21. In its resolution 8/13, 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 conventions and national constitutions and law. Before anything else, the dignity of the human person should be affirmed in formulating a set of principles and guidelines. Consequently, as one of the principles, “Persons affected by leprosy should be treated as persons with dignity and are entitled to all basic human rights and fundamental freedoms under customary international law, relevant conventions and national constitutions and law” should be included. A guideline that corresponds to this principle would be “The States recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law,” which should equally be included..

Non-Discrimination

22. In a draft set of principles and guidelines, the principle of non-discrimination stipulated in the international human rights instruments should be placed in the context

of leprosy. For example, 1) Persons affected by leprosy and their families shall not be discriminated on the basis of his/her current or previous leprosy disease or disability resulting from leprosy. 2) Access to means of transportation, public place including hotels, opportunities for employment shall not be denied Persons affected by leprosy and their family members. As a matter of fact, some hotels and temples in a country carry a notice that persons affected by leprosy are not allowed inside.

23. In formulating guidelines, we should enumerate the anti-discrimination measures to be taken by Governments¹⁶. For example, 1) States should abolish or repeal all existing laws, policies, regulations and practices that discriminate, directly or indirectly against persons affected by leprosy and their families. 2) States should provide an effective protection to persons affected by leprosy and their families from discriminatory practices in employment, education, health, marriage, religion, use of public utilities and places. 3) States should formulate policies and action plans to end discrimination against persons affected by leprosy and their families through public awareness campaigns and community health education. 4) States should immediately abolish or repeal all existing laws, policies, regulations and practices that forcefully or compulsorily segregate and isolate persons affected by leprosy and their families. 5) States should provide effective and adequate compensation, rehabilitation and other remedies to persons affected leprosy who have suffered from compulsory segregations and isolation policies of the Government in the past. In addition, participation in public affairs is another area that should be highlighted, because some countries still have regulations that prevent people with leprosy from holding public offices¹⁷. The issues of housing , health care, personal property and inheritance as well as participation in public life should be included in the guidelines.

Women and Children affected by leprosy

24. Particular treatment and protection should be provided to women and children affected by leprosy. States should recognize that women affected by leprosy are subject to multiple discrimination, observed in numerous, deplorable examples. In Japan, the abortion was forced upon pregnant women with leprosy. In the case of marriage, municipal law in Nepal permits a spouse to seek divorce, on the grounds of leprosy. And worse yet, if it is the female spouse who contracted leprosy, she is forbidden to seek support for her life from her spouse¹⁸. States should equally ensure that children affected by leprosy are provided with adequate access to education and ample opportunities to develop their skills. States should take appropriate steps to make such education accessible to them. It shall be unlawful for any learning 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.

Human Rights and Rights to Health

25. 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, with special emphasis on those who are vulnerable to threats to their physical, mental or social well-being¹⁹. Thus, health and human rights complement and reinforce each other in any context, including our particular context, leprosy.

26. The lack of accurate understanding is a cause for many issue for leprosy and other neglected diseases. These disease primarily affect people living in the poorest parts of the developing world²⁰. Leprosy, however, in contrast to other diseases, may result in the “visible disfiguration” such as the damage to the skin, so the people affected with this disease, continue to be discriminated even after the recovery. Therefore, in formulating a set of principles and guidelines, there is a need to focus on the distinctiveness of leprosy, while taking into account of the relationship between the human rights and health.

Human Rights Education

27. 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 tens of

millions of people cured of leprosy and their family members still face stigma. For example, although a country abolished its forced segregation law against people affected by leprosy, the same people continue to be excluded from their families and communities, discriminated in their job hunting, and forced to beg on the streets. In another country, people tell their children not to play with children affected by leprosy, do not eat with people affected by leprosy, and do not even greet them. To eradicate such practices, human rights education is required. The human rights education is valuable for increasing people's awareness of the stigma and discrimination against persons affected by leprosy and their families. Therefore, in drafting a set of principles and guidelines, the need of the human rights education should be included that provides the public with accurate information about leprosy as a disease and then to eliminate discrimination against the people with leprosy.

