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**ANNUAL REPORT OF THE UNITED NATIONS HIGH COMMISSIONER  
FOR HUMAN RIGHTS AND REPORTS OF THE OFFICE OF THE HIGH  
COMMISSIONER AND THE SECRETARY-GENERAL**

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

**Report of the Office of the United Nations High Commissioner  
for Human Rights\***

**Summary**

The present report is submitted in accordance with Human Rights Council resolution 8/13, in which the Council requested the Office of the United Nations High Commissioner for Human Rights to collect information on measures that Governments had taken to eliminate discrimination against persons affected by leprosy and their family members and to organize an expert meeting with all stakeholders in relation to that issue. The report contains a summary of the submissions received from Governments, non-governmental organizations and other stakeholders, as well as the main outcome of the discussions at the open-ended consultation held on 15 January 2009 in Geneva, with the participation of Member States, international and non-governmental organizations, experts and persons affected by leprosy.

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\* The present report is submitted late in order to take into account the outcome of the open-ended consultation held on 15 January 2009, in accordance with Human Rights Council resolution 8/13, para. 4.

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## I. INTRODUCTION

1. In accordance with Human Rights Council resolution 8/13, the Office of the United Nations High Commissioner for Human Rights (OHCHR) organized an open-ended consultation on 15 January 2009, for an exchange of views on the impact of health-related discrimination, including against persons affected by leprosy and their family members, on the enjoyment of human rights (see annex I). In compliance with a request of the Council on the same resolution, OHCHR sought information on measures taken at the national level to eliminate discrimination against persons affected by leprosy and their family members.<sup>1</sup>

2. In order to facilitate the discussions of the Council and its Advisory Committee, the present report includes the conclusions and recommendations excerpted from the preliminary working paper on discrimination against leprosy victims and their families submitted by Prof. Yozo Yokota to the Subcommission on the Promotion and Protection of Human Rights at its fifty-seventh session (A/HRC/Sub.1/58/CRP.7) (see annex II).

## II. OUTCOME OF THE OPEN-ENDED CONSULTATION

3. On 15 January 2009, OHCHR convened an open-ended consultation to exchange views on the impact of discrimination on the human rights of persons affected by leprosy and their family members, particularly with regard to health status. The consultation was attended by Governments, independent experts, relevant United Nations bodies, specialized agencies and programmes, non-governmental organizations, medical experts, as well as representatives of and persons affected by leprosy.

4. The discussions focused on the principle of non-discrimination under international human rights law, health-related discrimination and more specifically discrimination against persons affected by leprosy and their family members. Comparisons were drawn from experiences of persons affected by HIV/AIDS and persons with disabilities in combating discrimination.

5. The discussions were wide-ranging and included experiences and testimonies relating to discrimination against persons affected by leprosy and their family members at the national and international levels. Several substantive issues emerged and there was general agreement on the need for a draft set of principles and guidelines to be developed by the Advisory Committee. These may be summarized as follows:

(a) Despite significant medical advances that have successfully eliminated leprosy as a public health concern, deeply-rooted discrimination, misinformation and stigma persist in many countries, resulting in a range of human rights violations and the social exclusion of persons affected by leprosy and their family members;

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<sup>1</sup> For a more comprehensive summary of the meeting, see the OHCHR website at [www.ohchr.org](http://www.ohchr.org).

(b) While certain groups, such as people living with HIV/AIDS, those with disabilities or those affected by other neglected diseases (which can be tackled in similar ways) endure common forms of discrimination, there is also a need for focused attention on leprosy-related discrimination at the national and international levels. Some participants referred to “twin tracks” of work in combating discrimination more broadly while also addressing the particularities of stigma derived from specific diseases. Similarly, there was consensus on the importance of devoting attention to the multiple layers of discrimination, particularly in relation to sex, age and socio-economic conditions;

(c) The inclusion and informed participation of persons affected by leprosy, their family members and their representative organizations in policy, administrative and legislative processes affecting their lives needed to be ensured more systematically. Such participation would contribute to empowering persons affected by leprosy and their family members to combat discrimination, including through the recognition of their human rights as legal entitlements;

(d) A multipronged approach to fighting leprosy and leprosy-related discrimination should go beyond treatment, access to health care and prevention to include comprehensive strategies for legal and policy reform, raising social awareness, education, programmatic interventions and accountability. This is particularly relevant in the light of the linkages between leprosy and poverty, extreme poverty and isolation;

(e) Due attention should be paid to eliminate the use of discriminatory language, terminology and images which would further affect the rights of persons affected by leprosy and their family members. The use of “Hansen’s disease” was often mentioned;

(f) Any draft guidelines and principles to eliminate discrimination against persons affected by leprosy and their family members should be addressed not only to Governments, but also to medical professionals, the media, non-governmental organizations, public officials, as well as the general population and communities.

