**Presentation at the UN Human Rights Council Advisory Committee**

**12 August 2015**

**“A Need for Effective Implementation of the Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members”**

**Thank you very much, Mr. Chairperson.**

1. **To start with, I should like to express my heartfelt gratitude to all the members of the Human Rights Council Advisory Committee for giving me the opportunity to speak about a topic that I have personally been committed to, and involved in, in the past twelve years.**
2. **I am also thankful that this august body conducted, in the early years of its establishment, a comprehensive study of the issue of discrimination associated with Hansen’s disease, or more commonly known as “leprosy”, and elaborated and adopted, in 2010, a set of “Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members”. These Principles and Guidelines were accepted by the Human Rights Council and the General Assembly successively later in the same year. The General Assembly Resolution A/RES/65/215 of 21 December 2010 took note, in particular, “with appreciation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family member”, and, encouraged “Governments, relevant United Nations bodies, specialized agencies, funds and programmes, other intergovernmental organizations and national human rights institutions to give due consideration to the principles and guidelines in the formulation of their policies and measures concerning persons affected by leprosy and their family members”.**
3. **Mr. Chairperson, for me who was involved in the discussion, in the years between 2003 and 2006, during the successive sessions of the UN Sub-Commission on the Promotion and Protection of Human Rights as a member as well as Rapporteur on this topic, I am most pleased to see this positive development under the initiative of the newly created human rights bodies, namely, Human Rights Council and its Advisory Committee. At the same time, millions of persons affected by leprosy and their family members welcomed this move at the UN which is definitely a great leap forward. They have long waited for an authoritative document to rely on in order to defend them from unreasonable discrimination and exclusion. Thanks to medical and scientific advancement, leprosy is one hundred percent curable today. Yet, due to long-held and deep-rooted fear and stigma associated with this disease, persons affected by leprosy and their family members have continued to suffer from unfounded forced confinement, isolation, loss of jobs and separation from their families.**
4. **Mr. Chairperson, let me share with you some stories that persons affected by leprosy and their family members told me when I met them in the course of conducting research as Rapporteur of the UN Sub-Commission.**
   * **A Japanese lady who had been forcefully hospitalized in a leprosy sanatorium at the age of twelve showed me a letter she wrote to her mother when she found out that she could not go home and live with her family because of the disease. “Dear Mother, please come and bring me back home. I will be a good girl. I would follow your words. I would do everything you tell me. So, please come and take me home.” She was not allowed to go home until the Leprosy Prevention Law was repealed in 1996. She was already over sixty. Her mother had already passed away. In the sanatorium, she was sterilized and had no children.**
   * **A Japanese man who was hospitalized at the age of ten. His mother came to see him regularly and encouraged him to live happy. He tried to run away from the facility to go home but the sanatorium was surrounded by thick, thorny plants and could not get away. When he was hospitalized, his name and identity were totally changed. Later, he found out that his friends and relatives were told that he had died. When he was released from the sanatorium soon after the abolition of the Leprosy Prevention Law, he tried to contact his brothers and sisters but they did not want him back home because his return home would contradict the earlier story that he had died. They did not want to tell their friends and neighbors that their brother had been in a leprosy sanatorium. He thought that his mother would have welcomed him home but she had died some years before.**
   * **A son of a former Ethiopian patient told me that, in classrooms at school, he was given a separate desk and chair far away from the rest of his classmates. At lunch time, he was not allowed to eat on the same table with his friends.**
   * **An Indian lady testified that after leading a happy married life with her husband, she was divorced when it was found out that her sister was hospitalized for leprosy treatment.**
   * **A Chinese man, who had been hospitalized in a leprosy sanatorium for over 30 years, was released after change of law. He tried to get home but the bus driver, knowing that he had just come out of the sanatorium, rejected him. He had to walk half a day to reach home. He rang the door bell. He noticed his father peeping through a small door window. Recognizing him, instead of opening the door, his father shut down the door window. The man rang the bell again but no more answer. He realized that he was not welcome home by his father. When he told me this story, he cried and cried. He had to even stop speaking several times because he was overwhelmed by his uncontrollable emotion.**
5. **These stories are only tiny portion of many sad experiences that the persons affected by leprosy and their family members had gone through. The special aspect of discrimination related to leprosy is that the attitude of social exclusion and ostracism often continues even after complete cure of the disease and, in many cases, it extends to their family members. Or, in some cases, even their family members reject them. This is due to a misunderstanding that leprosy is incurable and highly contagious. It is also due to a superstitious belief that leprosy is hereditary or punishment for wrongdoings by their ancestors.**
6. **No wonder, the persons who had undergone such unreasonable discrimination, rejection, exclusion and isolation wholeheartedly welcomed the adoption of the Principles and Guidelines by the UN human rights bodies. Now, they are eagerly awaiting the next stage, namely, their actual, effective implementation. In order to disseminate correct understanding of the disease and discuss the ways and means to achieve the goal of actual, effective implementation of the Principles and Guidelines, I have participated in a series of regional symposia organized by the Nippon Foundation. Such international conferences were held in Rio de Janeiro in 2012, and successively in Delhi, Addis Ababa, Rabat and more recently in Geneva in June of this year.**
7. **Meanwhile, the first regional symposium held in Rio established an International Working Group (IWG) composed of renowned experts to study a possible procedure to follow-up and review the actual state of the implementation of the Principles and Guidelines. I was honored to serve as its Chair. This group met several times over the past three years and submitted its final report to the last of the series of the regional symposia held in Geneva this year.**
8. **In concluding, I should like to highlight the most important provisions included in the Principles and Guidelines:**
9. **Paragraph 1 of the Principles states: “Persons affected by leprosy and their family members should be treated as people with dignity and are entitled, on an equal basis with others, to all the human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights.”**
10. **Paragraph 2 of the Principles states: “Persons affected by leprosy and their family members should not be discriminated against on the grounds of having or having had leprosy.”**
11. **Paragraph 3 of the Principles states: “Persons affected by leprosy and their family members should have the same rights as everyone else with respect to marriage, family and parenthood.”**
12. **Paragraph 9 of the Principles states: “Persons affected by leprosy and their family members have the right to be, and should be, actively involved in decision-making processes regarding policies and programmes that directly concern their lives.”**
13. **Paragraph 1.1 of the Guidelines stipulates: “States should promote, protect and ensure the full realization of all human rights and fundamental freedoms for all persons affected by leprosy and their family members without discrimination on the grounds of leprosy.”**

**Mr. Chairperson, thank you very much for giving me this opportunity to address to this session of the Advisory Committee, and I am most grateful to your and all the members’ kind attention.**