

A Handbook for Parliamentarians

Eliminating Discrimination Against Persons Affected By Leprosy and Their Families



The Nippon Foundation

www.nippon-foundation.or.jp/en/

Written by Takahiro Nanri with Jonathan Lloyd-Owen

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Think about leprosy, think about people.



Ram Barai Sah

Board member of the Association of People Affected by Leprosy, India

I discovered I had leprosy when I was 10. I was abandoned in a hut about 1 kilometer from my home. All alone, I had no food and survived by begging. I thought about killing myself many times. By chance, after two years, a person affected by leprosy passed by and told me there was a place I could go to be cured. It was a

turning point in my life. I was treated, I studied hard and I married someone I met there. Now we have a shop and have been able to educate our sons. This is the happiest I have been. But there have been times when I and even my sons have been refused tea. Prejudice is difficult to eradicate. We want to change society.



Naima Azzouzi

President of an organization of people affected by leprosy, Morocco

After my parents died within a short time of each other, this hospital room became my home because I had nowhere else to live. From 1990, this was my bed for 10 years. I was without hopes or dreams. I felt like I had been thrown away. But even worse

was the fear I felt at venturing out of the hospital. As time went by, I came to think there needed to be a way to help people with leprosy find work. I created an organization and now my goal is to expand its activities.



Yohei Sasakawa
Chairman, The Nippon Foundation

I am most grateful that the Inter-Parliamentary Union has endorsed the 2017 Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy. Parliamentarians have a vital part to play in working to amend or abolish outdated legislation that discriminates unjustly on the grounds of leprosy. Also, through your words and deeds, you can play an influential role in raising societal awareness about leprosy and helping to dispel the myths and misconceptions that allow discrimination to flourish. I hope that this handbook will serve to guide you in this work. I will be delighted if it brings closer the day when the world is free of leprosy and the discrimination that accompanies it.



Hon. Saber H. Chowdhury MP
President, Inter-Parliamentary Union

Protecting and promoting human rights is one of the priorities of the Inter-Parliamentary Union (IPU), the world organization of national parliaments. It was therefore without hesitation that the IPU Executive Committee decided to endorse the 2017 Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy. As parliamentarians, one of the principal tools at our disposal is legislation. We constantly review how it can be used to ensure a better life for the people we represent; we also have a responsibility to examine existing laws and amend or repeal any that are discriminatory. I am grateful to the Nippon Foundation for producing this handbook and for drawing parliamentarians' attention to the issues that impact the lives of persons affected by leprosy today. I am sure it will prove invaluable to us in our mission.

This handbook has been published in conjunction with the 2017 Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy, launched on 30 January 2017 in New Delhi, India. The annual appeal, endorsed this year by the Inter-Parliamentary Union, is an initiative of The Nippon Foundation.

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What is leprosy?

- ▶ Leprosy is curable.
- ▶ Treatment is available free of charge throughout the world.
- ▶ Leprosy is not highly infectious.
- ▶ There are no grounds for isolating a person with leprosy.

Leprosy is an infectious disease affecting the skin and peripheral nerves caused by the bacillus *M. leprae*. Common initial symptoms are numb patches on the skin. As the disease progresses, it can lead to loss of sensation in the hands and feet, resulting in injuries that become infected and cause permanent disability. Without cure until the 20th century, leprosy's disfiguring effects, fears that it was highly contagious or even that it was divine punishment exposed those who developed the disease to severe discrimination.

Leprosy is thought to spread via droplets from the nose and mouth during close and frequent contact with a person who has the disease but has not been treated. However, most people will never develop leprosy, even if they are exposed to the bacteria. The disease is cured with a course of multidrug therapy (MDT), which is available free of charge throughout the world. Early diagnosis and prompt treatment with MDT helps reduce the risk of disability. In some parts of the world, leprosy is known as Hansen's disease, so-called after Dr. Gerhard Armauer Hansen, the Norwegian doctor who discovered *M. leprae* in 1873.



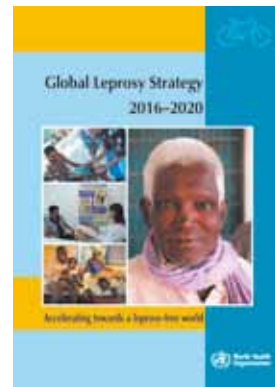
M. leprae (top); the effects of the disease (center); MDT (bottom)



In times past, those who developed leprosy were often isolated on islands or banished to other remote locations to protect the rest of the population from the disease. Such island colonies were found all over the world.

