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Report of the International Working Group on Leprosy and Human Rights

Sponsored and Supported by The Nippon Foundation

“Working Together to Eliminate All Forms of Discrimination Associated with Leprosy”

－ How to Follow-up the UN Principles and Guidelines －

1. **Introduction**
2. Leprosy, or Hansen’s disease, is curable and medication and treatment are available free of charge basically anywhere in the world. Since the early 1980s, when an effective multiple-drug therapy (MDT) was established, some 16 million persons have been cured of the disease worldwide. Thanks to the efforts made by Governments, international organizations—in particular, the World Health Organization (WHO)—and non-governmental organizations, including The Nippon Foundation, the annual number of new cases has dropped to below 250,000.
3. While leprosy is no longer a major public health problem in most countries, at the social level, stigma and discrimination are still experienced by tens of millions of persons affected by the disease regardless of whether it is still a public health problem or not. The persons who have been diagnosed with the disease and their family members have been impacted by various forms of discrimination, exclusion, maltreatment and stigmatisation. In light of these factors, persons affected by leprosy, especially women, should be partners in the planning, development and implementation of policies and programmes that affect them. In the early 2000s, the United Nations Sub-Commission on the Promotion and Protection of Human Rights began to look into the issue of discrimination against persons affected by leprosy and their families.
4. Due to the reform of the UN human rights machinery, however, it took some years before this issue was formally addressed. On 21 December 2010, the General Assembly of the United Nations adopted Resolution A/RES/65/215 (Appendix III), noting “*with appreciation*” the “principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members” (“Principles and Guidelines”), that had been elaborated by the Human Rights Council resolutions of 8/13 of 18 June 2008, 12/7 of 1 October 2009 and 15/10 of 30 September 2010. The General Assembly further 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 and implementation of their policies and measures concerning persons affected by leprosy and their family members.”
5. In 2011, The Nippon Foundation initiated a programme to disseminate and ensure effective implementation of the Principles and Guidelines throughout the world by organizing regional symposiums in five regions, *i.e*., the Americas, Asia, Africa, the Middle East and Europe (Appendix V) as follows:
6. For the Americas, on 31 January and 1 February 2012 in Rio de Janeiro, Brazil;
7. For Asia, on 3-4 October 2012 in New Delhi, India;
8. For Africa, on 17-18 September 2013 in Addis Ababa, Ethiopia;
9. For the Middle East, on 27-28 October 2014 in Rabat, Morocco; and
10. For Europe, on 17-18 June 2015 in Geneva, Switzerland.
11. At the end of the first symposium in Rio de Janeiro, the participants—persons affected by leprosy and their family members, representatives of the UN and other relevant intergovernmental organizations (the World Health Organization [WHO] in particular), support organizations, human rights NGOs, journalists, medical doctors and health-care workers, specialists and experts as well as Government officials from the region—unanimously adopted a resolution (Appendix VI) which proposed to establish “a working group to discuss and formulate plans of action and a mechanism to monitor actions taken by the States and other actors.” The Nippon Foundation was entrusted with the task of taking the lead role in this process.
12. Accordingly, in October 2012, The Nippon Foundation created the International Working Group (IWG) on Leprosy and Human Rights, with the following members, taking into account various factors including geographical representation, special knowledge, experience and expertise, representation of the communities and organizations of persons affected by leprosy, and gender balance[[1]](#footnote-1):
13. Dr. Yozo Yokota (Japan)－Chairperson: President, Center for Human Rights Education and Training, Japan;
14. Prof. Anwar Ahmad Al-Fuzaie (Kuwait): Professor, University of Kuwait;
15. Mr. Artur Custódio Moreira de Sousa (Brazil): National Coordinator, Movimento de Reintegração das Pessoas Atingidas pela Hanseníase (MORHAN);
16. Prof. Barbara Frey (U.S.A.): Director, Human Rights Program, University of Minnesota;
17. Ms. Cecilia R. V. Quisumbing (Philippines): Commissioner, Commission on Human Rights of the Philippines;
18. Prof. Deepika Udagama (Sri Lanka): Professor, Department of Law, University of Peradeniya;
19. Mr. Javed Abidi (India): Chairperson, Disabled Peoples International (DPI) ;
20. Mr. José Ramirez, Jr. (U.S.A.): U.S.A. Coordinator, International Association for Integration, Dignity and Economic Advancement (IDEA);
21. Mr. Menberu Adane Yihunie (Ethiopia): Managing Director, The Ethiopian National Association of Persons Affected by Leprosy (ENAPAL);
22. Dr. Mousa S. Burayzat (Jordan): Commissioner General, The National Centre for Human Rights, Jordan;
23. Dr. P. K. Gopal (India): Senior Consultant, National Forum India;
24. Ms. Tâmara Biolo Soares (Brazil): Director, Department of Human Rights on the Justice Department of Rio Grande do Sul State; and
