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Item 2 (a) (vi) of the provisional agenda **Requests addressed to the Advisory Committee stemming from Human Rights resolutions:
Elimination of discrimination against persons affected by leprosy and their family members**

 Progress report on the implementation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members

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I. Background

1. The concern regarding discrimination against persons affected by leprosy and their family members was initially expressed by the Sub-Commission on the Promotion and Protection of Human Rights (the Sub-Commission) at its fifty-sixth session in 2004. In this resolution, the Sub-Commission requested one of its members, Professor Yozo Yokota, to prepare a preliminary working paper on the issue[[1]](#footnote-2).

2. A preliminary working paper was submitted by the rapporteur at the fifty-seventh session of the Sub-Commission in which he highlighted various forms of discrimination against persons affected by leprosy and their family members and emphasized that the persisting practice of discrimination against persons affected by leprosy such as discriminatory practices in terms of employment, marriage, education, use of public places, including hotels, restaurants and means of transportation should be stopped immediately[[2]](#footnote-3).

3. The work started by the Sub-Commission was, however, discontinued due to the reform of the UN human rights machinery in 2006 and it took some years before the Human Rights Council took up the issue in 2008, taking note of the previous work done by the Commission on Human Rights and its subsidiary body. In its resolution 8/13, the Human Rights Council requested the Office of the United Nations High Commissioner for Human Rights (OHCHR) to collect information on the measures that Governments have taken to eliminate discrimination against persons affected by leprosy and their family members, and to hold a meeting to exchange views among relevant actors, including Governments, observers of the United Nations, relevant United Nations bodies, specialized agencies and funds and programmes, non-governmental organizations, scientists, medical experts as well as representatives of persons affected by leprosy and their family members. In the same resolution, the Human Rights Council requested its Advisory Committee to examine the report prepared by the OHCHR and to formulate a draft set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and to submit same to the Council for its consideration by September 2009[[3]](#footnote-4).

4. At its third session, the Advisory Committee endorsed the draft set of principles and guidelines prepared by the designated rapporteur, Professor Shigeki Sakomoto, taking into account the report of the OHCHR[[4]](#footnote-5), and submitted the draft principles and guidelines to the Human Rights Council for consideration at its twelfth session. In its resolution 12/7, the Human Rights Council further requested the OHCHR to collect the views of relevant actors on the draft set of principles and guidelines, including Governments, observers of the United Nations, relevant United Nations bodies, specialized agencies and funds and programmes, non-governmental organizations, scientists and medical experts, as well as representatives of persons affected by leprosy and their family members and to make those views available to the Advisory Committee[[5]](#footnote-6).

5. Accordingly, a revised draft of the Principles and Guidelines against persons affected by leprosy and their family members (hereinafter “the Principles and Guidelines”) was adopted by the Advisory Committee at its fifth session and submitted to the Council at its fifteenth session[[6]](#footnote-7). In its resolution 15/10, the Human Rights Council took note with appreciation of the revised draft and invited the General Assembly to consider, as appropriate, the issue of discrimination against persons affected by leprosy and their family members, including possible ways to promote the Principles and Guidelines[[7]](#footnote-8).

6. In December 2010, the United Nations General Assembly adopted without a vote resolution 65/215, in which it noted with appreciation the principles and guidelines prepared by the Advisory Committee and submitted it to the Human Rights Council. 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 leprosy affected persons and their family members. The resolution also encourages all relevant actors in society, including hospitals, schools, universities, religious groups and organizations, business enterprises, newspapers, broadcasting networks and other non-governmental organization, to give due consideration, as appropriate, to the Principles and Guidelines in the course of their activities. formulation and implementation of their policies and measures concerning leprosy affected persons and their family members[[8]](#footnote-9).

7. At its twenty-ninth session in June 2015, the Human Rights Council adopted resolution 29/5 on the elimination of discrimination against persons affected by leprosy and their family members. The Council noted, among others, that persons affected by leprosy and their family members still face multiple forms of prejudice and discrimination stemming from misinformation about and misunderstanding of the disease throughout the world and stressed the importance of implementing the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members in accordance with General Assembly Resolution 65/215[[9]](#footnote-10).

8. Accordingly, the Human Rights Council requested the Advisory Committee to undertake a study which reviews the implementation of the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members, together with obstacles thereto, and to submit a report at its thirty-fifth session (June 2017) containing practical suggestions for the wider dissemination and more effective implementation of the Principles and Guidelines in order to eliminate discrimination and stigma associated with leprosy and to promote, protect and respect the human rights of those affected by leprosy and their family members. The resolution also encourages the Advisory Committee, when elaborating the report, to take into account the views of Member States, and as appropriate, relevant international and regional organizations, including the World Health Organization, the Office of the United Nations High Commissioner for Human Rights and relevant special procedures, national human rights institutions and non-governmental organizations, as well as the work done on the issue by relevant United Nations bodies, specialized agencies, funds and programmes within their respective mandates[[10]](#footnote-11).

9. It should also be noted that the mandate given to the Advisory Committee under resolution 29/5, is a follow-up to the previous work done by the Advisory Committee which prepared the Principles and Guidelines. The current mandate given to the Advisory Committee by the Human Rights Council is to examine and recommend what needs to be done to effectively implement the Principles and Guidelines by States and other stakeholders as provided by the United Nations General Assembly Resolution 65/215.

10. In response to its mandate pursuant to resolution 29/5, the Advisory Committee at its fifteenth session, designated a drafting group composed of eight experts, namely, Ms. Boisson de Chazournes, Ms. Carciunean, Mr. Coriolano, Mr. Obata, Mr. Soofi, Mr. Zhang, Mr. Soh, and Mr. Yigezu. Mr. Okafor joined the drafting group subsequently. The drafting group elected Mr. Obata as Chairperson and Mr. Yigezu as its Rapporteur[[11]](#footnote-12). The Advisory Committee also requested the drafting group to submit a preliminary report at its sixteenth session, taking into account the replies to the questionnaires prepared during the session and subsequently sent to States, national human rights institutions, international organizations, United Nations agencies, relevant treaty bodies and special procedures as well as international and national non-governmental organizations.

11. The drafting group submitted the preliminary report to the Advisory Committee at its sixteenth session in February 2016[[12]](#footnote-13). At this session, members of the Advisory Committee as well as States and non-governmental organizations provided useful comments and suggestions on the preliminary report. In its decision 16/3, the Advisory Committee took note of the preliminary report and requested the drafting group to recirculate the questionnaires to the various stakeholders that did not respond to the questionnaire in order to allow for better informed work. The Advisory Committee also noted that in light of the nature of the mandate, namely the implementation of the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members, the replies of States and national human rights institutions are especially welcome. It further requested the drafting group to submit a progress report at its seventeenth session. The present progress report is therefore submitted based on this request of the Advisory Committee.

12. As of July 2016, 54 responses to the questionnaires have been received from 11 States; 8 national human rights institutions and 35 national and international non-governmental organizations (NGOs)[[13]](#footnote-14). No responses were received from international organizations, United Nations agencies and relevant special procedures and treaty bodies. Subsequent to the submission of the progress report by the Advisory Committee and additional 3 responses were received from States, 1 from a national human rights institution and 8 from non-government organizations. It may be noted here that the majority of the responses from States came from leprosy non-endemic countries.

13. Two members of the drafting group of the Advisory Committee, namely Professor Okafor and Professor Soh, participated in an international symposium titled “Towards Holistic Care for People with Hansen’s Disease, Respectful of their Dignity” held during 9-10 June, 2016 at Vatican City jointly organized by the Pontifical Council for Health Care Workers, the Good Samaritan Foundation and the Nippon Foundation in cooperation with the Fondation Raoul Follereau, the Sovereign Order of Malta and the Sasakawa Memorial Health Foundation. The meeting brought together prominent representatives from different religious faiths, governments, medical experts, experts on human rights, organizations of persons affected by leprosy, international organizations working on leprosy issues and participants from civil society to discuss the medical and human rights aspects of leprosy. During this meeting, members of the drafting group had an opportunity to discuss and hear first-hand the testimonies of persons affected by leprosy and obtained relevant feedback on what measures they expect from their Governments in order to eliminate the stigma and discrimination they face as well as measures that should be taken to effectively implement the Principles and Guidelines at both the national and international levels. The relevant information gathered during this international symposium has been incorporated in this report.