### **III. GOVERNMENT SUBMISSIONS**

#### **Armenia**

[Original: English]

[7 November 2008]

6. Armenia referred to recent research carried out on epidemic and social peculiarities of leprosy, taking into account a total of 370 people affected by leprosy since 1921 (only 7 newly affected had been registered since 1970). While some of those affected by leprosy are undergoing hospitalized treatment in different leprosaria in the Russian Federation, others are treated by the Armenian Medical-Scientific Centre of Dermatology and Sexually Transmitted Infections, which has also organized a series of seminars for family doctors on leprosy, with emphasis on vigilance, stigmatization, rehabilitation and the provision of job opportunities.

### **Azerbaijan**

[Original: English]

[27 October 2008]

7. Azerbaijan has devoted political and financial support to the elimination of discrimination against registered leprosy patients and their family members in order to protect their human rights. In Azerbaijan, it was reported that the World Health Organization (WHO) provided patients with medicines for treatment. Public awareness campaigns were available through the media, patient care institutions and other publications. In recent years, there has been recognition of the rights of those affected by leprosy to have access to free treatment, education and work, as well as to receive State compensation. Each patient who had undergone a cure was provided with a one-time financial package, as well as with a job and private dwelling by the local executive power.

### **Canada**

[Original: English]

[26 September 2008]

8. The Canadian International Development Agency provided some modest primary care-related intervention in the area of leprosy but did not have any human rights-related programming addressing the discrimination faced by persons living with leprosy.

### **Costa Rica**

[Original: Spanish]

[August 2008]

9. Costa Rica had taken steps since 1974 to eliminate discrimination against persons affected by leprosy, ever since it introduced ambulatory treatment without confinement and public education campaigns to combat discrimination. From 1990 to 1997, Costa Rica achieved a prevalence rate of minus one case per 10,000 inhabitants. In 2002, the commitments to eliminating the disease by 2005 were strengthened by various protocols and public health measures, the re-institution of epidemiological vigilance and the strengthening of capacities for health professionals. Costa Rica was currently compliant with WHO standards and all patients received diagnosis and treatment through the national social security system.

### **Cuba**

[Original: Spanish]

[29 September 2008]

10. Cuba addressed the link between poverty and diseases such as leprosy, and the existing inequality in access to health services and resources, particularly in countries in the southern hemisphere. Since 1962, Cuba has linked a programme on prevention and control of leprosy with sensitization of the population about the human rights of persons affected by the disease. The Cuban public health system was universal, free to all, decentralized, accessible and provided diagnosis and treatment for leprosy everywhere in the country. Multi-drug treatment was donated

by WHO. People affected by leprosy and their family members took part in all activities and had no restrictions with regard to access to education, social security and employment. Legislation and policies guarantee non-discrimination in the enjoyment of all human rights.

### **Cyprus**

[Original: English]  
[17 November 2008]

11. There was no discrimination in the provision of health care either against persons affected by leprosy or their family members. There was confidentiality considering personal data. After diagnosis, treatment started immediately and patients continued to live with their families and community. Leprosy had been almost eliminated and only sporadic cases were reported.

### **Egypt**

[Original: English]  
[29 September 2008]

12. People affected by leprosy and their family members enjoyed the right to full medical treatment at any medical establishment without discrimination, free of charge, until full cure and recovery were achieved. In cases where leprosy had led to disabilities, persons affected would undergo medical and social rehabilitation with a view to integrating them, as well as their family members, in society. Although Law No. 131 of 1946 was still in force, and provided that persons affected by leprosy should be segregated until healing was reached, it had not been enforced since 1984 when multi-drug treatment for persons affected by leprosy was introduced, as recommended by WHO.

### **Ecuador**

[Original: Spanish]  
[22 October 2008]

13. The right to free access to health is guaranteed in the new Constitution (arts. 32 and 50), which refers to preferential and specialized treatment for persons suffering from catastrophic diseases. Multi-drug treatment is made available free of charge thanks to the donations from WHO and the Pan American Health Organization. On the basis of statistical information and disease control, Ecuador had designed specific steps for the four provinces where 80 per cent of the few cases were concentrated (0.8 cases per 10,000). These measures included the training of health personnel, coordination with national and international civil society organizations for education campaigns to eliminate social stigma, specialized medical attention for persons with disabilities as a result of the disease, and systematic control and monitoring, including in areas where leprosy might be hidden.

### **Estonia**

[Original: English]  
[26 September 2008]

14. Estonia had registered only one case of leprosy since 1999. Treatment was fully compensated in compliance with Government regulation No. 308 of 26 September 2002, as a disease which was treatable and curable. People affected by leprosy and their family members were guaranteed all the rights prescribed by law and therefore it was not necessary to implement any supplementary measures.

### **Finland**

[Original: English]  
[23 September 2008]

15. Leprosy was combated successfully in the 1960s and there was no separate legislation in relation to this disease. General non-discrimination standards as laid down in section 6 of the Constitution ensured that every person, including those affected by leprosy and their family members, were treated equally before the law. Furthermore, the Non-Discrimination Act provided a general framework for equal treatment in all aspects of employment, occupation and education. The Act defined discrimination broadly, covering both direct and indirect discrimination. Finally, Finland had also included provisions to prevent discrimination on any grounds in the Penal Code, in its Employment Contracts Act and in the Act on the Status and Rights of Patients.