25. Dr. Vesselin Popovski (Bulgaria): Senior Academic Programme Officer, United Nations University.
26. The IWG held four meetings as follows:
27. On 3 October 2012 in New Delhi, India;
28. On 15 March 2013 in Tokyo, Japan;
29. On 26-27 August 2013 in Gunma, Japan; and
30. On 27 October 2014 in Rabat, Morocco.
31. In order to assist the work of the IWG, a national advisory committee composed of the following members was created:
32. Dr. Yozo Yokota－Chairperson: President, Center for Human Rights Education and Training, Japan;
33. Dr. Mariko Akuzawa: Professor, Graduate School for Creative Cities, Osaka City University;
34. Ms. Sawako Hirai: Associate Professor, Faculty of Law, Seinan Gakuin University;
35. Dr. Shigeki Sakamoto: Professor, Kobe University;
36. Ms. Hiroe Soyagimi: Director, Sasakawa Memorial Health Foundation;
37. Dr. Misako Takizawa: Professor, J. F. Oberlin University;
38. Mr. Tatsuya Tanami: Executive Director, The Nippon Foundation;
39. Dr. Marie Tomita: Associate Professor, Faculty of Law, Seinan Gakuin University; and
40. Ms. Kazuko Yamaguchi: Trustee, Sasakawa Memorial Health Foundation.
41. The present report is a result of the joint work of the IWG, the national advisory committee and the participants in the regional symposiums.
42. **Content of the Principles and Guidelines**
43. The Principles and Guidelines consist of two parts: the First Part, titled “Principles”, recognizes the following basic rights of persons affected by leprosy and their family members:
44. The right to be treated as persons with dignity and the right to enjoy all human rights;
45. The right of non-discrimination on the grounds of having or having had leprosy;
46. The same rights as everyone else with respect to marriage, family and parenthood;
47. The same rights as everyone else in relation to citizenship;
48. The right to serve the public, to stand for elections and to hold office at all levels of government;
49. The right to work and to be treated on an equal basis with others with respect to recruitment, hiring, promotion, salary, continuance of employment and career development;
50. The right to be admitted to schools or training programmes;
51. The right to develop their human potential to the fullest extent and to realize their dignity and self-worth; and
52. The right to be actively involved in decision-making processes regarding policies and programmes that directly concern their lives.
53. The Second Part, titled “Guidelines”, provides in concrete terms for the responsibility of States to promote, protect and ensure the full realization of all human rights for all persons affected by leprosy and their family members. This Part is divided into 14 sections.
54. Section 1 (“General”) stipulates that States should:
55. take all appropriate legislative, administrative and other measures to modify, repeal or abolish existing laws, regulations, policies, customs and practices that discriminate against persons affected by leprosy and their family members;
56. ensure that all authorities and institutions take measures to eliminate discrimination on the grounds of leprosy by any person, organization or private enterprise;
57. ensure full realization of all human rights to persons affected by leprosy and their family members; and
58. consult closely with, and actively involve, persons affected by leprosy and their family members in the development and implementation of legislation and policies concerning them.
59. Section 2 (“Equality and non-discrimination”) provides that States should ensure equality for all and prohibit any discrimination on the grounds of having or having had leprosy.
60. Section 3 (“Women, children and other vulnerable groups”) provides that 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, as well as their family members. It further provides that States should promote full development, advancement and empowerment of persons affected by leprosy and their family members.