TIMELINE	
1500 B.C.	In India, texts describe a disease that appears to be leprosy.
1000–1400	The leprosy epidemic in Europe reaches its peak.
1500–1800	Leprosy spreads from Europe to Central and South America. Leprosy spreads from Africa to South America.
1700–1800	Leprosy spreads from Europe to North America.
1850–1930	Leprosy spreads from Asia to Pacific island countries.
1873	Dr. Gerhard Armauer Hansen of Norway discovers the bacillus <i>M. leprae</i> .
1894	Carville Leprosarium opens in Louisiana, the United States.
1897	The 1st International Leprosy Congress is held in Berlin. It recommends a policy of isolating patients.
1941	Promin, a sulfone drug, is successfully used as a treatment for leprosy at Carville Leprosarium. By the 1950s, it has been superseded by dapsone.
1954	French journalist and philosopher Raoul Follereau declares the last Sunday in January as World Leprosy Day.
1958	The 7th International Leprosy Congress held in Tokyo recommends discontinuing the policy of isolation.
1981	A WHO study group recommends multidrug therapy (MDT) as the treatment for leprosy, in response to growing resistance to dapsone.
1985	Leprosy is still a public health problem in 122 countries, defined by the WHO as a disease prevalence rate of over 1 case per 10,000 population.
1991	The 44th World Health Assembly adopts a resolution to eliminate leprosy as a public health problem by 2000.
1994	The Nippon Foundation announces it will distribute MDT free of charge around the world for five years from 1995 to 1999. The Novartis Foundation assumes this role from 2000.
1999	Carville Leprosarium closes.
2006	The annual Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy, an initiative of The Nippon Foundation, is launched.
2008	The UN Human Rights Council unanimously adopts a resolution on elimination of discrimination against persons affected by leprosy and their family members.
2010	The UN General Assembly unanimously adopts a resolution on elimination of discrimination against persons affected by leprosy and their family members, accompanied by Principles and Guidelines.
2013	An International Leprosy Summit held in Thailand issues the Bangkok Declaration Towards a Leprosy-free World, signed by the health ministers of 17 high-burden leprosy countries.
2016	“Towards Holistic Care for People with Hansen’s Disease, Respectful of Their Dignity,” a symposium hosted by the Vatican, calls on leaders of all faiths to contribute to the elimination of discrimination as a matter of urgency. The 19th International Leprosy Congress is held in Beijing, China, on the theme “Unfinished Business: Stopping transmission, preventing disability, promoting inclusion.”
2017	The 12th Global Appeal is launched in New Delhi, India, endorsed by the Inter-Parliamentary Union.

Leprosy in the world



www.wpro.who.int/leprosy/documents/globalleprosystrategy2016-2020.pdf



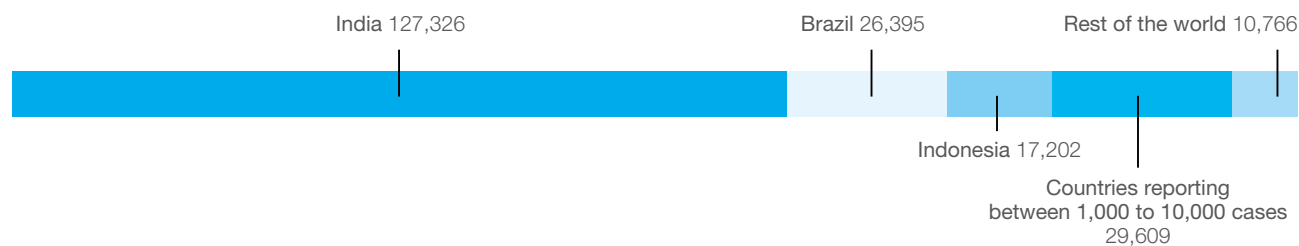
At the beginning of the 1980s, there were over 5 million registered leprosy patients worldwide. Following the introduction of multidrug therapy (MDT), there has been a drastic reduction in numbers. In recent years, annual new cases have hovered around the 200,000 mark.

In 2015, there were 210,758 new cases of leprosy reported to the WHO. The top three reporting countries were India (127,326 cases), Brazil (26,395 cases) and Indonesia (17,202 cases). Together with Bangladesh, Democratic Republic of Congo, Ethiopia, Madagascar, Mozambique, Myanmar, Nepal, Nigeria, Philippines, Sri Lanka and Tanzania, which each reported between 1,000 and 10,000 cases, these 14 countries represented 95% of the global leprosy burden.

The WHO's *Global Leprosy Strategy 2016-2020* sets the goal of achieving the following targets by 2020:

- Reduction in the rate of newly diagnosed cases with visible deformities to less than 1 per million population.
- Reduction in the number of children with visible deformities at time of diagnosis to zero.
- Reduction in the number of countries with legislation allowing discrimination on the basis of leprosy to zero.

Annual New Case Numbers Worldwide (2015)



Number of persons treated with MDT since 1985



Number of registered leprosy patients on treatment (December 31, 1985 / December 31, 2015)



Proportion of new cases with visible deformity (2015)



Proportion of children among new cases (2015)



Proportion of women among new cases (2015)



As of December 2016, Brazil was the only country with a population of more than 1 million that had yet to eliminate leprosy as a public health problem, with elimination defined as a prevalence rate of below 1 case per 10,000 people. But leprosy still presents a challenge in other countries. Endemic states, regions and “hotspots” of the disease exist at sub-national level, transmission of the disease is ongoing, and many people already cured of leprosy are left requiring ongoing care for disabilities and residual complications.

