**Appendix I**

Suggested Framework for National Plans of Action on the Principles and Guidelines for the Elimination of Discrimination

against Persons Affected by Leprosy and Their Family Members

Background

The number of new cases of leprosy detected worldwide in 2013 was 215,656. While still large, the number has declined over the last three decades due to early diagnosis and effective treatment by multi-drug therapy (MDT).

Although leprosy is curable today, deep-rooted stigma and discrimination associated with the disease are still widespread. Tens of millions of persons affected by leprosy are subjected to various forms of discrimination and exclusion from their societies. Such a situation does not help efforts to eradicate leprosy.

In 2009, the World Health Organization (WHO) hosted a meeting for persons affected by leprosy to create “Guidelines to Strengthen the Participation of Persons Affected by Leprosy in Leprosy Services.” The focus of the meeting, and the development of the Guidelines, was on self-empowerment. In unison, the participants representing many nations embraced a standard of equality for the full participation of persons affected by leprosy in all aspects of leprosy-related services. This suggested framework is, in part, inspired by the WHO Guidelines, which are available from the WHO.

In order to address the issue of discrimination associated with leprosy, the UN Human Rights Council adopted the Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members (“Principles and Guidelines”) in August 2010. In December 2010, the General Assembly adopted Resolution A/RES/65/215 on elimination of discrimination against persons affected by leprosy and their family members in which it took note with appreciation of the Principles and Guidelines.

The UN General Assembly Resolution encourages Governments to give due consideration to the Principles and Guidelines in the formulation and implementation of their policies and measures concerning persons affected by leprosy and their family members. Governments should take action in fulfillment of the principles of equality and non-discrimination under international human rights law and the Principles and Guidelines. **Therefore, an international follow-up mechanism is needed to ensure the effective implementation of the Principles and Guidelines.**

In order to disseminate the Principles and Guidelines, the Nippon Foundation organized regional symposiums on “Leprosy and Human Rights: Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members” through 2012-2014. By the resolution adopted at the first regional symposium held in Rio de Janeiro, Brazil in February 2012, the International Working Group (IWG) was created with a mandate to discuss and recommend a sustainable mechanism to follow up on the Principles and Guidelines. The IWG members consist of human rights experts, representatives of various NGOs, and organizations of persons affected by leprosy. Pursuant to that resolution, the IWG discussed and formulated this suggested framework for consideration by States.

States, when drafting their national plans of action as well as implementing them, are encouraged to take into account the following:

1. **Objective**

The plan of action should have a clear statement of objectives. Such a statement should emphasize the importance of respecting, protecting and fulfilling all human rights of persons affected by leprosy and their family members as required by international human rights law and enshrined in various human rights instruments including the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities (Principle 1, Guideline 1.2).

1. **Timeframe**

The plan of action should indicate the timeframe for achieving the stated objectives.

1. **Budget**

The plan of action should include information in particular regarding a budget for financing its implementation.

1. **Cooperation with the stakeholders**

The plan of action should emphasize the importance of cooperation with the stakeholders. Therefore, during the development and implementation of the action plan, legislation and policies, as well as in any other decision-making processes that concern persons affected by leprosy and their family members, States should take measures to consult closely with, and involve actively, persons affected by leprosy and their family members, individually or through their respective local and national organizations, or any other stakeholders concerned. Information on those stakeholders should be included in the plan (Principle 9, Guideline 1.3).

1. **Establishment of a national committee**

The Government should create or designate a committee to implement the Principles and Guidelines and the national plan of action which includes individuals affected by leprosy and their family members, representatives of organizations of persons affected by leprosy, human rights experts, representatives from the human rights and related fields, and representatives of Government. The committee should address the issues of the Principles and Guidelines and the national plan of action in order to respect, protect and fulfill the human rights of persons affected by leprosy and their family members. Similarly, when an existing structure, including the national human rights institution (NHRI), is designated as the national committee, special attention must be paid to ensure the representation of persons affected by leprosy and their family members, and related organizations (Principle 9, Guideline 1.1, 14.1).

1. **Law Reform**
	1. **Modification or repeal of laws and practices that violate human rights**

Governments, including federal units and local authorities, including provinces, should take all appropriate legislative and other measures to modify, repeal or abolish existing laws, regulations, policies, customs and practices that discriminate directly or indirectly against persons affected by leprosy and their family members, such as negative labeling. In addition, those laws and practices that forcefully or compulsorily segregate and isolate persons on the grounds of leprosy should be immediately modified or abolished in conformity with the principle that no one should be deprived of his/her liberty except on such grounds and in accordance with such procedures as established by law. (Guideline 1.1 (a), 2.1 and 2.2).

* 1. **Elimination of discrimination by private actors**

All authorities and institutions should take measures to eliminate discrimination on the grounds of leprosy by any person, organization or private enterprise (Guideline 1.1 (b)).

* 1. **Positive measures to achieve *de facto* equality**

States should take positive measures, including affirmative action, to achieve *de facto* equality of persons affected by leprosy and their family members. (Guideline 2.3).