61. Section 4 (“Home and family”) deals with cases of families separated in the past as a result of discriminatory policies and practices relating to persons diagnosed with leprosy. When such situation is identified, it is the responsibility of the States to support the reunification of the separated families.
62. Section 5 (“Living in the community and housing”) addresses the issue of reintegration into community of persons affected by leprosy and their family members who had been forcibly isolated or hospitalized by discriminatory State policies or otherwise ostracized from their community because of leprosy. In this connection, States should: (i) identify persons affected by leprosy and their family members living in isolation or segregated from their community because of leprosy; (ii) promote the full enjoyment of their human rights; (iii) ensure their full inclusion and participation in the community life; (iv) allow, if they so wish, to continue to live in the leprosariums; and (v) design, promote and implement plans for their gradual integration into community.
63. Section 6 (“Participation in political life”) provides that States should 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.
64. Section 7 (“Occupation”) requires States to encourage and support opportunities for self-employment, the formation of cooperatives and vocational training for persons affected by leprosy and their family member, as well as their employment in regular labour markets.
65. Section 8 (“Education”) provides that States should promote equal access to education for persons affected by leprosy and their family members.
66. Section 9 (“Discriminatory language”) provides that States should remove discriminatory language, including the discriminatory, labeling and offensive term “leper” or its equivalent in any language, from governmental publications.
67. Section 10 (“Participation in public, cultural and recreational activities”) stipulates that States should promote the equal enjoyment of the rights and freedoms of persons affected by leprosy and their family members enshrined in international human rights instruments, and, in particular, promote access on an equal basis with others, (i) to public places, including hotels, restaurants and buses, trains and other forms of public transport; (ii) to cultural and recreational facilities; and (iii) to places of worship.
68. Section 11 (“Health care”) provides that States should: (i) provide persons affected by leprosy and their family members with free or affordable health care; (ii) provide programmes for early diagnosis; (iii) ensure prompt treatment; (iv) include psychological and social work counseling as standard health care offered to persons affected by leprosy; and (v) ensure access to free medication for leprosy.
69. Section 12 (“Standard of living”) provides that States should recognize the right of persons affected by leprosy and their family members to an adequate standard of living with regard to food, clothing, housing, drinking water, sewage and other living conditions.
70. Section 13 (“Awareness-raising”) calls on States to formulate policies and plans of action to raise awareness throughout society and to foster respect for the rights and dignity of persons affected by leprosy and their family members. In doing so, States must work together with human rights institutions, non-governmental organizations, civil society and the media. Such policies and plans of action may include:
71. Dissemination of information on leprosy at all levels of the education system;
72. Production and dissemination of “know your rights” material to give to all persons diagnosed with leprosy;
73. Encouragement to the media to portray persons affected by leprosy and their family members with dignified images and terminologies;
74. Recognition of the skills, merits and abilities of persons affected by leprosy and their contribution to society;
75. Encouragement to creative persons, including artists, poets, musicians and writers, to make a contribution to awareness-raising through their talents;
76. Provision of information to social leaders, including religious leaders, on how addressing leprosy in their teachings or written materials may contribute to the elimination of discrimination against persons affected by leprosy and their family members;
77. Encouragement to higher education institutions to include information about leprosy in their curricula;
78. Promotion of education and dissemination of the rights of persons affected by leprosy and their family members through the UN World Programme for Human Rights Education as well as the national human rights education programmes;
79. Identification of 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 and publications; and
80. Support for grass-roots awareness-raising efforts to reach communities without access to traditional media.
81. Section 14 (“Development, implementation and follow-up to States’ activities”) strongly encourages States to create or designate a committee to address activities relating to the human rights of persons affected by leprosy and their family members. The committee should ideally include individuals affected by leprosy and their family members, representatives of organizations of persons affected by leprosy, human rights experts, representatives from the human rights field and related fields, and representatives of government. States are also encouraged to include in their State party reports to the relevant international human rights treaty bodies 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.
