



General Assembly

Distr.
GENERAL

A/HRC/6/NGO/7
31 August 2007

ENGLISH ONLY

HUMAN RIGHTS COUNCIL
Sixth session
Item 3 of the provisional agenda

**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.

[29 August 2007]

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

Leprosy and human rights

Leprosy is an issue of multiform discrimination on a far-reaching scale. The issue has been largely ignored by society, so awareness should be raised.

Principles and guidelines need to be established for defending the human rights of people affected by leprosy.

Leprosy, also called Hansen's disease, is one of the oldest diseases known to humankind. Caused by a bacillus that affects the skin and nerves, it destroys the ability to feel pain, leading to injury and infection. If not treated in a timely fashion, it can result in progressive deformity and permanent disablement.

Over the centuries, the appearance of sufferers and the fear of contagion led to the stigmatization of those affected by the disease. Typically, they would be rejected by society, banished to remote islands or other isolated locations, stripped of their individuality, and branded as "lepers." People affected by leprosy were also subjected to discriminatory and coercive legislation.

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 15 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 four (Brazil, DR Congo, Nepal, and Mozambique).

However, while the medical aspect of leprosy has been rigorously tackled as a "right to health" issue, its social aspect—prejudice and discrimination against people affected by the disease and even their family members—has not been adequately addressed. 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:

Self-determination (Article 1): In the case of leprosy-affected people, they do not determine the course of their lives; instead, they are defined by a disease that places severe social and economic constraints on them.

Right to work (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.

Just and favorable conditions of work (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.

Protection for the family (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.

Adequate living standards (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.

Physical and mental health (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.

Education (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.

Right to take part in cultural life (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 many-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.

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.

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 would like to call upon 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;
- appoint a Special Rapporteur to make fact-finding visits to countries concerned and investigate the condition and circumstances of individuals and groups affected by leprosy, interviewing not only residents of sanatoria and colonies, but also those living in the community, as well as persons working on their behalf;
- organize seminars to which all stakeholders, particularly representatives of persons affected by leprosy, are invited, and mobilize stakeholders to create a platform to formulate principles and guidelines ending leprosy-related discrimination; and
- issue a set of principles and guidelines that can be applied by all stakeholders, including governments, UN agencies, and NGOs, to eliminate the disease, end leprosy-related discrimination, and reintegrate all those subject to such discrimination.