### **France**

[Original: French]  
[7 October 2008]

16. Leprosy had been officially eradicated according to WHO standards (0.013 cases per 10,000).

### **Greece**

[Original: English]  
[6 November 2008]

17. Persons newly affected by leprosy amounted to one a year in the past 20 years, and the total population of leprosy affected persons was under 500 in total. Law No. 1137/1981 specifically addressed treatment and social protection of patients suffering from Hansen's disease and provided for doctors and hospital staff to ensure confidentiality, for the elimination of words such as "leprosy" and "leper" from public documents and for the provision of monthly income support for patients in treatment, already treated and cured, as well as for their family members, including children.

### **Israel**

[Original: English]

[14 August 2008]

18. Since 2000, people affected by Hansen's disease received all treatment within an ambulatory service at the Israel Hansen's Disease Center. Previously, persons affected by the disease had been hospitalized. Although there were only few patients registered at the Center, a few new cases still emerged every year. For statistical purposes, the Government required notification for the Ministry of Health, as this was considered an infectious disease.

### **Japan**

[Original: English]

[19 September 2008]

19. Japan had undertaken various initiatives to eliminate prejudice and discrimination against persons affected by leprosy in view of a previous history of segregation. Specifically, in March 2005, the members of the Verification Committee together with the Japan Law Foundation presented their final report on Hansen's disease. The Committee was set up by the Ministry of Health, Labour and Welfare in order to assess scientifically and historically the segregation policy in relation to persons affected by leprosy and to provide guidance for development of Government policies. The task emerged from a legal decision rendered in 2001 by the Kumamoto District Court, known as the "Hansen's Disease Government Liability Lawsuit". Japan also provided, in an annex, a summary version of the Verification Committee's report.

20. Other measures included the creation of the National Hansen's Disease Museum as a mechanism for raising awareness and restoring the honour of persons affected by leprosy. In 2001, an act on payment of compensation to inmates of Hansen's disease sanatoria was passed. In June 2008, a new law was enacted aimed at extending social welfare services and restoring the honour of these persons. The Ministry of Justice placed the elimination of prejudice against persons living with HIV and persons affected by leprosy as a priority for human rights week in 2008. As of 2009, 22 June had been designated as the annual Day of restoration of honour and remembrance of victims of Hansen's disease prevention act, as a measure to restore the honour of victims.

### **Kazakhstan**

[Original: English]

[29 October 2008]

21. Official data in 2008 referred to 640 registered persons affected by leprosy (0.4 cases per 10,000), which is regarded as the elimination limit. There were 10 children and young people affected in the past 20 years who were treated according to WHO protocols in terms of diagnosis and therapy. Leprosy was not a priority issue of health-care policy. There were no legal restrictions to persons affected by leprosy. At the end of treatment at a specialized medical hospital, the Kazakh State Leprosarium, those affected could leave and continue observation and



control at the dispensary. There were no restrictions to relatives in access to education. All people affected by leprosy could find jobs without restrictions, except in children's institutions and in public catering.

### **Oman**

[Original: Arabic]

[21 August 2008]

22. Oman considered the issue of human rights an ongoing pedagogical process whereby every member of society learned to respect others. Royal Decree No. 101/96 ensured material and medical assistance to Omani citizens and their families in the event of sickness, incapacity or old age. Islamic sharia law consolidated the values of solidarity and cooperation and ensured that justice, dignity and equality prevailed irrespective of social status, health and/or other considerations. The Ministry of Social Development was responsible for the issue of leprosy and for those affected by the disease and their families. Cases had greatly decreased in recent years. A Government house could accommodate 10 patients, who were given the best social, psychological and health services available; 3 of them continued to live there. Families received housing assistance and monthly social security grants while on treatment and after leaving these facilities. Based on the degree of convalescence, the Ministry supported their integration and respect by the general public. Children of persons affected by leprosy were placed in foster families so as to prevent them from contracting leprosy. Omani society considered all members of society to have equal rights; no one was subjected to discrimination and they fully enjoyed their rights, irrespective of any consideration.

### **Philippines**

[Original: English]

[25 August 2008]

23. On 28 January 2007, the Department of Health promulgated a declaration to support the Global Appeal 2007 to end stigma and discrimination against persons affected by leprosy. The declaration acknowledged that leprosy remained a misunderstood disease causing stigma, segregation and discrimination. Leprosy was a curable disease; however, if left untreated, it could result in disabilities and perpetuate stigma. Since the multi-drug therapy was offered free of charge at Government health facilities, this disease could be prevented. The declaration emphasized the need for early diagnosis, timely voluntary reporting at Government health facilities and the inclusion of persons affected by leprosy in all activities. It also called for the enactment of laws or the implementation of existing legislation to ensure equal opportunities for all persons, including in education, work, participation and economic development.

### **Portugal**

[Original: English]

[21 October 2008]

24. In Portugal, there were no specific measures regarding elimination of discrimination against persons affected by leprosy and their family members, as the national health service

ensured equal treatment and swift access to all patients, who had the right to a range of benefits in a special regime, lower medication costs, exemption from payment in all public medical services and sick leave for more than 18 months. Treatment was provided by WHO to the General Directorate for Health. The Friends of Raoul Follereau association provided annual contributions to projects for the treatment, cure and reintegration of persons affected by Hansen's disease and their family members.