82. **The Principles and Guidelines as International Human Rights Standards**
83. Since its founding, the United Nations has consistently proclaimed the principles of equality and non-discrimination for all persons. The principle of non-discrimination was initially included in the purposes of the UN Charter, which included "promoting and encouraging respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language, or religion." The principle of non-discrimination was further elaborated and reinforced in the Universal Declaration of Human Rights, the International Covenants on Human Rights, and subsequent human rights treaties. The Universal Declaration of Human Rights and the two Covenants guarantee that everyone is entitled to all the rights and freedoms set forth in those instruments, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. The principle of non-discrimination has been restated in many other human rights treaties, including the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families. The International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, adopted in 2006 and entered into force in 2008, recognizes that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person.
84. The Principles and Guidelines confirm and build upon the core principle of non-discrimination so deeply embedded in international human rights law. Drafted and adopted by the UN Human Rights Council and endorsed by the UN General Assembly, the Principles and Guidelines represent the standards of behavior that have been deemed to be necessary for States to achieve their responsibility to prohibit all forms of discrimination against persons affected by leprosy and their family members.

**IV. International Mechanism for Full Implementation**

1. The goal of the Principles and Guidelines is to ensure the full respect and realization of all human rights of persons affected by leprosy and their family members. This goal is critical for every society because of the common faith, expressed in the UN Charter, “in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small.” The global commitment to human rights cannot be achieved if the rights of any particular group of people, such as persons affected by leprosy and their family members, are not fully respected and protected. This is the premise that supports the centrality of the customary norm of non-discrimination in international human rights law.　Protection from certain forms of discrimination, such as those based on race or sex, is non-derogable and has already achieved the status of customary international law. The international community continues to take steps, through advances in law and practice, to ensure that the rights of all persons and groups are fully respected.
2. The centrality of the principles of equality and non-discrimination in international human rights law and the adoption and endorsement of the Principles and Guidelines by the UN human rights bodies carry authoritative weight as standards against which to measure　States’ responsibilities with regard of persons affected by leprosy and their family members. Even assuming that the Principles and Guidelines are not legally binding, they still constitute persuasive authority with regard to the State practice necessary to ensure the right to non-discrimination of persons affected by leprosy and their family members. Because of this, it is desirable to create a follow-up mechanism designed to encourage States and other actors to bring their conduct in line with the guidance provided in the instrument. In this connection, it may be useful to look at some examples of successful follow-up procedures. A good example is the case of the International Labour Organization (ILO).
3. The mission of the ILO, since its establishment in 1919, has been to promote and protect the rights of workers in the member States and to improve labour standards globally. For this purpose, it is engaged in two main activities: standard setting and monitoring (or “supervision”). The ILO has two forms of standards: legally binding Conventions and non-binding Recommendations. What is instructive for this report is the manner in which the ILO follows up on the Recommendations after their adoption by the International Labour Conference (“Conference”).[[2]](#footnote-2)
4. When the ILO Conference adopts a Recommendation by a two-thirds majority, it is then communicated to all member States for their consideration with a view to its enforcement through national legislation. The member States are required, within a designated period,[[3]](#footnote-3) to bring the Recommendation before the legislature for action. The Member States must report to the Director-General of the ILO the measures they have taken including any action taken by their legislatures, if any. After this, the Member States are required to report “at appropriate intervals as requested by the Governing Body” to the Director-General “the position of the law and practice in their country in regard to the matters dealt with in the Recommendation, showing the extent to which effect has been given, or is proposed to be given, to the provisions of the Recommendation.”
5. The follow-up procedure used for the ILO Recommendations is instructive in the sense that an instrument which is not legally binding or enforceable through normal administrative or judicial processes may still be given effect by legally requiring the Member States to follow certain procedures, such as bringing to the attention of the national legislature and reporting regularly to the ILO on its progress concerning the instrument.
6. The Principles and Guidelines can be given effect if States are called upon to take certain procedural actions, including conducting studies, collecting and analyzing data, on the situation of persons affected by leprosy (and how effective is their leprosy control activity to reach zero-disability), bringing these instruments to the attention of various governmental offices, and reporting back to a specified international body. **In order to effectively implement the Principles and Guidelines, therefore, the IWG recommends the establishment of a follow-up mechanism at the international level with such authority. For example, the UN Human Rights Council that adopted the Principles and Guidelines could entrust its Advisory Committee to study and recommend an appropriate follow-up mechanism. A similar mechanism should also be established at the national level in the States.**
7. Certain provisions of the Principles and Guidelines are already legally binding because they are recognized within binding international human rights laws. For instance, paragraph 1 of the Principles and Guidelines provides that “[p]ersons 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 human rights and fundamental freedoms.” The right of persons affected by leprosy and their family members to be treated “as people with dignity” and their entitlement to “all human rights and fundamental freedoms” are already guaranteed in the International Bills of Human Rights[[4]](#footnote-4) as well as other binding treaties and many national Constitutions.