 II. Leprosy as a disease: Misconceptions and reality

 A. Misconceptions

14. Throughout history leprosy has been feared and misunderstood. One of the major reasons for the stigma and discrimination directed against persons affected by leprosy and their family members is the deep rooted and various misconceptions that revolve around the understanding of leprosy as a disease both in the past and even in the present era despite being one of the least contagious human transmissible diseases. In the ancient era, leprosy was perceived by different societies, religious beliefs and cultural practices as being highly contagious, hereditary and received as a divine punishment. Moreover, the lack of scientific knowledge of the causative organism of the disease as well as its mode of transmission and lack of effective remedy, which often lead to different levels of physical disfigurement have also contributed to the stigma and discrimination against persons affected by leprosy and their family members[[14]](#footnote-15). For instance, in ancient India, religious laws prohibited contact with those affected by leprosy and punished those who married into their families, effectively ostracising those diagnosed with leprosy from the political, social and cultural life of the society[[15]](#footnote-16).This situation has been more or less similar across cultures all over the world where the disease occurred and was conceived in derogatory terms quite distinct from other diseases.

15. During the colonial period, the colonial powers in Asia, Africa, Latin America and the Pacific Islands advocated policies of mass segregation of persons affected by leprosy through the establishment of leprosy colonies and leprosaria mainly induced by the fear of the contagiousness of the disease and religious depictions equating the disease with ideas of sin and uncleanliness which resulted in those affected with the disease and their family members becoming outcasts from society[[16]](#footnote-17).

16. Even once it was established by Armauer Hansen in 1873 that the causative agent of the disease was an infectious bacillus, Mycobacterium leprae, the policy of isolation of persons affected by leprosy was further pursued due to the assertion that the disease was highly contagious although this was challenged by some medical experts of the time. The first international conference held in Berlin in 1897 recommended that isolation was the best means of preventing the spread of the disease and laws were passed to this effect in several countries thereby fostering the stigma and discriminatory attitudes on the part of the public against persons affected by leprosy and their family members[[17]](#footnote-18). For instance, in Japan several laws dating back to 1907 were issued for the compulsory segregation of persons affected by leprosy and national leprosariums were established. It was not until 1996 that the last of these laws, the revised Leprosy Prevention Law of 1953, was repealed in 1996 after concerted efforts were made by concerned medical and human rights experts and associations of persons affected by leprosy and their family members. Similarly in the United States the policy of quarantine and isolation measures for people affected by leprosy was first established in Hawaii in 1865 and the first legislation was passed in 1898, allowing for the establishment of a national leprosarium for the segregation of people affected by leprosy. This was effectively ended in 1997 when a law was passed to end compulsory isolation[[18]](#footnote-19). In other words, even in the post- second world war era, while scientific knowledge of the disease was at an advanced stage and an effective drug was discovered in the 1940s for the treatment of the disease, and decades later, multi-drug therapy (MDT) was discovered in the 1980s, clearly showing that the disease was scientifically and medically proven to be completely curable and not easily transmissible, the policy of forced isolation from society by way of quarantine, forced hospitalization and establishment of leprosaria were maintained in many countries thereby fostering the stigma and discrimination in the public mind and depriving people affected by leprosy as well as their family members of their human rights and dignity and reintegration into society[[19]](#footnote-20). Although leprosy as a disease is no longer a major public health problem in most countries today, the stigma and discrimination at the social level are still experienced by tens of millions of persons affected by the disease.

 B. The reality

17. Leprosy is a curable chronic infectious disease caused by the acid-fast, rod-shaped bacillus, Mycobacterium leprae. This organism was demonstrated as the causative agent of the disease by G. Armauer Hansen in 1873 and is now also known as Hansen’s disease. It mainly affects the cooler parts of the body such as the skin, respiratory mucosa and superficial nerves. The disease attacks peripheral nerves causing loss of movement and sensation in the hands, feet or face, which can lead to visible deformities and disabilities.

18. Leprosy is the least infectious disease of all communicable diseases and most people infected with the organism are thought not to develop the clinical disease. More than 85 per cent of persons affected by leprosy are non-infectious and do not spread the disease while over 95 to 98 percent of people in the world have a natural immunity to the disease. Leprosy is not hereditary. Leprosy is transmitted by airborne droplets from the nose and mouth during close and frequent contact with untreated cases. The disease progresses slowly and has an incubation period from two to twelve years. Symptoms can take as long as twenty years to develop.

19. With the advent of multi-drug therapy (MDT) in the 1980s, there is now an effective cure for leprosy. Since 1995, WHO has supplied MDT free of cost to persons affected by leprosy in all endemic countries, aiming to achieve a prevalence rate of less than 1 case per 10,000 population. Treatment with standard WHO MDT renders persons affected by leprosy non-infectious within a few days. Since the mid-1980s, prevalence of leprosy globally decreased from more than 5 million to less than 200,000 by 2015 and some 16 million people have been cured of the disease following the introduction of MDT.

 III. Summary of contents and status of the principles and guidelines

 A. Summary of contents of the principles and guidelines

20. The Principles and Guidelines consist of two parts: the first part titled “Principles” recognizes the basic human rights of persons affected by leprosy and their family members which are already enshrined in the Universal Declaration of Human Rights and in other relevant international human rights instruments such as 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. The second part entitled “Guidelines” translates the provisions set in the principles in concrete terms by providing the responsibilities of States to promote, respect, protect and ensure the full realization of all human rights for all persons affected by leprosy and their family members. The Principles and Guidelines are also modelled to meet the specific needs of persons affected by leprosy and their family members and the rights that are or may be denied them in countries globally.

21. Principle 1 reaffirms the right of persons affected by leprosy and their family members to be treated with dignity and their entitlement to all the rights specified in international human rights instruments. Principle 2 on non-discrimination provides for the rights of persons affected by leprosy and their family members not to be discriminated against on grounds of leprosy or having had leprosy. Principle 3 enunciates the principle that persons affected by leprosy and their family members have the same rights as everyone else with respect to marriage, family and parenthood while principles 4 and 5 stipulate the rights as everyone else in relation to citizenship and to participate in the political process. In relation to the right to work, principle 6 contains provisions on employment for persons affected by leprosy and their family members to have the right to work in an inclusive environment. On education, principle 7 provides the right to be admitted to schools or training programmes. Principle 8 provides for the right of persons affected by leprosy and their family members to develop their human potential to the fullest extent, and to fully realise their dignity and self-worth and Principle 9 provides that 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.

22. The second part, titled “Guidelines,” sets forth how States should implement the principles discussed above and is divided into 14 sections. Guideline 1 provides a number of obligations on States in relation to the realization and protection of the rights of persons affected by leprosy and their family members which include; implementation of legislative, administrative and other measures to modify, repeal or abolish laws, polices, customs and practices that discriminate directly or indirectly against persons affected by leprosy and their family members as well as laws that forcefully segregate such persons; ensure that institutions and authorities take steps to eliminate discrimination against persons on grounds of leprosy; take measures to ensure that persons affected by leprosy and their family members are able to realize the rights set out in the different human rights instruments and to consult with persons affected by leprosy and their family members when making decisions affecting them. Guideline 2 reiterates the provisions of equality and non-discrimination while Guideline 3 addresses the protection of the rights of women, children and other vulnerable persons affected by leprosy. Guideline 4 provides for the reunification of family members separated as a result of policies and practices on leprosy. Guideline 5 requires states to provide adequate living and housing standard to persons affected by leprosy and their family members including taking measures such as ensuring that persons affected by leprosy are reintegrated into the community, provision of social support and ensuring that they be allowed to live in leprosariums and hospitals if they so wish.