### **Qatar**

[Original: Arabic]  
[24 October 2008]

25. In the past five years, a revision of the rights of persons affected by leprosy had taken place in Qatar, in order to protect them and those who were in direct contact with them. Previously, leprosy had been considered a contagious disease and persons affected by it were isolated or expelled from the country. Currently, the policy was based on four different aspects: (a) persons affected by leprosy are no longer expelled from the country, except upon request; (b) persons affected by leprosy and their families or others in direct contact with them are offered medical examinations and their condition is registered; (c) a specialized health department offers examinations, medical services and treatment to persons affected by leprosy and those in direct contact with them; and (d) all services and treatment are provided free of charge or at a reasonable financial cost. No scientific research or studies about discrimination had been conducted since there had been no complaints or discriminatory practices brought to the attention of the authorities. All information about cases and treatment of patients were handled with full confidentiality.

### **Romania**

[Original: English]  
[20 October 2008]

26. Although in recent decades no new cases of leprosy had been diagnosed in Romania, 21 people affected by the disease continue to benefit from specialized services at a hospital in Tichilesti. The average age of those persons was 60 years and they preferred to live in the hospital as the disease was too advanced to be cured. They were regularly visited by their relatives and could leave if they wished. Medical treatment, food and clothing was provided free of charge in these facilities. There were no policies or practices with discriminatory effects against leprosy-affected persons. Informative media campaigns about leprosy at the local and national levels had been conducted as a way of combating prejudice.

### **Spain**

[Original: Spanish]  
[26 September 2008]

27. Leprosy was only a residual issue and hence did not require detailed registration of patients. Nevertheless, the general policy of the Ministry of Health and Consumption had been to combat stigma and discrimination in all its activities and in relation to any health problems.

### **Turkey**

[Original: English]  
[8 September 2008]

28. Turkey had promoted a culture of inclusiveness, receptiveness and tolerance for persons with leprosy in society, as well as public awareness campaigns about the disease being curable. The Government had consistently allocated resources for diagnosis, multidrug therapy and disease control and promoted an integrated approach by health personnel when dealing with leprosy.

### **Ukraine**

[Original: Russian]  
[13 October 2008]

29. Medical assistance and treatment had been made available to all persons affected by leprosy, in compliance with article 27 of Law No. 1645-III dated 6 April 2000, which referred to the protection of persons affected by infectious diseases. Under the law, all persons affected by the disease were cared for in a specialized medical facility, and when they did not pose any risk of infecting other persons, they could live with their family in designated areas under regular medical supervision. According to existing legislation, persons affected by leprosy were given land for agricultural work. While living in the specialized medical facility, they continued to enjoy freedom of movement, regular communications and they had the right to vote. Furthermore, they were represented in local State organizations and municipalities through their own deputies selected from the staff. Authorities at the specialized facility had created the conditions to ensure non-discrimination among all residents, to guarantee social life and to provide the highest ethical standards.

## **IV. SUBMISSIONS FROM NON-GOVERNMENTAL AND CIVIL SOCIETY ORGANIZATIONS**

30. The International Association for Integration, Dignity and Economic Advancement, a non-governmental organization in consultative status with the Economic and Social Council, is an international network that focuses on the promotion of human rights and dignity of individuals affected by leprosy, and on advocacy efforts on behalf of these individuals to address stigma and discrimination. In 2003, the Association launched its global campaign to eliminate stigma associated with leprosy. It referred to contributions from countries where members of the network work, as well as a contribution from the General Secretariat, some of which are summarized below:

(a) Testimonies from Angola stressed that stigma attached to leprosy continued to lead people to isolate themselves out of fear of rejection. People affected by leprosy faced great obstacles to social reintegration after the cure, particularly when they had lived in isolation and found it difficult to become self-sufficient;

(b) In Brazil, testimonies pointed to existing discriminatory practices against people affected by Hansen's disease which were mostly subtle and silent, such as social rejection. Nevertheless, there were also overt practices such as dismissal from work, verbal abuse and eviction from rented flats;

(c) In China, the Regulation on the Prevention and Control of Leprosy (chapter IV, article 16) issued by the Ministry of Health in September 1988 clearly prohibited discrimination against people affected by leprosy and their families in terms of education, employment, army service and marriage. However, social discrimination against people affected by leprosy and their families was still being witnessed by medical staff and the general public, especially in areas surrounding villages historically related to the disease;

(d) Testimonies stated that such discrimination may lead to medical staff failing to provide treatment in time or to even enter specific villages where there was knowledge of persons affected by leprosy, even if already cured. Similarly, separation from the family was particularly felt by older villagers cut off from their family for decades. Reference was also made to children of persons affected by leprosy who were still facing restrictions in education, employment and other areas of life;