8. Based on these binding obligations, certain courts have enforced the human rights of persons affected by leprosy and, as a result of these cases, States have been ordered to address issues of discrimination and to provide remedies to the victims. In Japan, for example, the Leprosy Prevention Law, which required forcible hospitalization of persons diagnosed with leprosy, was repealed in 1996 due to the longstanding efforts by the organized movement of persons affected by leprosy, the League of the Directors of Leprosariums and the Japanese Medical Association of Leprosy. In spite of the repeal of this discriminatory law, however, no remedies were provided by the Government to the persons who had been forcefully hospitalized without their consent for many years. In an attempt to remedy this, in 1998-99, a group of formerly-interned persons brought court cases in Kumamoto, Tokyo and Okayama. In 2001, the Kumamoto District Court delivered a judgment which recognized the claims of the plaintiffs that forced hospitalization under the Leprosy Prevention Law was in violation of the human rights provisions of the Japanese Constitution and the formerly-interned persons should be compensated for their physical and mental suffering. After this court ruling, the Japanese Government decided to accept the judgment and took various measures including the promulgation of the Law to Compensate the Former Interned Persons in the Leprosariums (“Leprosy Compensation Law”), which provided for remedies to all former internees, regardless of whether they had been parties in court cases.
9. In 2003, a hotel in Kurokawa Onsen (Kurokawa Hotspring), Kumamoto Prefecture, refused to accommodate a group of visitors because of their leprosy history. Kumamoto Prefecture, which had organized the stay, requested the hotel to accommodate the guests, explaining that leprosy is not easily transmitted in ordinary human contacts, that the disease is curable without hospitalization, and that the refusal to accept persons affected by leprosy as guests violated their human rights. The hotel, in spite of the repeated requests by the Prefectural Government together with the protest letter sent by the Governor of Kumamoto, did not change its policy of non-accommodation. In 2004, at the request of the Prefectural Government and the Kumamoto District Legal Affairs Bureau, the Kumamoto District Public Prosecutors Office indicted the President, General Manager and the hotel itself for violations of the provisions of the Ryokangyo Ho (Hotel Business Law). All the accused were found responsible for their discriminatory actions by The Kumamoto District Court.
10. Human rights of persons affected by leprosy and their family members, as enshrined in various human rights conventions and treaties, national constitutions and legislation, and court jurisprudence, should be respected and protected under the law. Violations of the human rights of persons affected by leprosy and their family members should be remedied through administrative and judicial means. Regrettably, as the need for these Principles and Guidelines demonstrates, and as many persons affected by leprosy and their family members testify, there continues to be widespread discrimination worldwide, in schools, work places, communities, public places, religious sites, restaurants, hotels, buses and trains, and displacement from old settlements in suburbs and irrigated farms without due consideration of their preference and consultation on alternatives and other forms of public transport. Social stigma sometimes affects family relations, such as those between husband and wife and parent and child, and can lead to divorce. In order to overcome such injustice, the Principles and Guidelines were adopted. **It is critical that a mechanism be established to follow-up the conduct of States and other actors in order to implement the Principles and Guidelines effectively.**
    1. **Actors Expected to Implement the Principles and Guidelines**
11. There are many actors who are called upon to respect the standards of conduct specified in the Principles and Guidelines. The first and foremost are the States which have the general obligation to respect, protect, fulfill and ensure all human rights for all. For this reason, the Second Part (“Guidelines”) of the Principles and Guidelines start with the following statement: “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 discriminations on the grounds of leprosy.” Accordingly, all the provisions contained in the Second Part of the Principles and Guidelines are directly addressed to States.