23. Guideline 6 is a rehash of principle 5 on the right of persons affected by leprosy and their family members to participate in the political process while Guideline 7 emphasizes support for the promotion of schemes to help with employment and vocational training of persons affected by leprosy. Guideline 8 is also an elaboration of principle 7 on the right to education. Guideline 9 requires States to remove derogatory terms like “lepers” from government publications. Guideline 10 encourages states to create access for persons affected by leprosy and their family members to public places including transport system, places of recreation, sports and worship. Guideline 11 requires States to provide access to health care on an equal basis as others to persons affected by leprosy; institute early detection programmes and treatments to prevent the development of stigmatic consequences associated with leprosy and provision of free leprosy treatment, psychological and social counselling. Guideline 12 provides for the economic social and cultural rights of persons affected by leprosy and their family members, such as provision of housing, financial assistance and vocational training. Guideline 13 of the United Nations Principles and Guidelines on Leprosy provides for States to increase knowledge and awareness about leprosy to the community, media and in schools. Finally, guideline 14 provides for States to designate a committee in charge of coordinating activities of persons affected by leprosy and their family members and encourages States to include measures they have taken to end discrimination against persons affected by leprosy and their family members in reports to relevant treaty bodies.

 B. The Principles and guidelines as international human rights standards

24. The Principles and Guidelines build upon and are essentially a re-statement of the core principles of international human rights law. Adopted by the Human Rights Council and endorsed by the United Nations General Assembly, the Principles and Guidelines constitute the standards of behaviour that have been deemed necessary for States to carry out their responsibility to prohibit all forms of discrimination against persons affected by leprosy and their family members.

25. 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 enshrined in the United Nations 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 or protected. Thus, even assuming, that the Principles and Guidelines are not legal binding on States *per se*, they still constitute persuasive authority with regard to State practice necessary to ensure the right to non-discrimination of persons affected by leprosy and their family members. In general terms, it may be underlined that aspects of the Guidelines are also binding on States which have ratified human rights treaties with similar obligations.

 IV. Review of the implementation of the principles and guidelines

26. This section is based on the responses received to the questionnaires by States, national human rights institutions, and national and international non-governmental organizations[[20]](#footnote-21) and forms the main basis for the review regarding what steps have been taken to date by States and other stakeholders towards the wider dissemination and more effective implementation of the Principles and Guidelines. The main thematic components of the Principles and Guidelines have been taken as the basis for this review.

27. It is to be noted that the overwhelming responses to the questionnaire came from national and international NGOs, particularly from individuals and associations of persons affected by leprosy and their family members. As mentioned earlier only a few responses were received from States, and national human rights institutions and most of these responses, particularly from States, came from non-endemic countries. Having said that, however, the responses received from organizations of persons affected by leprosy and international non-government organizations provide a more or less full picture of both positive measures taken by States concerned and gaps that need to be addressed towards the effective implementation of the Principles and Guidelines.

 A. Awareness raising and dissemination of the principles and guidelines

28. The responses received to the questionnaire so far reveal that, to date, States have not yet developed comprehensive policies and action plans that involve both government and non-government stakeholders in raising awareness about the issue of leprosy to overcome the stigma and discrimination towards persons affected by leprosy and their family members including awareness raising and dissemination of the Principles and Guidelines. However, there are several positive steps that have been taken by a number of States towards raising awareness about the issue of leprosy and promoting non-discrimination against persons affected by leprosy including the dissemination of the Principles and Guidelines at the national level.

29. In terms of a more systematic and coordinated way of raising awareness about the issue of leprosy and disseminating the Principles and Guidelines, the Government of Japan can be considered to have played an important role in this respect. Key points of the Principles and Guidelines have been translated into Japanese and are posted on the Ministry of Foreign Affairs website[[21]](#footnote-22). The human rights section of the Ministry of Justice undertakes public awareness activities on the Principles and Guidelines by holding “Parent-Child Symposium” on Hansen’s disease with the participation of students as panelists. It also distributes brochures of the Principles and Guidelines in Japanese prepared by the Centre for Human Rights Education and Training (a non-profit organization) which are also posted on its website[[22]](#footnote-23). The Ministry of Health, Labor and Welfare also organizes various symposia on the issue of leprosy and distributes awareness raising brochures titled “Hansen-byo no Mukogawa” (the other side of Hansen’s disease) for school children which provides facts about leprosy and Japan’s history of forcible isolation in the past. The Ministry of Education, Culture, Sports, Science and Technology also calls on medical schools across Japan to provide accurate medical knowledge on leprosy. Several museums that have been established at the thirteen national sanatoria in Japan also serve as important centres of information on the issue of leprosy and as lessons on Japan’s past experience of discriminatory practices against leprosy affected persons and their family members. The National Hansen’s Disease Sanatoria Resident’s Association-Zen-Ryo-Kyo- also believes that the Japanese Government is making efforts to conduct as much awareness raising as possible on the issue of leprosy at both the national and local levels [[23]](#footnote-24).

30. Some other States have also taken certain positive steps to raise awareness of the issue of leprosy and the dissemination of the Principles and Guidelines although such activities seem to have been undertaken sporadically or are limited to certain sectors within society. Such awareness-raising, promoting non-discrimination against persons affected by leprosy, has been undertaken by the National Leprosy Eradication and Control Programs under their respective Health Ministries and also by their National Human Rights Institutions, and have focussed mainly on training health workers and providing education to local communities. In addition to this, the Principles and Guidelines have also been disseminated through the print and electronic media and through organizing workshops and annual events such as the World Leprosy Day [[24]](#footnote-25).

31. Most of the awareness raising activities and the dissemination of the Principles and Guidelines including translation into local languages have been undertaken by the associations of leprosy affected persons themselves in their respective countries. However, they also point out that such awareness raising activities, including the use of the Principles and Guidelines as a guidepost for tackling discrimination against persons affected by leprosy and their family members, have been far from adequate or limited to certain sections of the society. Many non-governmental organizations have also pointed out that there have been few or no visible policies or action plans prepared by their respective governments to raise awareness on the specific issue of leprosy or the dissemination of the Principles and Guidelines at the national level, although there may be policies and strategies that are in place for promoting non-discrimination in a general manner or to specific groups, such as those challenged with disabilities, which may apply to persons affected by leprosy with disabilities[[25]](#footnote-26).

32. With respect to non-endemic countries or countries with few leprosy cases, the responses given were that though all are aware of the Principles and Guidelines, there has not existed a practical necessity of taking particular actions, mostly due to the favourable leprosy-related epidemiological situation in their respective countries.

 B. Participation and consultation in decision-making processes

33. The responses received show that some States have taken certain positive steps towards enabling persons affected by leprosy to participate and consult on issues that affect them and in decision-making processes on such matters.

34. In Japan, the Ministry of Health, Labor and Welfare of the Government of Japan holds an annual conference with representatives of persons affected by leprosy on measures to be taken regarding Hansen’s disease. In this conference, persons affected by leprosy give advice and suggestions on issues that concern them, as well as suggestions on improvement of policies that are in place. The Ministry takes into account the outcomes of the discussions at these annual meetings when formulating subsequent policies and laws [[26]](#footnote-27). The 2009 Act on the Promotion of Resolution of Hansen’s Disease Issues specifically provides that the government shall take the necessary measures to reflect the opinions of persons affected by Hansen’s disease and other relevant persons in the formulation and implementation of measures concerning persons affected by leprosy as well as the establishment of forums for consultations.

35. In India, organizations of persons affected by leprosy have a strong voice and are invited by the government to some related meetings at the district, state and national levels. These organizations have been able to influence government policies and measures to a certain extent but still have a long way to go. It has also been pointed out in the Indian case that self-help groups have sometimes been formed where peer group discussions are held and local communities decide about the support required by persons affected by leprosy and that there is better participation of leprosy affected persons on issues concerning them among organizations working in the field of leprosy[[27]](#footnote-28). In other words, a bottom-up approach initiated by representatives of persons affected by leprosy to influence government policies and in advocating changes to discriminatory legislation, as well as to participate in decision-making processes, seems to be the approach taken to date in India.