(e) Testimonies from Ethiopia referred to laws and practices that discriminated against persons affected by leprosy. It was noted that there were no legal frameworks to protect them and to promote their rights. The lack of such legislation had a serious impact on the right to housing and the right to work. During the establishment of the Organization of African Union in the 1960s, people affected by leprosy and their families were relocated from Addis Ababa to the remote villages of Shashemene and Addis Tesfa Hiwot. Financial support secured from the Canadian International Development Agency and the technical assistance provided by the Ministry of Labour and Social Affairs enabled these people to support themselves through agriculture until 1991. However, when the newly established regional governments in these areas devised new policies, it was decided that those affected by leprosy and their family members should move and their land was given away to investors without any compensation. Many individuals who lost their land were reported to have serious disabilities or were elderly. Reference was also made to the lack of awareness-raising campaigns about the disease, and to misguided religious attitudes, according to which leprosy was a curse for sins committed. According to testimonies, this attitude has had also a significant impact on the social status and benefits of persons affected by leprosy and their families, for instance in relation to marriage;

(f) Testimonies from Ghana referred to obstacles linked to marriage and employment. Social rejection remained part of daily life. There was a belief that a person affected by leprosy would bring bad luck;

(g) In India, testimonies referred to existing discriminatory laws relating to leprosy, such as the recently publicized Orissa Municipal Act, which disqualified persons affected by leprosy from contesting elections or holding the post of councillor of a municipality. The Supreme Court upheld this law in September 2008, when a man who had been disqualified from holding a post brought his case before the Court. There were also discriminatory provisions relating to marriage and divorce, juvenile justice, transportation, life insurance and industrial disputes for persons affected by leprosy in existing laws;

(h) It was reported that, although Kenya had largely been able to reduce the incidence of leprosy, stigma and sociocultural prejudices and discrimination still persisted. People affected by leprosy were expected to stay in their homes and avoid attending public and social functions such as meetings, markets, churches and schools. People would avoid trade relations with those affected by the disease. It was also reported that the Government programme and plan were based on the belief that leprosy was highly infectious, hence leprosy patients were isolated in public health institutions. Additionally, leprosy and tuberculosis had been included in one programme, which had reduced attention to leprosy, as resources were allocated in favour of tuberculosis. Moreover, the general public and people affected by leprosy were unaware of the programme and services available. Many of those affected by leprosy in remote rural areas, where communication and transport infrastructure were still poor, were usually unable to have access to services. With regard to cultural rights, some testimonies from Kenya indicated that, in tribal clans, people affected by leprosy are stigmatized and discriminated against. The disease was equated with witchcraft, and people affected by it were thought to be paying for their sins. In some clans, isolation in life followed them to their grave. It was reported that they were not buried within the homestead like other members of the family, but rather in shallow graves in the bushes. Other tribes did not mourn the death of a person affected by leprosy. It was also noted that while the Government land policy did not discriminate against people affected by leprosy in the tenure system, this important resource was administered through communal and tribal inheritance systems, which in most cases discriminated against these individuals. In communities where people affected by leprosy were excommunicated, their land was taken over by their relatives. This forced people affected by leprosy to live in poverty;

(i) Testimonies reported that, in Mali and Mozambique, isolation and fear continued, including against elderly people affected by leprosy. Persons affected by leprosy faced discrimination in the health system and were unable to work or sell their products;

(j) Testimonies about remote areas of Nepal mentioned that people affected by leprosy were not cared for by their families or society; most did not have their human rights, such as those to food, clothing and shelter, met. As a result of social stigma and discrimination, people with leprosy hid their disease. Difficulties faced by persons affected with leprosy in Nepal included the denial of access to religious services, social and community functions and family property. Women affected by leprosy faced further stigma and multiple forms of discrimination. Legislation in Nepal had not yet been modified in relation to non-discrimination. The eleventh edition of the law code of the land (Muluki Ain) 2058 B.S. stated that if a person was affected by leprosy, he or she must be transferred to where the Central District Officer would refer them. In this case, they would lose their family and all their human rights. The same code permitted divorce on the grounds that the spouse had leprosy. The discrimination doubled in the case of female spouses. As leprosy had been categorized as a highly contagious disease, interaction with people affected by leprosy in public places was forbidden. On the basis of this law, those affected by leprosy were still discriminated against and prevented from integrating into their community;

(k) In the Niger, apart from the three specialized centres, people affected by leprosy faced rejection from medical staff, particularly because of their ulcers and other forms of leprosy-related complications. Because of stigma, discrimination and rejection, people affected by leprosy had left their homes to be treated at leprosy centres and had formed communities in different regions of the country. In Maradi, Zinder and Niamey, people affected by leprosy had

been evicted by the Government several times. In Niamey, some remained homeless. The main challenge continued to be the high level of poverty, which had led to begging as the only option for people to feed their families. It was reported that there was no specific action planned by the Government to address the socio-economic rehabilitation of people affected by leprosy, but this was left to non-governmental organizations. Few children of people affected by leprosy attended secondary school owing to the living situation of their parents;