12. The UN General Assembly resolution of 2010(A/RES/65/215) and the Principles and Guidelines also assume other relevant actors to comply with the standards of conduct laid down therein, or otherwise to pay due consideration to them. For instance, the General Assembly resolution, in operative paragraph 3, encourages “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 and implementation of their policies and measures concerning persons affected by leprosy and their family members”.
13. Part One (“Principles”) of the Principles and Guidelines in paragraph 9 also states that: “[p]ersons 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.” Its paragraph 8 also states that: “[p]ersons affected by leprosy and their family members who have been empowered and who have had the opportunity to develop their abilities can be powerful agents of social change.” Furthermore, paragraph 1.3 states that: “States should consult closely with and actively involve persons affected by leprosy and their family members, individually or through their respective local and national organizations”. These statements demonstrate that persons affected by leprosy and their family members are not only negatively impacted by discrimination but also are important actors to promote and protect their own human rights. They also indicate that the persons affected by leprosy and their family members should act individually, or collectively through their respective local and national (as well as international) organizations.
14. Part Two (“Guidelines”) of the Principles and Guidelines in paragraph 1.1 (a) states that: “(States should) [t]ake all appropriate legislative, administrative 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, or that forcefully or compulsorily segregate and isolate persons on the grounds of leprosy in the context of such discrimination.” This statement specifies the responsibility of the Government and the legislature, as well as by implication the judiciary (which can be included in “other” entities), to take necessary measures to abolish the discriminatory legislation and practices related to leprosy. In the same line, paragraph1.1 (b) provides that: “(States should) [e]nsure that all authorities and institutions take measures to eliminate discrimination on the grounds of leprosy by any person, organization or private enterprise.” **These statements assume that all parts of the government, including local governments and organizations and institutions under the control of the government, as well as individuals, organizations and private enterprises, are also regarded as actors who are expected to act in accordance with the standards of conduct specified in the Principles and Guidelines.**
15. In addition, paragraph 12.1 (a) stresses the importance of collaborative programmes with the government, civil society and private institutions to raise funds and develop programmes to improve the standards of living of the persons affected by leprosy and their family members.
16. In the important area of awareness-raising, paragraph 13 requests States to work together with “human rights institutions, non-governmental organizations, civil society and the media” to formulate policies and plans of action to raise awareness throughout society. In paragraph 13 (c), the media are advised to portray persons affected by leprosy and their family members with dignified images and terminology. Paragraph 13 (e) further encourages “creative persons, including artists, poets, musicians and writers, particularly those who have personally faced the challenges of leprosy, to make a contribution to awareness-raising through their specific talents.”
17. As noted above, the Principles and Guidelines themselves identify various actors who should respect, promote and ensure the human rights of persons affected by leprosy and their family members. In this regard it should be underlined that the actors explicitly mentioned in the General Assembly resolution and the Principles and Guidelines are not exhaustive but rather illustrative. A broad range of actors should act and collaborate in order to fully implement the Principles and Guidelines.