* 1. **Remedies**

States should ensure that those affected by leprosy and their family members, whose rights or freedoms are violated, shall have an effective remedy, including judicial remedies, even if the violation has been committed by persons acting in an official capacity.

1. **Special attention to women, children , the elderly and other vulnerable groups**

States should pay special attention to the promotion and protection of the human rights of women, children and members of other vulnerable groups who have or have had leprosy and their family members. States should also promote the full development, advancement and empowerment of those who have or have had leprosy, as well as their family members, especially women, children, the elderly and members of other vulnerable groups (Guideline 3.1 and 3.2).

1. **Rights related to family**

Persons affected by leprosy and their family members should have the same rights as everyone else with respect to marriage, family and parenthood. To this end:

1. No one should be denied the right to marry on the grounds of leprosy. Leprosy should not constitute a ground for divorce (Principle 3 (a) and (b));
2. A child should not be separated from his or her parent(s) on the grounds of leprosy (Principle 3 (c)); and
3. The reunification of families that were separated in the past as a result of policies and practices related to persons diagnosed with leprosy should, where possible, be supported (Guideline 4).
4. **Living in the community and housing**
	1. **Inclusion and participation in the community**

States should promote full inclusion and participation for persons affected by leprosy and their family members in the community, based on research and testimonies demonstrating the negative impact of exclusion. (Guideline 5.1 and 5.2).

* 1. **Right to choose the place of residence**

Persons affected by leprosy and their family members should be able to choose their place of residence (Guideline 5.3). With due regard to the wishes of the persons affected by leprosy and their family members, the State should guarantee their right to continue to live in leprosy colonies, leprosariums and other sites that have become their homes. However, these sites should not serve as a form of forced isolation for those newly diagnosed. States should improve and maintain living conditions and support services in those leprosariums and other sites. States should, with the full participation and consent of the persons affected by leprosy and their family members, design, promote, and implement plans for full integration into society and gradual phasing out of all sites of segregation (Guideline 5.4).

1. **Political participation**

Persons affected by leprosy and their family members should have the same rights as everyone else in relation to full citizenship and obtaining identity documents (Principle 4). States should fully ensure that persons affected by leprosy and their family members enjoy voting rights, the right to stand for election and the right to hold public office at all levels of government, on an equal basis with others (Guideline 6).

1. **Right to work**

Those affected by leprosy, including those with physical disabilities, and their family members should have the right to work in an inclusive environment, and to be treated on an equal basis with others in relation to recruitment, hiring, promotion, salary, continuance of employment and career advancement (Principle 6). States should encourage and support opportunities for self-employment, the formation of cooperatives and vocational training and employment in regular labour markets of those persons affected by leprosy and their family members (Guideline 7).

1. **Right to education**
	1. **Access to education**

States should ensure equal access to education for persons affected by leprosy and their family members. They should not be denied admission to, or be expelled from, schools or training programmes on the grounds of leprosy (Principle 7, Guideline 8).

* 1. **Training**

States should ensure education for full development of human potential and realization of dignity and self-worth of persons affected by leprosy and their family members, by providing rights-based learning environments (cf. World Programme for Human Rights Education Phase I) where human rights principles are respected and practiced. Schools at all levels play a key role in raising awareness about human rights. Therefore, teachers should be offered training to learn about the negative effects of discriminatory practices against persons affected by leprosy, and to provide learning opportunities to their students. Willing and available persons affected by leprosy and their family members are encouraged to take part in such educational and training activities. (Principle 8).

* 1. **“Know your rights”**

On the basis of the United Nations Declaration on Human Rights Education and Training, persons affected by leprosy and their family members are entitled to know, seek and receive information about their own rights through human rights education. States should produce and disseminate “know your rights” materials (Guideline 13(b)).

1. **Discriminatory language**

States should take all effective measures to remove discriminatory, labeling and offensive terminology such as the use of the term “leper” or its equivalent, including hate speech in any language or dialect, from all forms of expression, including social media (Guideline 9).

1. **Participation in public, cultural and recreational activities**
	1. **Public places**

States should respect, protect and fulfill the principle of non-discrimination by ensuring access for persons affected by leprosy and their family members to public places, including hotels, restaurants, and buses, trains and other forms of public transport on an equal basis with others (Guideline 10.2).

* 1. **Cultural and recreational facilities**

States should promote access, on an equal basis with others, to cultural and recreational facilities for persons affected by leprosy and their family members (Guideline 10.3).

* 1. **Religious places**

States should take effective measures to ensure access on an equal basis with others, to places of worship for persons affected by leprosy and their family members (Guideline 10.4).

1. **Health Care**
	1. **Early diagnosis and prompt treatment for leprosy**

In conformity with the principle of the right to health under international human rights law as enshrined in the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities, States should ensure that persons affected by leprosy and their family members are provided with healthcare that is available and accessible. Such healthcare should include free medication. Other healthcare services should be free or affordable with the same range, quality and standard as with persons with other diseases. Similarly, States should provide early diagnosis programmes to ensure prompt and free treatment of leprosy. States should also provide access to medical service by either establishing a travel team of medical staff trained in the disease, or provide a travel allowance and adequate footwear for those going to difficult remote areas without easy access to medical treatment (Guideline 11.1).