(l) In Nigeria, it was reported that laws did not discriminate against people affected by leprosy; however, neglect by family and society continued. In some parts of the country, if someone had leprosy, family members would hide or kill and burn them in order to avoid shame for the family. People affected by leprosy were denied participation, socially, politically and economically, and some committed suicide. In the past, health-care providers had contributed to discrimination against people affected by leprosy as it had been considered an incurable disease. The Government had aggravated this situation by settling patients in villages distant from main towns. Marriage and commercial relations had been forbidden and hence charity was the only option. People affected by leprosy were rejected and separated from the national association of people with disabilities. The Independent Electoral Commission, a body vested with the responsibility of conducting elections, was reported to be highly discriminatory; for example, one person affected by leprosy whose thumbprint was not legible was not allowed to vote because a thumbprint was needed for identification. There were no alternative provisions on how people in such situations could exercise their right to vote;

(m) In the Philippines, testimonies reported that a television programme, *Imbestigador*, on the GMA Network Center implied that the residents of Culion were still affected by leprosy today, and showed pictures which did not reflect the island's current situation. This was contrary to the fact that Culion had been declared a leprosy-free island by WHO on 6 May 2006. It was reported that the television programme had been misleading, and debased the people, name and reputation of the island;

(n) It was reported that, in the Republic of Korea, people affected by Hansen's disease had to be registered in the health management system. Their records were maintained until the end of their lives, even if they were cured. Except for this specific administrative regulation, there was no formal discrimination against people affected by Hansen's disease; nonetheless, many people had misguided notions about people affected by the disease, so those affected by the disease were not free from stigma and discrimination;

(o) In Taiwan Province of China, the Lo-Sheng sanatorium was established in 1930 to isolate people affected by leprosy. People living there were deprived of their freedom, dignity, health, families, homeland, employment and education. They faced forced labour, prohibition of marriage, forced sterilizations, forced abortions, forced enrolment in clinical trials and medical malpractice. It was reported that, at present, there were about 280 residents who have been living in the sanatorium for years. It was reported that they faced the possible destruction of their homes and relocation owing to the construction of a transit system;

(p) In the United States of America, it was reported that, on 6 October 2008, the Department of Health and the Human Services Center for Disease Control posted an interim final rule regarding medical screening of immigrants for entry into the United States, according to which "aliens" were not admitted into the United States if they had a communicable disease of

“public health significance”, defined as, inter alia, active tuberculosis, infectious syphilis, gonorrhoea or infectious leprosy. The grounds of inadmissibility for specified health-related conditions also pertained to aliens in the United States who were applying for adjustment of their immigration status to that of lawful permanent resident;

(q) In Indonesia, it was reported that, in one case, a hotel refused to accommodate persons affected by leprosy, even after having received objective information from authorities and experts participating in a workshop about the disease, its treatable and curable characteristics and the lack of risk for the hotel staff and other guests.

31. The General Secretariat of the International Federation of Anti-Leprosy Associations, as well as individual members, submitted detailed information in relation to Human Rights Council resolution 8/13. In several of these submissions, specific reference was made to the legal framework offered by the Convention on the Rights of Persons with Disabilities and its limitations. With regard to measures taken by Governments to eliminate discrimination against persons affected by leprosy and their family members, the General Secretariat submitted a summary record of the newsletters of the WHO Goodwill Ambassador for the Elimination of Leprosy, as well as responses from individual members of the Federation in response to a questionnaire, some of which are summarized below:

(a) In 2008, the Brazilian Ministry of Health published “Leprosy and human rights: unified health system users rights and moral obligations”, which provides information about the human rights of persons affected by leprosy and their access to education, cultural activities, work, transport and social welfare. The National Sanitary Dermatology Division adopted a decree on 14 May 1976 according to which the term “leprosy” was to be replaced by the term “Hansen’s disease”;

(b) It was reported that, in China, legislative change was needed to remove obstacles for immigration procedures of persons affected by leprosy (in force since 1989), as well as broader protection for persons affected by leprosy without disabilities;

(c) In India, it was reported that the Government had passed the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995. The National Policy for Persons with Disabilities included disability caused by leprosy;

(d) In the Republic of Korea, the National Assembly passed a legislative bill for people affected by leprosy on 20 September 2007. The Government had apologized and offered compensation for their systematic wrongdoing towards people affected by leprosy. The law, which was to become operational towards the end of 2008, examined violations of human rights against persons affected by leprosy and how such violations might be prevented in the future;

(e) It was reported that, in 2004, Nigeria called a meeting of the Joint Association of Persons with Disabilities, excluding people affected by leprosy. There had, however, been positive developments since then: the Government had taken various measures, such as passing a law for social security welfare for persons with disabilities; appointing special advisers for the Government on disability matters who are themselves persons with disabilities from different

groups, including persons affected by leprosy; and organizing specialized training for the unemployed, including those with disabilities. An association of persons affected by leprosy to liaise with Government was also created. An initiative by the Federal Ministry of Social Welfare to initiate in 2010 a country-wide media campaign on leprosy and disabilities was implemented;

(f) It was reported that the Philippines had converted the Culion leprosarium into a local Government unit, so that residents, regardless of status and condition in life, were entitled to exercise all their constitutional rights. Stigma and discrimination were being gradually eliminated. The Ministry of Health had put in place an Internet-based information campaign to fight discrimination;