18. The first category of such actors is the States. States, including their federal units, can be broadly divided into the following five parts:
19. Legislature: Repealing or amending discriminatory legislation; enacting new laws or amending existing laws to prohibit direct and indirect discrimination and provide remedies;
20. Judiciary: Applying the principles of non-discrimination to protect and promote human rights of persons affected by leprosy and their family members, and provide remedies; training judges and lawyers to be aware of the Principles and Guidelines;
21. Executive: Implementing the relevant parts of the Principles and Guidelines through the Ministry (or Department) concerned, for instance:
22. General protection of human rights, equal enjoyment of human rights and prohibition of discrimination－Ministry of Justice
23. Provision of adequate healthcare with a view to eliminating leprosy as a disease and provision of public health education programmes on leprosy－Ministry of Health
24. Protection of women, children and other vulnerable groups－Ministries concerned
25. Reunification of families－Ministries concerned
26. Reintegration and inclusion into society－Ministry of Justice / Ministry of Labour and Social Affairs and other ministries concerned
27. Housing and relevant infrastructure, including adequate sewage systems－Ministry of Housing, Ministry of Construction and other ministries concerned, city municipalities
28. Ensuring access to means of public transportation－Ministry of Transportation
29. Full participation in political life including voting and standing for election－National and local election commissions, Ministry of Justice and other ministries concerned
30. Equal opportunity for employment and non-discrimination at work－Ministry of Labour and labour inspectorate
31. Equal opportunity for education and vocational training－Ministry of Education, Ministry of Labour
32. Participation in public, cultural and recreational activities－Ministries responsible for culture, recreation, sport and religion
33. Standard of living and social welfare－Ministry of Health, Ministry of Welfare, Ministry of Finance
34. Awareness-raising－Ministry of Education, Ministry of Justice, Ministry of Information, Ministry of Culture
35. Inclusion of information in national State party reports to the international human rights treaty bodies and the UN Human Rights Council about the policies and measures to eliminate discrimination associated with leprosy－Ministry of Foreign Affairs, Ministry of Labour and Social Affairs
36. Provision of adequate monthly pension for dignified living to the leprosy affected persons with disabilities－Ministry of Social Justice & Empowerment;
37. Local governments: Implementing the relevant parts of the Principles and Guidelines; and
38. Independent national human rights institution: Gathering information and data about the human rights situation of persons affected by leprosy and their family members, protecting and advocating their human rights, reviewing the government policies and programmes regarding the human rights of persons affected by leprosy and their family members and recommending their improvement.
39. The next category of actors involved is “the United Nations and other intergovernmental organizations” which can be divided into the following four types:
40. UN organs: General Assembly, Economic and Social Council (ECOSOC), Human Rights Council, Human Rights Council Advisory Committee, human rights treaty bodies, High Commissioner for Human Rights (UNHCHR);
41. UN funds and programmes: UN Children’s Fund (UNICEF), UN Development Programme (UNDP), World Food Programme (WFP);
42. UN specialized agencies: World Health Organization (WHO), International Labour Organisation (ILO), UN Educational, Scientific and Cultural Organization (UNESCO), the World Bank; and
43. Regional intergovernmental organizations: for example, European Union (EU), Organization of American States (OAS), African Union (AU), Association of Southeast Asian Nations (ASEAN), Council of Europe, South Asian Association for Regional Cooperation (SAARC).
44. There is another important category of actors under the broad concept of civil society organizations, which can be divided into the following four types:
45. Organizations of persons affected by leprosy: for example, International Association for Integration Dignity and Economic Advancement (IDEA), Movimento de Reintegração das Pessoas Atingidas pela Hanseníase (MORHAN), Ethiopian National Association of Persons Affected by Leprosy (ENAPAL), Association of People Affected by Leprosy India (APAL), National Association of Sanatoria Residents, Japan (Zenryokyo);
46. National non-profit organizations: for example, Center for Human Rights Education and Training, Japan; Sasakawa India Leprosy Foundation (S-ILF), Raj Pracha Samasai Foundation, Thailand (RPSF);
47. International non-governmental organizations (NGOs): for example, International Federation of Anti-Leprosy Associations (ILEP), The Nippon Foundation, Amnesty International, Save the Children, Disabled Peoples International, International Commission of Jurists, World Council of Churches, ATD Fourth World International; and
48. International professional associations: for example, International Bar Association, World Medical Association, International Council of Nurses, International Association of Social Workers, and International Association of Psychologists.
49. The last category encompasses various social institutions and actors such as schools, universities, research institutions, hospitals, religious organizations, all forms of media, business enterprises, artists, writers, poets, musicians, political leaders, religious leaders, and social clubs like Rotary Club, Lions Club, etc. They play an important role in removing the misconceptions and stigma associated with leprosy, and raising public awareness about the disease and its impacts.
    1. **Suggested Framework for National Plans of Action**
50. As noted above, the actors which are called upon to implement the Principles and Guidelines are diverse, complex and numerous. The ideal situation is that all such actors would adopt plans of action suited to the nature of the entities and the field of their specialty to implement the Principles and Guidelines. As the Principles and Guidelines have no legal authority to require these actors to implement them, there is no guarantee that they will in fact do so. States are strongly encouraged to: (a) adopt their own plan of action to implement the Principles and Guidelines; (b) invite or encourage various actors under their jurisdiction to adopt plans of action; (c) engage in an activity to monitor how other actors are doing, or not doing, for the purpose of the implementation of the Principles and Guidelines; and (d) 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 committee under 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. In fact, the Principles and Guidelines suggest in paragraph 14.1 that: “States should consider creating or designating a committee to address activities relating to the human rights of persons affected by leprosy and their family members.”