36. Similarly, in Brazil, the Movement for the Reintegration of Persons Affected by Hansen’s Disease (MORHAN), is a strong force at the national level and often has a seat at the National Health Council and also participates actively in the national/state/municipal health conferences. The organization undertakes evaluations every three years on the promises made by the government concerning the human rights and health care of persons affected by leprosy and has witnessed more openness on the part of the government in regard to policy and legislative matters. However, it is pointed out that the political platform for consultation and participation at the national level is still not adequate[[28]](#footnote-29).

37. However, the majority of the responses made by non-governmental organizations representing persons affected by leprosy in their respective countries note that there has been minimal or no consultations and participation in the government decision-making process to date concerning them, except that they themselves have formed self-help groups and are involved in local-level advocacy and in projects that affect them[[29]](#footnote-30).

 C. Civil and political rights

38. All of the responses received from States, national human rights institutions and non-governmental organisations invariably point out that the Constitutional provisions in their respective countries provide for the enjoyment of civil and political rights for their citizens without discrimination, including in relation to persons affected by leprosy and their family members. However, a significant number of the responses, particularly from the associations of persons affected by leprosy and international non-government organizations representing them in the respective countries, indicate that, in practice, the exercise of civil and political rights by persons affected by leprosy still leaves much to be desired and, in some cases, is curtailed by subsidiary laws.

39. In India, the right to stand for elections is curtailed at present under six Municipal and Panchayati Raj Acts (local level acts) of the States of Rajasthan, Andhra Pradesh, Orissa, Chattishgarh and Madhya Pradesh. This fact is corroborated by a decision passed by the Supreme Court of India in 2008 which upheld a decision of the lower court disqualifying a person affected by leprosy from contesting civic elections or hold municipal office by citing discriminatory provisions in place against persons affected by leprosy in a 2005 Orissa Municipal Act[[30]](#footnote-31). Moreover, although the right to citizenship and the right to vote are legally allowed for persons affected by leprosy, it is not easy to exercise such rights in practice for those living in the leprosy colonies since most of them cannot obtain a national identity card as proof of residence as they do not have rights to the land and houses they live in[[31]](#footnote-32). A similar concern has also been pointed out in the case of Myanmar where a high proportion of persons affected by leprosy with moderate or severe disabilities do not have a national identity card thereby being an obstacle to their right to vote[[32]](#footnote-33).

40. Many of the responses from associations of persons affected by leprosy point out that although their civil and political rights is constitutionally guaranteed and some governments have formulated policies in this respect, the actual exercise of such rights by persons affected by leprosy is made difficult because of the persistent stigma and discrimination existing in society, in particular against those persons who have visible signs of disability[[33]](#footnote-34). One case that stands out is of a man affected by leprosy in Brazil, who was denied a voting card by the registration officer because he was illiterate and required the assistance of the registration officer to affix his finger print[[34]](#footnote-35). Moreover, most of the NGOs also underline the need for their respective governments to take specific policy and legal measures to ensure the full enjoyment of civil and political by persons affected by leprosy.[[35]](#footnote-36)

41. In the case of Brazil, the government has a wide range of legislation ensuring the enjoyment of human rights by persons affected by leprosy. The independent Public Prosecutor’s Office is often called upon in case of violations of human rights against persons affected by leprosy. In many states, the Movement for the Reintegration of Persons Affected by Hansen’s Disease (MORHAN) and members of the International Federation of Anti-Leprosy Associations (ILEP) have created partnerships with the Government to not only review individual case of rights abuse against persons affected by leprosy but also ensure that public policies and laws related to Hansen’s disease are upheld by the Government[[36]](#footnote-37).

 D. Economic, social and cultural rights

42. Again, most of the responses indicate that the social, economic and cultural rights of every citizen, including persons affected by leprosy and their family members, are provided for in the Constitutions of their respective countries as well as in policies, guidelines and laws issued by some countries in this respect. However, many of the responses from NGOs point out that several of these core human rights are violated in practice and also cite specific cases of violations of the economic, social and cultural rights of persons affected by leprosy such as the right to marriage and found a family; the right to education; the right to work; the right to access public services; the right to adequate health care and the right to participate in political, social and cultural life because of the prevalent and institutionalized stigma and discrimination that exists in different sectors of the society.

43. With respect to the right to found a family, recent examples were given of two women who were forced to leave their homes and family in Nepal after being diagnosed with leprosy[[37]](#footnote-38). One other respondent from Nepal shared his own personal experience by saying, ‘I was forced to sign a divorce paper within four months of my marriage’[[38]](#footnote-39). Several responses from other NGOs also expressed that marriage and family break-ups occur in their countries when either of the spouses, particularly women, are diagnosed with leprosy[[39]](#footnote-40).

44. Discrimination at school, particularly against children coming from parents who have had leprosy has also been cited as a problem by several NGOs[[40]](#footnote-41). In China, for example, a case was mentioned where a primary school refused to accept 30 children, although they provided medical certificates. Some parents of students were also against their enrollment because their parents or grandparents were once affected by leprosy mainly because of fear of discrimination[[41]](#footnote-42). Another recent incident in Brazil was also mentioned where it was discovered that a public school was abandoned by professionals and students[[42]](#footnote-43). A nursing student in India was recently discriminated against at college since she developed early symptoms of leprosy[[43]](#footnote-44). Several cases of workers dismissed from their work place on grounds of having had leprosy were also cited by some NGOs[[44]](#footnote-45).

45. In the Democratic Republic of the Congo, persons affected by leprosy do not have the right to marry because of the belief that leprosy is transmissible and is a curse from God. Moreover, persons affected by leprosy are not allowed to bathe in the same water as other healthy people and are considered an economic burden to the family because leprosy is considered as an incurable disease[[45]](#footnote-46).

46. In India, it was mentioned that discrimination in the health sector for persons affected by leprosy still occurs. Two cases were cited where hospitals in Delhi denied admission for persons affected by leprosy, and in one of the instances, this led to the death of the patient[[46]](#footnote-47). A similar case of rejection and mistreatment by a hospital was also mentioned in Indonesia[[47]](#footnote-48).

47. Several responses from NGOs pointed out that discrimination with respect to the social, economic, and cultural rights of persons affected by leprosy and their family members is more pronounced in the case of persons with visible deformities[[48]](#footnote-49).

48. In India, it has been mentioned that laws enacted to ensure the rights of persons with disabilities also cover some categories of persons affected by leprosy but are difficult to exercise because of the scope and limits of the benefits[[49]](#footnote-50).

49. Most of the responses from NGOs indicate that there is an overall lack of measures by their respective Governments that address the social, economic and cultural rights of persons affected by leprosy and their family members and stress the importance for their respective Governments to issue policies and laws that address their specific needs to ensure and exercise their rights in this respect. They also point out that there still persists a host of attitudinal and structural barriers in society alongside a silent acceptance of age-old norms and practices of segregation and exclusion by society in their respective countries[[50]](#footnote-51).

 E. Women, children and other vulnerable groups

50. With respect to the promotion and protection of the human rights of women, children and other vulnerable groups of persons affected by leprosy and their family members, almost all of the responses generally state that the relevant national legal instruments, consistent with the obligations that States have under the relevant core human rights treaties that they are a party to, do bar discrimination against such groups.

51. Several responses have mentioned some positive steps that have been taken in their respective countries in regard to the protection and promotion of human rights of women, children and other vulnerable groups of persons affected by leprosy and their family members. In Japan, the Ministry of Justice Legal Affairs Bureau and its branches at the district level conduct various annual awareness raising activities on the human rights issues of women, children and older persons for persons affected by leprosy and their family members under different themes such as “Protect Women’s Rights”, “Protect Children’s Rights” and “Nurture a High Regard for Elderly People”. They also offer counselling services on human rights issues including for women, children and other vulnerable groups affected by leprosy and their family members and conduct investigation of suspected human rights violations in this regard and based on such investigations take appropriate measures[[51]](#footnote-52). It has also been pointed out that the 2009 Act on the Promotion of Issues Related to Hansen’s Disease covers women, children, older persons and other vulnerable groups and its full implementation would ensure the non-discrimination and promotion and protection of the human rights of such groups[[52]](#footnote-53).