28. The World Programme for Human Rights Education launched by the General Assembly of the United Nations on 1 January 2005, and relevant national plans of action, should include education to provide accurate information about leprosy as a disease²¹. In addition, the United Nations should designate January 29 as the World Leprosy Day and organize seminars, meetings and other awareness campaigns using a wide range of media such as televisions, newspapers and magazines that provide accurate information regarding leprosy as a curable disease and its treatment, in order to eliminate discrimination against persons affected by leprosy and their families.

IV Conclusion

29. Leprosy is one of the oldest diseases known to humankind. References to it go back as far as the 6th century BC. In order to eradicate this most deep-rooted prejudice against this disease that causes discrimination, the cooperation of the human rights experts is essential²². The principles and guidelines for elimination of discrimination against persons affected by leprosy and their family members to end the stigma and discrimination against them should be completed with all the cooperation possible of the members of the Advisory Committee.

30. The draft principles and guidelines for elimination of discrimination against persons affected by leprosy will be ready by the end of May, which will then receive the comments from all the members of the Advisory Committee. Incorporating the revisions, the final draft will be completed by the end of June. This final draft will be submitted to the Third Meeting of the Advisory Committee, and if approved and adopted, will then submitted to the Human Rights Council.

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¹ 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).

² 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, Nippon Foundation and so on.

³ Preliminary report of Yoso Yokota on discrimination against leprosy affected persons and their families, A/HRC/Sub.1/58/CRP.7, p.14.

⁴ Armenia's submission to Resolution 8/13-Leprosy, registered on 11/11/2008.

⁵ Egypt's submission to Resolution 8/13-Leprosy, registered on 29/09/2008 and Ukraine's submission to Resolution 8/13-Leprosy, registered on 20/10/2008.

⁶ Royal Tropical Institute's submission to Resolution 8/13-Leprosy, registered on 29/09/2008.

⁷ The International Association for Integration, Dignity and Economic Advancement (IDEA)'s submission to Resolution 8/13-Leprosy, registered on 31/10/2008.

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

⁹ For example, Canada's submission to Resolution 8/13-Leprosy, registered on 26/09/2008.

¹⁰ In Article 1, the Convention gives a definition of "discrimination on the basis of disability." It means any distinction, exclusion or restriction on the basis of disability

which has the 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. It includes all forms of discrimination, including denial of reasonable accommodation.

¹¹ Remarks of Ms. Anwei Law, IDEA in the open- ended consultation.

¹² Discrimination against leprosy victims and their families, Note by the Secretariat, E/CN.4/Sub.2/2005/29, 15 July 2005, pp.5-6.

¹³ The National Sanitary Dermatology Division adopted by decree on 14th May 1976 the term “hanseniasis”, or “Hansen’s disease” as it is known in English, to replace use of “leprosy”. See International Federation of Anti-Leprosy Associations (ILEP) ’s submission registered on 24/10/2008.

¹⁴ Needless to say, States should remove discriminatory language from any government publication and revise existing publications containing such language.

¹⁵ Cf. IDEA’s submission, *supra* note 5.

¹⁶ In Japan, “Law for the Promotion on the Resolution of the Leprosy Issue” was enacted in 2008. 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 former leprosy patients, whether physical, financial, or social, (2) When measures related to the leprosy issue are taken, it must be kept in mind that leprosy patients entering national sanatorium should be afforded a reassuring and comfortable lifestyle not in isolation from the local social environment, (3) No one shall discriminate against or infringe upon the rights of persons affected by leprosy, including those who have recovered from leprosy. Statement by the Delegation of Japan in open-ended consultation meeting on 15 January 2009.

¹⁷ The Orissa Municipal Act of 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 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. 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.

¹⁸ Cf. IDEA's submission, *supra* note 5. In Ethiopia, the civil code used to refer to leprosy as one of the legally accepted factors for dissolving marriage until 2008. This article was replaced by Special Family Law Proclamation No.1/2008, *ibid.*, p.11..

¹⁹ 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.

²⁰ For the neglected diseases, see Report of 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.

²¹ Starting from 2009, 22 June has been designated as the “Day of restoration of honour and remembrance of victims of Hansen’s Disease prevention act”, as a measure to restore the honour of victims in Japan.

²² Speech by Yohei Sasakawa, Japanese Government Goodwill ambassador for the Human Rights of People Affected by Leprosy in the open-ended consultation on 15 January 2009.