51. For the purpose of facilitating the adoption of an effective plan of action by States, a draft model national plan of action is proposed and attached to this report (Appendix I). The proposed model plan of action for States is a model offered for consideration by States, who may adapt and strengthen it, taking into account their respective political, social and economic realities and conditions.

**VII. A Need for an Effective International Follow-up Mechanism**

1. In order to encourage States to adopt and carry out effective plans of action and collect information regarding the actual status of implementation of the Principles and Guidelines in their respective jurisdictions, **the IWG recommends the creation of an effective international follow-up mechanism**.
2. For example, in the case of international human rights treaties, a committee of experts is created under respective treaties to receive State party reports for examination[[5]](#footnote-5). In the case of ILO Conventions and Recommendations, the Committee of Experts on the Application of Conventions and Recommendations examines the reports submitted by the member States[[6]](#footnote-6). The Principles and Guidelines would be implemented more effectively once a similar follow-up mechanism is established.
3. **In view of that, the IWG recommends that the UN Human Rights Council, which adopted the Principles and Guidelines, entrust its Advisory Committee to study and recommend an appropriate follow-up mechanism to ensure effective implementation of the Principles and Guidelines.**
   * 1. **Proposed Questionnaire**
4. The first thing that the proposed international follow-up mechanism would be expected to take up is to investigate the actual status of implementation of the Principles and Guidelines by States through sending out questionnaires and collecting data. The collected responses to the questionnaires would be published to encourage States to understand the actual status of implementation of the Principles and Guidelines in other States, and to learn from the experiences and practices, including the cases of progress, in other States and to endeavour to improve the situation in their own countries.
5. In order to facilitate the process of sending out such questionnaires, a draft proposed questionnaire is attached hereto (Appendix II).
   1. **Conclusion**
6. **The adoption by the UN General Assembly of Resolution A/RES/65/215 which endorsed the Principles and Guidelines to Eliminate Discrimination against Persons Affected by Leprosy and Their Family Members is a landmark achievement in the field of human rights. It has been welcomed by tens of millions of persons who have endured so much discriminatory treatment as a result of legislation/laws, policies and practices and stigma associated with leprosy. Nevertheless, persons affected by leprosy and their family members continue to experience widespread discrimination and serious violations of human rights. Effective implementation of the Principles and Guidelines is urgently needed. It is hoped that the international follow-up mechanism suggested in this report will ensure full realization of immediate and effective elimination of discrimination and stigma associated with leprosy. By working together, it will be achieved.**

1. The titles of the persons listed here reflect the positions held at the time of their appointment to the IWG. The same applies to the list of persons that appears below. [↑](#footnote-ref-1)
2. In the case of the ILO Conventions, in addition to various national and international mechanisms, including courts of law, used to give effect to their provisions, there is a sophisticated mechanism to supervise their effective application and implementation. See Lee Swepston, “The International Labour Organization’s System of Human Rights Protection,” Janusz Symonides, ed., *Human rights: International Protection, Monitoring, Enforcement,* UNESCO, 2003. [↑](#footnote-ref-2)
3. Usually “within a period of one year at most from the closing of the session of the Conference,” but if this is not possible due to exceptional circumstances, “at the earliest practicable moment and in no case later than 18 months after the closing of the Conference.” ILO Constitution, Art. 19 (6) (b). [↑](#footnote-ref-3)
4. Among the various international human rights treaties, conventions and instruments, there are several documents that have a broad, general, fundamental and universal nature. These are often categorized as the “International Bills of Human Rights” and include the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, and the International Covenant on Civil and Political Rights. [↑](#footnote-ref-4)
5. See Philip Alston, ed., *The United Nations and Human Rights: a Critical Appraisal*, Oxford University Press, 1995. [↑](#footnote-ref-5)
6. For more detail, see Swepston, *op.cit*. [↑](#footnote-ref-6)