52. In Rwanda, persons with disabilities including those affected by leprosy can submit application for work to all vacancies for vocational training. The notices of vacancies state that no discrimination is allowed. Non-discrimination at school against children from families of persons affected by leprosy is ensured while adults can also benefit from adult literacy programs on an equal basis with other adults[[53]](#footnote-54).

53. In India, a proposed new Bill on disability, if passed by the Government, will include recommendations on the reintegration of women and children with disabilities, and will go a long way in protecting the rights of women and children affected by leprosy. In addition to this, the proposed Bill recommended by the Law Commission of India clearly affords full protection of the rights of women, children and other vulnerable groups if acted upon by the Government[[54]](#footnote-55). It has also been mentioned that the National Human Rights Commission, in partnership with the Sasakawa-India Leprosy Foundation organized the Young Partners Program to sensitize school children on the issue of leprosy, so as to stop stigma and discrimination faced by persons affected by leprosy and their family members[[55]](#footnote-56). The National Human Rights Commission of India has also conducted workshops recently on the topic of discrimination against persons affected by leprosy and their family members and has passed several recommendations submitted to the Government including on the implementation of the Principles and Guidelines but still awaits actions by the Governments in this respect[[56]](#footnote-57).

54. However, most of the responses from associations of persons affected by leprosy and NGOs working with them have underlined the fact that although there may be policies and laws including laws for persons with disabilities that are applicable to women, children and other vulnerable groups, these policies and laws and some measure taken by their Governments have not been effectively implemented, the evidence being that the stigma and discrimination against women, children and other vulnerable groups still prevail within their respective societies. They therefore underline the importance of the need for Governments to take specific policy and legal measures in order to promote and protect the human rights of women, children and other vulnerable groups affected by leprosy and their family members[[57]](#footnote-58).

 F. Discriminatory policies and laws

55. The responses to the questionnaire shows that some States have taken positive steps in repealing or amending laws that discriminated against persons affected by leprosy and their family members including laws that provided for forced segregation and isolation of persons affected by leprosy and their family members[[58]](#footnote-59).

56. The Government of Japan repealed the 1953 revised Leprosy Prevention Law in 1996 and put an end to the policy of isolation and segregation of persons affected by leprosy and their family members. Persons affected by leprosy have since had the freedom to choose where to live. In 2001, the government issued a law to compensate interned persons in the leprosia. Subsequently, the Act on Promotion of Resolution of Issues Related to Hansen’s Disease, which came into force in 2009 (hereinafter “the 2009 Act”) was issued by the Government. This Act obliges the central and local governments to implement measures for the promotion of welfare, restoration of honor and other issues in order to realize a society free from discrimination including of women, children and other vulnerable groups. The 2009 Act also provides that no person shall act in a manner that discriminates against or infringes on any rights or interests of, persons affected by leprosy. It is believed that the full implementation of the 2009 Act will amount to the implementation of the Principles and Guidelines.

57. In Brazil, the last discriminatory law against persons affected by Hansen’s disease was repealed in the 1990s. In 2007, a bill was passed by the Government to provide financial support and compensation for persons affected by Hansen’s disease in leprosy colonies. This includes lifetime public pensions and access to quality leprosy services at all levels. Currently, legislation is being considered to provide similar support to children forcibly separated from their parents at birth in these leprosy colonies. It has also been pointed out that 2 out of the 27 States in Brazil have transferred property to the Hansen’s disease patients making them owners of the property within the leprosy colonies and in one State discussion is in progress to this effect but that one State has recently demolished public buildings and is attempting to relocate persons affected by leprosy from the colony to a farther region[[59]](#footnote-60).

58. Bangladesh enacted a law in 2011 repealing the “Lepers Act” of 1898 which was passed to isolate persons affected by leprosy from the society and from their own families[[60]](#footnote-61). China has repealed a law in 2011 which had prohibited persons affected by leprosy to conclude marriage and Ethiopia repealed a provision in the family which previously allowed dissolution of marriage on ground of leprosy[[61]](#footnote-62). In Rwanda, the National Commission for Human Rights participates in the review of laws tabled in the Parliament to ensure that no law is passed that violates the human rights of citizens including persons affected by leprosy and their family members[[62]](#footnote-63). In 2015, organizations of persons affected by leprosy in Nepal and other NGOs working closely with them lobbied the parliament not to pass a legislation which would have allowed the spouse of a person affected by leprosy to claim for a divorce. They were successful in stopping the law from being passed[[63]](#footnote-64).

59. On the other hand, in India, one of the serious gaps mentioned by both the National Human Rights Commission and all of the NGOs is the existence of several laws that are discriminatory against persons affected by leprosy and their family members[[64]](#footnote-65). In this respect, all have made reference to a very important recent step taken by the Law Commission of India, a recommendatory body to the Government of India on the issue of laws, produced a comprehensive report entitled “Eliminating Discrimination Against Persons Affected by Leprosy” in April 2015, which identifies several discriminatory laws against persons affected by leprosy and their family members, and calls for such laws to either be repealed or amended by the Government of India or its constituent State Governments[[65]](#footnote-66). Apart from the “Leprosy Act” which provided for the segregation of persons affected by leprosy and their family members from the general community, several laws provide that “leprosy” is a legitimate ground for divorce or separation between the spouses. Under the State Beggary Acts, among others, leprosy affected people are classified under the same category as persons suffering from lunacy. Generally, it is pointed out that around sixteen discriminatory laws against persons affected by leprosy and their family members are still in place in India[[66]](#footnote-67). In addition to this, in its report, the Indian Law Commission has also prepared a model draft legislation titled “Eliminating Discrimination against Persons Affected by Leprosy, which it has suggested be approved by the Government of India[[67]](#footnote-68). According to the information provided in the responses received, the Indian Law Commission Report has been submitted to the Parliament and is awaiting adoption by the Government. Very recently, the Ministry of Law and Justice of India has issued a notification of the Repealing and Amending Act 2016 repealing the 1898 “Lepers Act” of India[[68]](#footnote-69). However, it remains to be seen whether the Government will take the appropriate measures to repeal or amend the other discriminatory laws and pass the draft bill proposed by the Indian Law Commission in the future. Moreover, all respondents believe that if the recommendation made by the Law Commission of India is approved by the Government of India and implemented effectively, it would amount to implementing the Principles and Guidelines since in most respects the provisions recommended in the Act are in line with the Principles and Guidelines.

60. Although to date, India has been cited as a country that still retains several laws that are discriminatory against persons affected by leprosy and their family members, a recent study by the International Federation of Anti-Leprosy Associations (ILEP) reveals that several countries have discriminatory laws still in place which have not yet been repealed[[69]](#footnote-70).

61. Most of the responses from organizations of persons affected by leprosy and NGOs working with them have also pointed out that although the policies and laws in their respective countries may allow persons affected by leprosy and their family members to freely choose where to live, a host of attitudinal and structural stigma and discrimination prevailing in the society in which they live and the fear of being discriminated against significantly contributes as a barrier for the reintegration of persons affected by leprosy and their family members into society.

 G. Follow-up and monitoring the implementation of the principles and guidelines

 (i) National level

62. All responses to the questionnaire indicate that in no country has a national committee been established and there is no country that has formulated a comprehensive set of policies and other measures in the form of national action plans prepared as a basis to follow up the implementation of the Principles and Guidelines at the national level. However, some of the responses have noted that despite the absence of a specific national action plan or committee established at the national level, policies and laws have been put place in their respective countries that, if fully implemented, would amount to partial or full implementation of the Principles and Guidelines[[70]](#footnote-71).