(g) In Ethiopia, in 1995, the Constitution incorporated provisions to ensure the protection of persons with disabilities (art. 41.5). The Convention on the Rights of Persons with Disabilities had also been signed. In 2008, the Government issued a proclamation providing for the right to employment of persons with disabilities (No. 568/2008 G.C.). It was noted that, until 2008, the civil code referred to leprosy as one of the legally accepted factors for dissolving marriage. The article was repealed by Special Family Law Proclamation No. 1/2008;

(h) With reference to the United Republic of Tanzania, there was a policy on services for rehabilitation of persons with disabilities, including those affected by leprosy. A new law to end discrimination against persons with disabilities was under discussion in Parliament, applicable also to persons affected by leprosy;

(i) In the Democratic Republic of the Congo, a network of non-governmental organizations, in conjunction with the Government's Community-Based Rehabilitation Office, was preparing a leprosy-related anti-discrimination draft law to be submitted to Parliament in January 2009;

(j) With reference to Indonesia, persons affected by leprosy lived a normal life in their communities, enjoying freedom from discrimination and access to opportunities to support themselves and their families.

32. In its submission, the International Federation of Anti-Leprosy Associations addressed studies carried out by civil society organizations and independent research institutions at the international level on the existence and impact of discriminatory policies and practices related to leprosy on the enjoyment of human rights. It referred to various studies carried out by experts of the Royal Tropical Institute in the Netherlands. In recent years, studies have aimed at addressing social isolation, discussing risk factors of restriction to participation, and assessing whether there had been progress with regard to stigma against persons affected by leprosy in relation to various areas of their lives, such as social status, employment opportunities, family relationships, marriage and participation in social and religious life.

33. With regard to studies carried out by civil society organizations and independent research institutions at the national level, the Federation listed a wide range of medical studies, articles, press notes and Internet sites, as well as testimonials from people affected by leprosy and their family members in Australia, Bangladesh, Brazil, Cambodia, China, Ethiopia, India, Indonesia, Japan, Kenya, Malaysia, Nepal, Nigeria, the Republic of Korea, Saudi Arabia, Sierra Leone, the Sudan, Taiwan Province of China, Thailand, the United Republic of Tanzania, the United States



of America and Zambia. Several of the publications discussed stigma and discrimination, including de facto discrimination, highlighting the obstacles in enforcing laws and challenging discriminatory practices even after laws and policies have been reformed.

34. The International Leprosy Union from India submitted a report on laws and leprosy covering the period 2006-2007, summarizing various meetings convened in different parts of India in order to review existing legislation and to make recommendations to Government institutions. The report concluded that existing discriminatory legislation must be modified in order to ensure that the leprosy-affected are not denied their human rights. In some cases, amendments were proposed, while in others the Government was requested to clarify the nature of the disease and to remove references to leprosy as an incurable disease.

35. In its submission, the Nippon Foundation referred to various individual cases and testimonies in which people affected by leprosy or their family members had been discriminated against in cases of marriage, health services, employment, education, social life, public places and religious rituals, in Brazil, China, Ethiopia, Ghana, India, Indonesia, Myanmar, Nepal, Nigeria, Pakistan, the Philippines, United Republic of Tanzania, the United States of America, and Zambia. The Foundation also referred to requests made by persons affected by leprosy to continue to reside in a leprosy settlement and not to be forcibly relocated. Other issues noted were the self-stigmatization of people affected by leprosy, which prevented them from realizing their human rights and caused loss of family ties, which might even lead to suicide, isolation and depression, the need to educate health staff and the need to provide support for physical rehabilitation.

36. The PerMaTa organization of People Affected by Leprosy of Indonesia reported that discrimination had been experienced in relation to medical treatment, applying for work positions and in access to hotel facilities. Some teachers had lost their jobs owing to leprosy-related discrimination.

37. In its contribution, the Royal Tropical Institute of the Netherlands referred to the persistence of stigma and fear of discrimination, despite evidence that it had decreased in many leprosy-endemic areas of the world in the past two decades. While there were some good local health education campaigns on the curability of leprosy, these initiatives had rarely addressed local beliefs, fears and practices. Attention was drawn to the fact that there had been little development by Governments and organizations of a specific rights-based approach to addressing stigma and to empowering people affected by this disease.

## **Annex I**

### **LIST OF PARTICIPANTS**

#### **Human Rights Council Advisory Committee members**

Prof. Shigeki Sakamoto

Dr. Chen Shiqiu

#### **Panellists**

Mr. Leulseged Berhane Asres, Executive Director, Ethiopia National Association of Persons Affected by Leprosy; Ms. Zilda Borges, International Association for Integration, Dignity and Economic Advancement; Dr. Arturo Cunanan Jr., Culion Leprosy Control & Rehabilitation Program, Philippines; Ms. Valdenora Da Cruz Rodrigues, Movimento de Reintegração das Pessoas Atingidas pela Hanseníase, Brasil; Mr. Denis Daumerie, World Health Organization, Neglected Tropical Diseases Department; Dr. Karuppannan Gopal, National Forum, India/International Association for Integration, Dignity and Economic Advancement; Mr. Yohei Sasakawa, The Nippon Foundation and WHO/Japanese Government Goodwill Ambassador for human rights of people affected by leprosy; Mr. Douglas Soutar, International Federation of Anti-Leprosy Associations; Ms. Susan Timberlake, UNAIDS; Mr. Stefan Trömel, International Disability Alliance/Convention on the Rights of Persons with Disabilities Forum; and Prof. Yozo Yokota, former member of the United Nations Sub-Commission on the Promotion and Protection of Human Rights.

