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PROMOTION AND PROTECTION OF ALL HUMAN RIGHTS, CIVIL, POLITICAL, ECONOMIC, SOCIAL AND CULTURAL RIGHTS, INCLUDING THE RIGHT TO DEVELOPMENT

Written statement^{*} submitted by the Nippon Foundation, a non-governmental organization on the Roster

The Secretary-General has received the following written statement which is circulated in accordance with Economic and Social Council resolution 1996/31.

[19 May 2008]

^{*} This written statement is issued, unedited, in the language(s) received from the submitting non-governmental organization(s).

Leprosy and human rights

Tens of millions of people today suffer from political, legal, economic and social discrimination on the basis of leprosy.

Once dreaded as untreatable and disfiguring, leprosy is now completely curable. Yet outdated notions of leprosy persist, with the result that people diagnosed with the disease, former patients, and even family members continue to face rejection and social exclusion.

Society's ignorance and indifference, and the lack of legislative and administrative measures to prohibit such discrimination, are denying millions of people their fundamental human rights.

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One of the oldest diseases known to humankind, leprosy is a chronic bacterial condition that mainly affects the skin and nerves. Left untreated, it can result in progressive deformity and permanent disablement.

Contrary to popular belief, leprosy is one of the least infectious of infectious diseases. More than 85% of leprosy cases are non-infectious, and do not spread the disease, and over 99% of people have a natural immunity or resistance to leprosy.

With the development of multidrug therapy (MDT) in the 1980s, leprosy has become a curable disease. Since the mid-1990s, MDT has been provided free of charge.

Worldwide, some 16 million people have been cured to date. Of 122 leprosy-endemic countries in 1985 with a disease prevalence rate of more than 1 patient per 10,000 people at the national level, leprosy remains a public health problem in only three countries today (Brazil, Nepal, and Mozambique).

Nevertheless, people affected by the disease continue to be marginalized by mainstream society. 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.

People affected by leprosy are denied the basic human rights, as proclaimed in *the International Covenant on Economic, Social and Cultural Rights*, to which all human beings are entitled. These include:

<u>Self-determination</u> (Article 1): People affected by leprosy are defined by a disease that places severe social and economic constraints on them.

<u>Right to work</u> (Article 6): Attitudes toward leprosy make it harder for someone affected by the disease to find work, and a diagnosis of leprosy can result in dismissal.

<u>Just and favorable conditions of work</u> (Article 7): Wage abuse is a serious problem. People who are desperate for a mouthful of food do not have the leverage to fight back, especially when stigmatized by leprosy.

<u>Protection for the family</u> (Article 10): Leprosy can tear families apart, even today. Moreover, finding a marriage partner can be difficult for those affected by the disease, and even for their family members, depriving them of the opportunity to start families of their own.

<u>Adequate living standards</u> (Article 11): In any given country, people in leprosy villages, colonies, or sanatoria face financial difficulties because of the lack of job opportunities open to them, forcing them to endure substandard living conditions.

<u>Physical and mental health</u> (Article 12): Social rejection, lack of education and financial constraints make good health difficult to attain. Frequently, people affected by leprosy and their family members are seized by feelings of shame, thus adding "self-stigmatization" to the burden they must bear.

<u>Education</u> (Article 13): Schools will often deny access to children affected by leprosy, or to the children of a parent affected by the disease. Further, lack of income and the remote location of leprosy villages also erect barriers to being educated.

<u>Right to take part in cultural life</u> (Article 15a): A person affected by leprosy's geographical as well as social isolation denies him or her access to culture.

As manifested in the above, discrimination against people affected by leprosy and their families is multi-layered. This discrimination is most keenly felt by those in a vulnerable position: women, children, persons with disabilities, and the elderly.

Over the centuries, no other disease has so stigmatized and marginalized sufferers—even after they have been completely cured—and stigmatized other family members too.

No other discriminated-against group of people, of a comparable size, has escaped the attention of human rights defenders to this degree.

Defining a person's life by a disease is NOT acceptable.

Millions of people stand to benefit if this discrimination is brought to an end.

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In 2004, the Sub-Commission on the Promotion and Protection of Human Rights of the United Nations Commission on Human Rights appointed Professor Yozo Yokota as a Special Rapporteur to submit a working paper on the issue of leprosy and human rights.

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In August 2005, based upon the paper submitted by Professor Yokota, the Sub-Commission unanimously adopted a resolution requesting all governments to:

- abolish legislation requiring the forced hospitalization of leprosy patients and provide prompt and effective treatment on an outpatient basis;
- provide appropriate remedies to former patients forcibly hospitalized;
- prohibit discrimination against those with leprosy and their families; and
- include education about leprosy in school curricula.

The Sub-Commission again appointed Professor Yokota to prepare a further study on the issue. In August 2006, based upon the comprehensive paper submitted by Professor Yokota, the Sub-Commission passed a follow-up resolution once more requesting governments to act.

We fully endorse the above-mentioned resolutions issued by the Sub-Commission on the Promotion of Protection of Human Rights, and we call on the Human Rights Council to:

- build on the work of the Sub-Commission and take up leprosy and human rights as an issue of discrimination, studying the subject as a distinct and separate item;
- request the Office of the High Commissioner for Human Rights to take up, within existing resources, the issue of discrimination against persons affected by leprosy and their families in its human rights education and awareness promotion activities;
- request the Office of the High Commissioner for Human Rights, if extra-budgetary funding is available, to hold a consultation meeting to hear the views of governments, United Nations agencies, non-governmental organizations and representatives of persons affected by leprosy, and to report the conclusion to the Human Rights Council and the Human Rights Advisory Committee;
- request the Human Rights Advisory Committee to examine and formulate principles and guidelines to eradicate discrimination against leprosy affected persons and their families, and to present them to the Human Rights Council by September 2009;
- consider this issue based on these reports at the Human Rights Council in September 2009, and move swiftly to take concrete steps to eradicate stigma and discrimination against persons affected by leprosy.

We issue this call on behalf of people affected by leprosy around the world, for whom the day when their basic human rights are acknowledged and their dignity is restored cannot come quickly enough.

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