63. On the other hand, almost all of the responses by organizations of persons affected by leprosy and their family members and NGOs working with them, as well as some of the national human rights institutions, underline the need for their respective Governments to develop specific measures to implement the Principles and Guidelines, mainly in the form of a time-bound national action plan, and to designate broad-based stakeholder committees from the national down to the community level. This can then form a basis for subsequent follow-up and reporting to a designated Government body on steps taken towards the implementation of the Principles and Guidelines in their respective countries. Furthermore, the responses received underline that persons affected by leprosy and their family members either as individuals or through their associations as well as NGOs and civil society organizations working closely with them should be actively involved and consulted at all levels and stages of the decision-making process in order for the Government and other stakeholders to adequately address the prevalent stigma and discrimination that persons affected by leprosy and their family members face and to follow up and report on the implementation of the Principles and Guidelines.

64. Most of the responses also point out that there should be a designated body within the Government that should coordinate the national action plan for the implementation of the Principles and Guidelines and point out in particular Ministries of Health and national human rights institutions in their respective countries that are already engaged or should be engaged directly or indirectly in promoting the human rights of persons and combatting stigma and discrimination of persons affected by leprosy and their family members.

65. Many of the responses have mentioned some of the priority measures that their respective Governments should take towards the implementation of the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members, among which are:

 (a) Promote awareness raising and dissemination of the principles and guidelines

66. Most of the respondents point out that awareness and dissemination of the Principles and Guidelines at the national level is either limited to certain sections of the society or is non-existent. Accordingly, they suggest that one of the priority areas is for their respective Governments to bolster their efforts to promote awareness and widely disseminate the Principles and Guidelines nation-wide, including information on the disease, treatment, discrimination and stigma faced by persons affected by leprosy and their family members with their active participation and in collaboration with stakeholders, both within the Government and other relevant social groups within the society, such as religious leaders, human rights bodies, the media, opinion makers and the like. In this regard, it has also been mentioned that issues incorporated in the Principles and Guidelines should be mainstreamed in school curricula and that the media play an active role in highlighting discriminatory issues of persons affected by leprosy and their family members and give wider coverage to advocacy programs.

 (b) Repeal of discriminatory laws

67. The other priority area mentioned in many of the responses is for Governments to take appropriate measures to repeal discriminatory laws in countries where such laws exist, as well as to formulate and implement policies and laws that ensure the protection of the human rights and dignity of persons affected by leprosy and their family members, in accordance with what is provided in the Principles and Guidelines. It is pointed out that such discriminatory policies and laws have reinforced the persistent discrimination against persons affected by leprosy and their family members in all spheres of social life, more particularly in the areas of education, work place and marriage.

 (c) Promote social integration and rehabilitation of persons affected by leprosy and their family members

68. It is underlined in most responses that concerted efforts should be made for the reintegration and rehabilitation of persons affected by leprosy and their family members through promotion of programs for those living in isolation both within leprosy colonies and in communities. In this respect, support for the rehabilitation of persons affected by leprosy and their family members and provision of subsidized education for children of persons affected by leprosy is emphasized.

 (d) Use of appropriate and dignified language

69. Many of the responses received have indicated that age-old misconceptions about leprosy as a disease that still persist to this day are being reinforced by the use of inappropriate and often denigrating language used to refer to persons affected by leprosy and their family members in many countries, both leprosy-endemic and non-endemic countries. The use of the term “leper” and its equivalent in other languages contributes to the on-going discrimination faced by persons affected by leprosy and their family members. It has been therefore strongly suggested that States and other social groups, including the media, come up with and use appropriate terminology that expresses the human dignity and respect for persons affected by leprosy and their family members. It has been suggested that terms such as persons affected by leprosy or Hansen’s disease are better expressions in the current context.

 (e) Empowerment of persons affected by leprosy and their family members

70. One of the cross-cutting priorities pointed out in most of the responses is that persons affected by leprosy and their family members should be considered as the primary stakeholders in combatting the disease and the stigma and discrimination they face. They have underlined that their involvement in the formulation and implementation of policies and any other measures that States undertake that directly or indirectly affect their lives would be a crucial step towards the recognition of their fundamental human rights and dignity and for the elimination of the stigma and discrimination that have persisted to date and as called for by the Principles and Guidelines that their respective States have adopted unanimously.

 (ii) International level

71. Most of the responses received have mentioned that, to date, there is an absence of a specific mechanism to follow-up and monitor the progress of the implementation of the Principles and Guidelines by States and other concerned stakeholders at the international level. They suggest that an appropriate body be established within the existing international human rights mechanism to follow-up and monitor the implementation of the Principles and Guidelines. Most of the responses have also pointed out that the appropriate mechanism for follow-up and monitoring of the implementation of the Principles and Guidelines should be within the auspices of the Human Rights Council which had already initiated and subsequently adopted the Principles and Guidelines, and which eventually led to its unanimous adoption by the United Nations Generally Assembly in 2010.

 V. Findings and recommendations

72. The Principles and Guidelines, which was unanimously adopted by the United Nations General Assembly in December 2010, upon the recommendations of the Human Rights Council, has been a milestone instrument towards affirming the human dignity and rights of persons affected by leprosy and their family members. Yet, although some States have taken certain steps towards its implementation, there still remains a lot to be done by States and other relevant stakeholders to ensure the full implementation of the Principles and Guidelines and to once and for all eliminate the discrimination, stigma and ostracization of persons affected by leprosy and their family members prevalent in many countries. In most cases, efforts made to date are often fragmented and limited to certain government sectors such as Health Ministries or national human rights institutions and are not done holistically or in a coordinated manner that involves other actors in society including persons affected by leprosy and their family members.

73. In most countries, it is persons affected by leprosy and their family members represented by their associations and those international organizations working closely with them who have been actively working to influence their own Governments and other stakeholders to effectively implement the Principles and Guidelines while the response by Governments to take actions to eliminate discrimination against persons affected by leprosy and their family members is at best lukewarm or absent in some cases. Indeed, due to this lack of effective and concerted State and societal actions needed to implement the Principles and Guidelines, various forms of discrimination that impede the exercise of the fundamental human rights of persons affected by leprosy and their family members still persist in many parts of the world to this day.

74. Although awareness of the Principles and Guidelines seems to exist to a certain degree in almost all countries, such awareness does not seem to be sufficiently widespread within all relevant Government sectors at all levels or the general population at large in the respective countries. It is also not being used as a guidepost for combatting discrimination and stigma against persons affected by leprosy and their family members.

75. In most countries there does not exist any comprehensive strategy, action plan or policy framework and no designated body to follow-up, monitor and report on the measures that have been taken to implement the Principles and Guidelines although in some countries one or more Government institution such as the Health Ministries or national human rights institutions have taken fragmented actions to follow-up the implementation of some aspects of the Principles and Guidelines. Thus, it can be concluded that little or no coordination exists at the national level to follow-up and monitor the implementation of the Principles and Guidelines. Moreover, full and meaningful participation of persons affected by leprosy and their family members at all levels of the decision-making process and activities on matters that directly or indirectly impact upon their lives, including in following-up on the effective implementation of the Principles and Guidelines, seems to be lacking in most countries.

76. Discriminatory policies and laws still exist in many countries and although the replies to questionnaires have not been able to specifically identify the existence of such discriminatory policies and laws, mainly due to lack of available information, there may be a need to review these in order to ensure that such policies and laws are changed or repealed. This situation may not only be limited to leprosy endemic countries, but may be manifested in non-endemic countries where leprosy is considered very rare and a “forgotten” disease. In addition to this, affirmative policies and laws that specifically address measures to eliminate stigma and discrimination against persons affected by leprosy and their family members and promote social inclusion in line with what is required by the Principles and Guidelines are lacking in most countries.

77. As has been gathered from most of the responses, inappropriate and offensive language that refers to persons affected by leprosy is still used in both leprosy endemic and non-endemic countries. This is sometimes perpetuated advertently or inadvertently by the media and in popular culture in certain countries.