* 1. **Free medication**

States should ensure that persons affected by leprosy receive free medication for leprosy (Guideline 11.3).

* 1. **Counseling**

States should ensure that psychological and social work services are provided as standard care for persons affected by leprosy, who are undergoing diagnosis and treatment, or who continue to experience trauma related to their diagnosis (Guideline 11.2).

**15.4 Rehabilitation**

States should ensure that programmes on medical and social rehabilitation of persons affected by leprosy and their family members are available and accessible which will empower them to fully participate in public life.

1. **Adequate standard of living**
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States should ensure an adequate standard of living, with regard to, *inter alia*, food, clothing, housing, drinking water, sewage systems and other living conditions to persons affected by leprosy and their family members. This should include:

1. Promotion of collaborative programmes involving the Government, civil society and private institutions to raise funds and develop programmes to improve the standard of living (Guideline 12.1 (a));
2. Provision or ensuring of education to children living in poverty, including provision of scholarships and other assistance programmes (Guideline 12.1 (b)); and
3. Ensuring access to vocational training programmes, microcredit and other means to those persons affected by leprosy and their family members living in poverty in order to improve their standard of living (Guideline 12.1 (a) and (b)).
	1. **Social Security**

Persons affected by leprosy and their family members who are not able to work due to their age, illness or disability should be provided with an adequate government pension for dignified living. Persons affected by leprosy and their family members living in poverty should be provided with adequate housing and healthcare (Guideline 12.2 (a) and (b)).

1. **Awareness-raising**
	1. **Plan of action related to awareness-raising**

States should formulate policies and plans of action through a participatory process of stakeholders to raise awareness and to foster respect for the rights and dignity of persons affected by leprosy and their family members, including the following goals:

1. To teach about leprosy at all levels of the education system, including correct information about the disease, in particular, stressing that leprosy should not be used as grounds for discrimination, and provide information in pupils’ native language and use appropriate technology for those who are visually and hearing impaired (Guideline 13(a));
2. To promote the production and dissemination of “know your rights” material to all persons affected by leprosy (Guideline 13(b));
3. To encourage the media to portray persons affected by leprosy and their family members with dignified images and terminology (Guideline 13(c));
4. To recognize skills, merits and abilities of persons affected by leprosy and their contribution to society, and to support such opportunities so as to present their artistic, cultural and scientific talents (Guideline 13(d));
5. To encourage creative persons, including artists, poets, musicians and writers, to actively participate in various activities in awareness-raising (Guideline 13(e));
6. To provide information to social leaders, including religious leaders, on how their teachings or written materials addressing leprosy may contribute to the elimination of discrimination against persons affected by leprosy and their family members (Guideline 13(f));
7. To encourage higher education institutions, including medical schools, nursing schools and social work schools to include information about leprosy in their curricula (Guideline 13(g));
8. To promote the implementation of the UN World Programme for Human Rights Education and to incorporate the human rights of persons affected by leprosy and their family members, including national campaigning for international World Leprosy Day, into the national human rights education programme of each State (Guideline 13(h));
9. To identify ways to recognize, honour and learn from the lives of individuals forcibly isolated by their governments for having been diagnosed with leprosy, including oral history programmes, museums, monuments, publications, and conservation of sanatoriums and related facilities, including designation of leprosy heritage sites (Guideline 13(i)); and
10. To support grass-roots awareness-raising efforts, including international World Leprosy Day, to reach communities without access to traditional media (Guideline 14(j)).
	1. **Training**

Training should be provided to cover a broad range of professionals including civil servants, law-enforcement officials, judges, lawyers, teachers and educators, journalists, medical and health-care professionals, and social workers. On the basis of the UN World Programme for Human Rights Education (Phase II), States should be responsible for the training of public servants with specific responsibility to respect, protect and fulfill the human rights of persons affected by leprosy and their family members. Such training should be provided in a sustainable manner by a permanent programme of training the trainers.

* 1. **Translation and dissemination**

Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members and its national plan of action should be translated into different languages used in the country or their respective regions so that all people within the State could understand, using devices and assistive technologies, and be widely disseminated.

* 1. **World Programme for Human Rights Education**

States, while taking evaluation actions under the second phase of the UN World Programme for Human Rights Education, should include information concerning the progress in the field of education, awareness-raising and training with regard to the rights of persons affected by leprosy and their family members into their national evaluation report to the Office of the UN High Commissioner for Human Rights (OHCHR)　(Guideline 13(h)).

1. **Implementation and follow-up**
	1. **Reporting**

States should include in their reports under the Universal Periodic Review of the UN Human Rights Council as well as reports to the relevant treaty bodies, including the UN Convention on the Rights of Persons with Disabilities (UNCRPD), the policies and measures that they have adopted and/or implemented with regard to the elimination of discrimination against persons affected by leprosy and their family members (Guideline 14.2).

* 1. **National implementing mechanism**

States should either create a committee or designate powers and responsibilities to national human rights institutions in order to monitor implementation of the Principles and Guidelines for the Elimination of Discrimination against Persons affected by Leprosy and their Family Members as well as the national plan of action.