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COMMISSION ON HUMAN RIGHTS
Sub-Commission on the Promotion
and Protection of Human Rights
Fifty-seventh session
Item 5 (c) of the provisional agenda

**PREVENTION OF DISCRIMINATION: PREVENTION OF DISCRIMINATION AND
PROTECTION OF MINORITIES**

**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.

[1 July 2005]

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

1. Last August, the Sub-Commission agreed to commission a preliminary working paper on “Discrimination against leprosy victims and their families” and to appoint Mr. Yozo Yokota, a member of the Sub-Commission, as special rapporteur. Mr. Yokota is to present his report at the fifty-seventh session under the agenda item entitled “Prevention of discrimination and protection of minorities”.

2. Leprosy (also known as 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. Left untreated, it results in the progressive deformity to face and limbs with which the disease has long been associated.

3. Over the centuries, the appearance of sufferers and the mystery surrounding the disease’s transmission have given rise to fear, which in turn has led to stigma and discrimination.

4. Typically, the response of society has been to cast out those with the disease. They would be banished to remote islands or other isolated locations, where they were forced to live out their days, stripped of their identity and individuality, and branded as “lepers.”

5. Today, thanks to multi-drug therapy, leprosy is a curable disease. Treatment is available free to anyone in the world who needs it. Since the mid-1980s, when MDT became widely available, some 14 million people worldwide have been cured. Only nine countries remain where the prevalence rate of the disease at the national level is more than 1 case per 10,000 people.

6. But even in the 21st century, leprosy remains a disease with two aspects: medical and non-medical. While the medical aspects are being addressed, the non-medical—namely, stigma, prejudice, and discrimination—are still far from being resolved.

7. Misunderstanding, ignorance, indifference—and fear—mean that persons affected by leprosy still suffer from political, legal, economic and social discrimination. Many people regard leprosy as dangerous, easily communicable, or hereditary. Some see it as divine punishment or a curse.

8. The problem is far reaching, and potentially affects as many as 100 million people in the world today if families and relatives of persons affected by leprosy are included.

9. For these people, it can be hard to marry, obtain jobs, or even acquire a solid education. In certain countries, such as India, laws and regulations that discriminate against persons affected by leprosy still exist.

10. Today, most national isolation policies have long since been abolished. But thousands of people who once had leprosy continue to live where they were forcibly isolated. Having been cut off from the outside world for so long, they have no families to return to, and nowhere else to go.

11. But in a cruel twist, as the population of those severely affected by the disease diminishes, many former isolation settlements face closure and demolition. The residents, who know no other life, face further dislocation. Society, which tore them from their homes once already, must not be allowed to destroy their lives all over again.

12. The fact leprosy has not been taken up as a human rights issue before now is a reflection of the nature of the disease and its devastating impact on the psyche of those who contracted it. Disowned by their families, and denied the use of their names, they felt unable to speak out because of the shame and stigma. Cowed into silence, they resigned themselves to their fate, and ceased to consider the discrimination they were subjected to as a violation of their human rights.

13. In recent times, there has been a gradual change in attitudes. Slowly, it is becoming possible for those with the disease to speak more openly about it. As the prevalence rate falls, and patients are treated promptly, there are fewer instances of deformity, one of the leading factors in shaping social attitudes toward the disease. The environment is changing. But it is not changing fast enough.

14. Lingering discrimination prevents people from coming forward and receiving the treatment they need; it means that even after being cured, there may be no improvement in a person's life opportunities; and it means that persons affected by leprosy—and even their children—are prevented from playing a full role in society as productive citizens.

15. However, with the cooperation of governments, NGOs, UN agencies, and all other stakeholders involved, the problem can be tackled. This process is already under way, but what is now required is a way to formalize and accelerate it.

16. We thus call on the Sub-Commission to draw up a resolution recommending that the UN Human Rights Commission take up this issue, in the hope and expectation that, following further study and verification, it will develop a set of guidelines that can be applied by all stakeholders, including governments, UN agencies, and NGOs, to root out leprosy-related discrimination.

17. For centuries, people with leprosy have been abandoned people. They have waited long enough for their rights to be recognized and restored to them. For those alive today, especially the elderly, there is no more time to waste.