78. At the international level, there is currently a clear absence of a specific follow-up and monitoring mechanism within the human rights machinery to assess and report on specific measures and progress made towards the effective implementation of the Principles and Guidelines. Most importantly, almost all of the responses received point out that there is a need to establish a follow-up mechanism at the international level, preferably within the human rights mechanism to monitor and report on measures that have been taken at the national level by States for the effective and full implementation of the Principles and Guidelines

79. Based on the above findings, the following recommendations are proposed for the wider dissemination and effective implementation of the Principles and Guidelines:

 (i). National level

80. States and relevant Government institutions at all levels should strengthen, promote and facilitate awareness raising campaigns and dissemination of the Principles and Guidelines as the main benchmark in the fight to eliminate the stigma and discrimination against persons affected by leprosy and their family members, in collaboration with representatives of persons affected by leprosy and their family members and all relevant actors, such as medical practitioners, educators, religious and community leaders, public figures and opinion makers, the media and all other relevant actors in society. In this respect, a sustained and proactive public education and awareness raising campaigns are necessary in order to do away with the unwarranted myths and superstitions surrounding leprosy as a disease, including in countries where leprosy is not a prominent issue. Mainstreaming the issue of leprosy in school curricula and the use of mass media providing information on new advances in leprosy treatment and that the disease is not easily transmissible or not infectious once treated is also important.

81. States should review and identify national policies, laws and discriminatory practices that may engender stigma and discrimination against persons affected by leprosy and their family members and amend or repeal such discriminatory laws. In addition to this, Governments should consider issuing policies and laws that prohibit any acts of discrimination and isolation against persons affected by leprosy and their family members, in line with what is provided in the Principles and Guidelines.

82. States should designate an appropriate body and establish a national committee that comprises of all stakeholders and that includes persons affected by leprosy and their family members in order to follow-up and monitor effective implementation of the Principles and Guidelines. In this respect, designating an already existing institution such as national human rights institutions, whose mandate is principally to ensure the promotion and protection of human rights of all citizens at the national level, or the respective Ministries of Health, under which the National Leprosy Eradication Programs are undertaken may be considered by States as viable options to coordinate, follow-up and monitor the measures taken by Government entities at all levels as well as other relevant actors towards the effective implementation of the Principles and Guidelines.

83. States should ensure and support the full and meaningful participation of persons affected by leprosy and their family members, including children, women and other vulnerable groups, at all levels of the decision-making process, or activities that have a direct or indirect impact in all aspects of their lives. This involvement provides a powerful message of recognition of the equal human dignity and rights for social inclusion of persons affected by leprosy and their family members and for eliminating the social stigma attached to them. “Nothing for us, without us” should be the motto that should be respected by all States concerned.

84. States should ensure the avoidance of the use of inappropriate and discriminatory languages that perpetuate the age-old stigma and social exclusion of persons affected by leprosy and their family members by all members of the society. In particular, the use of the term “leper” or its equivalent in other languages should once and for all be avoided, as the term evokes marginalization and rejection by society and also discourages those who need treatment from seeking help.

 (ii) International level

85. The Principles and Guidelines confirm and build upon the core principle of non-discrimination and constitute a milestone in upholding the human rights of persons affected by leprosy and their family members. They represent the standards of behaviour that are expected by States to achieve their responsibility to prohibit all forms of discrimination against persons affected by leprosy and their family members. The centrality of the principles of equality and non-discrimination in international human rights law and the adoption of the Principles and Guidelines by the United Nations human rights bodies carry authoritative weight as standards against which to measure States’ responsibilities with respect to persons affected by leprosy and their family members. Unfortunately, as the review in this study of the Advisory Committee reveals, various forms of discrimination against persons affected by leprosy and their family members continue to exist in many parts of the world to this day. Accordingly, it is recommended to establish a follow-up mechanism within the United Nations human rights machinery designed to encourage States and other relevant actors to bring their conduct in line with what is provided in the Principles and Guidelines.

86. Due to the multiple nature of discrimination and violation of human rights of persons affected by leprosy and their family members as well as to address their specific needs in terms of access to health care, education, employment and reintegration and rehabilitation into the society in a holistic manner, *it is recommended that a specific and dedicated mechanism be established to follow-up, monitor and report on progress made by States at the national level towards the effective implementation of the Principles and Guidelines.*

87. Existing special procedures deal only with certain aspects of human rights issues that may be associated with persons affected by leprosy and their family members. *It is* *therefore highly recommended that a special procedure mandate under the auspices of the Human Rights Council be created for the purpose of following up, monitoring and reporting on progress made and measures taken by States for the effective implementation.* Indeed, almost all responses received from organizations of persons affected by leprosy and NGOs working with them, including some national human rights institutions, have called for the establishment of such a mechanism under the auspices of the Human Rights Council. In this respect, the mandate holder should be able to have an independent access to information by conducting field visits to countries to gather information on progress made by States, as well as to develop further guidelines and manuals for use by States and other actors for the effective implementation of the Principles and Guidelines.