Statements were read out on behalf of Mr. Sang Kwon Jung, International Association for Integration, Dignity and Economic Advancement, Republic of Korea and Ms. Magdalena Sepulveda, United Nations Human Rights Council Independent Expert on Extreme Poverty.

#### **Governments**

Azerbaijan, Bahrain, Bangladesh, Bhutan, Bosnia and Herzegovina, Brazil, Chile, China, Ecuador, Ethiopia, Finland, France, Germany, Greece, India, Indonesia, Ireland, Japan, Malaysia, Myanmar, Nepal, Netherlands, Philippines, Portugal, Qatar, Republic of Korea, Serbia, Singapore, Sri Lanka, Thailand, Timor-Leste, United Kingdom of Great Britain and Northern Ireland, Venezuela (Bolivarian Republic of).

#### **United Nations organizations**

UNAIDS, World Health Organization.

#### **Other intergovernmental organizations**

European Union.

**Other observers**

Sovereign and Military Order of Malta.

**Non-governmental organizations**

Ethiopian National Association of Persons Affected by Leprosy (ENAPAL), Guangdong Handa Rehabilitation and Welfare Association, Hind Kusht Nivaran Sangh India, International Disability Alliance (IDA) - Convention on the Rights of Persons with Disabilities Forum (CRPD Forum), International Federation of Anti-Leprosy Associations (ILEP), Leprosy Relief, Movement for Reintegration of People Affected by Leprosy (MORHAN), PerMaTa Organisation of People Affected by Leprosy in Indonesia, Royal Tropical Institute Netherlands, Sasakawa India Leprosy Foundation, The International Association for Integration, Dignity and Economic Advancement (IDEA), The Leprosy Mission and The Nippon Foundation.

## **Annex II**

### **EXCERPTS FROM THE PRELIMINARY WORKING PAPER ON DISCRIMINATION AGAINST LEPROSY VICTIMS AND THEIR FAMILIES, BY PROF. YOZO YOKOTA<sup>a</sup>**

#### **Principles**

- (a) Leprosy is curable and the medication is available free of charge. Leprosy is not hereditary nor easily transmittable.
- (b) It is therefore wrong to adopt a policy to hospitalize, to segregate or to deprive of the basic freedoms of leprosy patients and their families against their will and by force.
- (c) Any law, policy or custom to forcefully intern leprosy patients and their families should be abolished immediately.
- (d) Any law, policy or custom to discriminate against leprosy affected persons, directly or indirectly, should be abolished as soon as possible.
- (e) Leprosy affected persons should be treated as persons with dignity and are entitled to all basic human rights and fundamental freedoms laid down in customary international law, relevant conventions, and national constitutions and laws.
- (f) The victims of forceful segregation and hospitalization as well as of other forms of violations of human rights should be entitled to appropriate compensation, rehabilitation and other remedies.
- (g) 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. Any person who commits such discriminatory behaviour should be adequately disciplined.

#### **Guidelines**

- (a) Governments should abolish immediately all existing laws, policies or practices to forcefully hospitalize or intern leprosy patients and their families.
- (b) Governments should abolish at the earliest possible time all existing laws, policies or practices to discriminate, directly or indirectly, against leprosy affected persons.
- (c) Governments should conduct a full survey of the situation of leprosy as a disease and provide every patient adequate treatment free of charge.

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<sup>a</sup> A/HRC/Sub.1/58/CRP.7.

(d) Governments should provide effective and adequate compensation, rehabilitation and remedies to the former patients who have suffered from forceful hospitalization.

(e) Governments should provide effective protection to the leprosy affected persons from discrimination practised at employment, marriage, education, social life, public places and religious rituals.

(f) Governments should formulate policies and action plans to end discrimination against leprosy affected persons through education, training and public awareness raising activities.

(g) The residents of present as well as former leprosy hospitals, sanatoria and colonies should be entitled to continue to live, if they so wish freely, in the houses or other facilities even after their emancipation.

(h) Any policy or programme affecting the life and well-being of leprosy affected persons and their families should be formulated and implemented with full participation of such affected persons.

(i) Governments should adopt special preferential measures to encourage the employment of leprosy affected persons.

(j) 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 disease and to eliminate discrimination against leprosy affected persons.

(k) The medical doctors, nurses, the academia and the media should actively contribute to rectify misunderstanding about leprosy as a disease.

(l) The United Nations should designate 29 January as the UN Leprosy Day and organize seminars, meetings and other awareness-raising events including television, newspaper and magazine campaigns to provide the public accurate information about leprosy as a disease and teach not to discriminate against leprosy affected persons.

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