1. See, Report of the Sub-Commission on the Promotion and Protection of Human Rights on its fifty-sixth session, E/CN.4/2005/2 E/CN.4/Sub.2/2004/48, p.35, 21 October 2004. [↑](#footnote-ref-2)
2. A/HRC/Sub.1/58/CRP.7, p.14. [↑](#footnote-ref-3)
3. A/HRC/8/13 [↑](#footnote-ref-4)
4. A/HRC/10/62 [↑](#footnote-ref-5)
5. A/HRC/12/7 [↑](#footnote-ref-6)
6. A/HRC/15/30, annex [↑](#footnote-ref-7)
7. A/HRC/RES/15/10 [↑](#footnote-ref-8)
8. A/RES/65/215, 25 March, 2011 [↑](#footnote-ref-9)
9. See preamble, paras. 9 and 12, A/HRC/29/15. [↑](#footnote-ref-10)
10. See paras. 1 and 2, Ibid. [↑](#footnote-ref-11)
11. The members of the Drafting Group would like to thank Mr. Nathaniel Melaku, LLB , Law Faculty, Addis Ababa University, Dr. Izevbuwa Ikhimiukor, Post-Doctoral Fellow, Osgoode Law School, York University, Toronto, Canada and Professor Yozo Yokota for their valuable research input to this study. They would also wish to thank the Nippon Foundation for availing and facilitating crucial information and support during the preparation of this report. [↑](#footnote-ref-12)
12. A/HRC/AC/16/CRP.2 [↑](#footnote-ref-13)
13. Responses were received from: **States**- Algeria, Bahrain, Chile, El Salvador, Estonia, Japan, Qatar, Saudi Arabia, Thailand, Viet Nam and the United States; **national human rights institutions**- Egypt, India, Denmark, Montenegro, Rwanda, Serbia, Tanzania and Venezuela; **international and national non-governmental organizations**- the Nippon Foundation, Sasakawa Memorial Health Foundation, IDEA international, IDEA India, the Leprosy Mission International- Bangladesh (TLMIB), the Leprosy Mission Netherlands, NLR Brazil, MORHAN (Brazil), Corsohansen (Colombia), ENAPAL (Ethiopia), FOKAD ( DRC), GPDL (Indonesia), FAIRMED Foundation (Sri Lanka) and Zen-Ryo-Kyo (Japan), HANDA Rehabilitation (China), the Leprosy Mission (Myanmar), Fontilles (India), Lepra-Bangladesh, Fontilles-Nicaragua, TLM-Niger, TLM-Nepal, LEPRA Society-India, NLR-Mekong, the Leprosy Mission England and Wales, TLM-Chad, IDEA-Nepal, Marcial Escobar and Mathias Duck (Paraguay), Sierra Leone, PerMaTa (national-Indonesia), PerMaTa, South Sulawesi-(Indonesia), YPPCK-Java, (Indonesia), Sole-(Angola) . [↑](#footnote-ref-14)
14. van Brakel, WH and Galarza, BM, Infectious diseases: a case study of leprosy-related stigma, pp.141-144, 2014: available at http://www.researchgate.net/publication/261179858\_Infectious\_diseases\_a\_case\_study\_of-leprosy-related-stigma. [↑](#footnote-ref-15)
15. Dogra, S, Narang, T and Kumar, B. Leprosy-evolution of the path to eradication, Indian J Med Res, 137, 2013, p.16. [↑](#footnote-ref-16)
16. Awofeso, N. Leprosy: International Public Health Policies and Public Health Eras, Adm Sci, 2011, pp.36-37. [↑](#footnote-ref-17)
17. Ibid, p37. See also, Mwani, R. The Island of the Unclean: Race, Colonialism and “Chinese Leprosy” in British Columbia, 1891-1924, Law, Social Justice and Global Development 2003, avaliable at: http://elj.warwick.ac.uk/global/03-1/mawani.html. [↑](#footnote-ref-18)
18. Sato, H. and Frantz, EJ. Termination of Leprosy isolation policy in the US and Japan, Science, policy changes, and the garbage can model, BMC International Health and Human Rights, vol. 5, No.3, available at: http://www.biomedcentral.com/1472-698X/5/3; Response to questionnaire by the Nippon Foundation. [↑](#footnote-ref-19)
19. Ibid. [↑](#footnote-ref-20)
20. Some of the responses received are not reflected in this progress report because they were not available in English or were received late for this report. They will be reflected in the subsequent report once translated versions are received. [↑](#footnote-ref-21)
21. Responses from the Government of Japan and the Nippon Foundation. [↑](#footnote-ref-22)
22. Ibid. [↑](#footnote-ref-23)
23. Responses by the Government of Japan, the Nippon Foundation and Zen-Ryo-Kyo [↑](#footnote-ref-24)
24. Reponses from Saudi Arabia, NHRIs of Rwanda, Tanzania and Egypt and India and Vietnam [↑](#footnote-ref-25)
25. Responses from GPDL-Indonesia; Fondation Kalipa-DRC; Fairmed- Sri Lanka, ENAPAL-Ethiopia, HANDA-China, Fontilles-Nicaragua, the Leprosy Mission-Myanmar. [↑](#footnote-ref-26)
26. Responses from the Government of Japan, Nippon Foundation, Zen Ryo Kyo [↑](#footnote-ref-27)
27. Responses from the National Human Rights Commission-India; LS-India and APAl-India [↑](#footnote-ref-28)
28. Responses from MORHAN and NLR Brazil [↑](#footnote-ref-29)
29. Responses from, FAIRMED-Sri Lanka; Fondation Kalipa-DRC; HANDA Rehabilation- China; GPDL- Indonesia; Marcial Escobar-Parguay; the Leprosy Mission-Myanmar; Corsohansen and Felahansen-Colombia; TLM-Nepal and IDEA-Nepal; Lepra Bangladesh, ENAPAL/Ethiopia. [↑](#footnote-ref-30)
30. Response from the Leprosy Mission Trust, India. [↑](#footnote-ref-31)
31. Ibid. [↑](#footnote-ref-32)
32. Response from the Leprosy Mission, Myanmar [↑](#footnote-ref-33)
33. Responses from Lepra Bangladesh; NLR Mekong-Vietnam; NLR-Brazil and MORHAN-Brazil; Mathias Duck-Paraguay; the Leprosy Mission International-Bangladesh. [↑](#footnote-ref-34)
34. Response from NLR-Brazil. [↑](#footnote-ref-35)
35. Responses from HANDA-China; the Leprosy Mission International-Bangladesh; GPDLI-Indonesia; FOKAD-DRC; Fontilles-Nicaragua; Felahansen-Colombia. [↑](#footnote-ref-36)
36. Responses from NLR-Brazil and MORHAN-Brazil. [↑](#footnote-ref-37)
37. TLM-Nepal. [↑](#footnote-ref-38)
38. Amar B. Timalsina, IDEA-Nepal. [↑](#footnote-ref-39)
39. Responses from IDEA-India; FAIRMED-Sri Lanka; TLM Niger. [↑](#footnote-ref-40)
40. Response from TLM-Nepal, MORHAN-Brazil; TLM-Niger; GPDL-Indonesia; IDEA-India; HANDA-China, Corsohansen-Colombia. [↑](#footnote-ref-41)
41. Response from HANDA-China [↑](#footnote-ref-42)
42. Response from MORHAN-Brazil [↑](#footnote-ref-43)
43. Response from IDEA-India [↑](#footnote-ref-44)
44. Response from NRL-Brazil; FAIRMED-Sri Lanka; TLM-Nepal; IDEA-Nepal;TLM-Niger [↑](#footnote-ref-45)
45. Response from Fondation Kalipa-DRC [↑](#footnote-ref-46)
46. Response from TLMTI-India [↑](#footnote-ref-47)
47. Response from GPDL-Indonesia [↑](#footnote-ref-48)
48. Response from IDEA-India; Lepra-Bangladesh; TLM-Nepal; Fontilles-Nicaragua [↑](#footnote-ref-49)
49. Response from TLMTI-India [↑](#footnote-ref-50)
50. Responses from Corsohansen-Colombia; Felahansen-Colombia; Leprosy International-Bangladesh; Lepra-Bangladesh; TLM-Nepal; TLM-Niger; Leprosy Mission Trust-India; IDEA-India; Fondation Kalipa-Congo; FAIRMED-Sri Lanka. [↑](#footnote-ref-51)
51. Response from Government of Japan. [↑](#footnote-ref-52)
52. Response from Nippon Foundation-Japan. [↑](#footnote-ref-53)
53. Response from CNDP-Rwanda [↑](#footnote-ref-54)
54. Response from Leprosy Mission Trust India [↑](#footnote-ref-55)
55. Response from NHRC-India [↑](#footnote-ref-56)
56. Response from IDEA-India [↑](#footnote-ref-57)
57. Response from IDEA-Nepal; Fondation Kalipa-DRC; ENAPAL-Ethiopia; HANDA Rehabilitation-China; IDEA-India; Leprosy Mission Trust-India; Leprosy Mission Bangladesh; MORHAN-Brazil; Fontilles-India; TLM-Nepal; NLR-Mekong [↑](#footnote-ref-58)
58. Responses by Japan, Vietnam and CNDP-Rwanda. [↑](#footnote-ref-59)
59. Response from MORHAN –Brazil and NLR Brazil [↑](#footnote-ref-60)
60. Response from Lepra-Bangladesh. [↑](#footnote-ref-61)
61. Response from HANDA Rehabilitation-China and ENAPAL-Ethiopia. [↑](#footnote-ref-62)
62. Response from National Human Rights Commission (CNDP)-Rwanda. [↑](#footnote-ref-63)
63. Response from IDEA-Nepal; TLM-Nepal. [↑](#footnote-ref-64)
64. Response from NHRC-India; Leprosy Mission Trust-India; IDEA-India; Fontilles-India; Leprosy Service-India. [↑](#footnote-ref-65)
65. See, Law Commission of India (2015), Report No.256, “Eliminating Discrimination Against Persons Affected by Leprosy” available at http//lawcommissionofindia.inc.in/reports/Report256.pdf. [↑](#footnote-ref-66)
66. Ibid. [↑](#footnote-ref-67)
67. Response from India L. Commission Report, also responses by Leprosy Mission Trust-India and LS-India [↑](#footnote-ref-68)
68. See, The Gazette of India, “The Repealing and Amending Act” (May, 2016), avalable at:lawmin.nic.in/Id/Act23of2016RepealingandAmending.pdf. [↑](#footnote-ref-69)
69. See, https:/www.fairmed.ch/en/current\_issues/news/?97/A-new-study-reveals-People-suffering-from-leprosy-are-discriminated-against-by-the-law; also ILEP has currently initiated a research to identify the status of discriminatory laws in place which will be reflected in the subsequent final report. [↑](#footnote-ref-70)
70. Responses received from Japan, Rwanda and Viet Nam. [↑](#footnote-ref-71)