What sets leprosy apart from many other diseases is that even after an individual has been cured, he or she—and other family members also—may suffer stigma and discrimination. Reasons for this include the fact that the public may not understand that leprosy is a curable disease, or mistakenly believe that leprosy runs in the family, or because an individual has been left visibly disfigured and disabled due to delayed diagnosis and treatment. Even today, there are cases of people forced to leave home because of leprosy, who find themselves ostracized by mainstream society. Opportunities for education, employment and marriage can be severely restricted, and some must turn to begging for a living.

Unfortunately, old perceptions of the disease die hard and are reinforced by stigmatizing language. The offensive term “leper” used to describe someone with the disease also carries the meaning of an outcast, sinner or a person who is rejected by others for moral or social reasons. Such terminology contributes to the discrimination that people affected by leprosy face and discourages those in need of treatment from seeking help.



At different times and places, people affected by leprosy have faced discrimination and prejudice due to misconceptions that the disease is incurable, highly infectious, a curse—and also because of its physical impact.

Leprosy and human rights

In 2003, The Nippon Foundation first approached the Office of the UN High Commissioner for Human Rights (OHCHR) seeking to have leprosy taken up as a human rights issue. Since then, the foundation, in cooperation with organizations of persons affected by leprosy, NGOs, researchers, governments and other bodies, has worked with the UN Commission on Human Rights and its successor the UN Human Rights Council on this issue. As a result of these efforts, resolutions on elimination of discrimination against persons affected by leprosy and their family members were adopted by the Human Rights Council in 2008, 2009, 2010 and 2015, and by the UN General Assembly in 2010. The General Assembly resolution noted with appreciation Principles and Guidelines for achieving the goals of the resolution drawn up by the Human Rights Council Advisory Committee.

UN Human Rights Council resolutions on leprosy (2008-2015)

Resolution 8/13

8th session of Human Rights Council (2-18 June 2008)

Clearly states that leprosy should be recognized as a human rights issue and makes the following recommendations: 1) Calls on governments to take measures to eliminate discrimination; 2) Requests OHCHR to include the issue of leprosy discrimination in its human rights education and awareness-raising activities; 3) Requests the Human Rights Council Advisory Committee to formulate a draft set of Principles and Guidelines for the elimination of leprosy-related discrimination and submit it by September 2009.

Resolution 12/7

12th session of Human Rights Council (14 September – 2 October 2009)

Requests the OHCHR to collect the views of governments, relevant UN bodies, NGOs, representatives of persons affected by leprosy and other relevant actors on the draft set of Principles and Guidelines drawn up the Human Rights Council Advisory Committee, and requests the Advisory Committee to finalize the draft set of Principles and Guidelines, taking into account these views, for submission to the Council by its 15th session.

Resolution 15/10

15th session of Human Rights Council (13 September – 1 October 2010)

Expresses appreciation to the Advisory Committee for finalizing the Principles and Guidelines, requests the OHCHR to distribute them as appropriate, encourages governments, UN bodies, national human rights institutions and all relevant actors in society (including hospitals, schools, universities, religious groups, businesses and media) to give due consideration to them, and invites the UN General Assembly to consider the issue of leprosy-related discrimination.

Resolution 29/5

29th session of Human Rights Council (15 June – 3 July 2015)

Mandates the Advisory Committee to undertake a study reviewing implementation of the Principles and Guidelines, together with the obstacles thereto, and submit a report containing practical suggestions for their wider dissemination and more effective implementation to the Council at its 35th session in June 2017.

“ I think of the fight against leprosy in terms of the two wheels of a motorcycle. The front wheel represents our efforts against the disease and the back wheel our efforts against discrimination. Unless both wheels turn at the same time, we won’t make progress.

Yohei Sasakawa, Chairman, The Nippon Foundation;
WHO Goodwill Ambassador for Leprosy Elimination

Principles and Guidelines

Gist of the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members

1. Principles

Persons affected by leprosy and their family members should be treated as people with dignity and are entitled to all human rights and fundamental freedoms.

2. Guidelines

- States should promote, protect and ensure the full realization of all human rights and fundamental freedoms for all persons affected by leprosy and their family members without discrimination on the grounds of leprosy.
- States should recognize that all persons are equal before and under the law.
- States should pay special attention to the promotion and protection of the rights of women, children and members of other vulnerable groups who have or have had leprosy.
- States should, where possible, support the reunification of families separated as a result of past policies and practices relating to leprosy.
- States should promote the enjoyment of the same rights for persons affected by leprosy and their family members as for everyone else, allowing their full inclusion and participation in the community.
- States should encourage and support opportunities for vocational training.
- States should promote equal access to education
- States should provide persons affected by leprosy with free or affordable health care of a standard on a par with that provided persons with other diseases.
- States should recognize the rights of persons affected by leprosy to an adequate standard of living, and should take appropriate steps to safeguard and promote that right.
- States should formulate policies and plans of action to raise awareness of and foster respect for the rights and dignity of persons affected by leprosy.

www.mofa.go.jp/files/000078250.pdf



Empowering people affected by leprosy

Around the world, groups and networks made up primarily of persons affected by leprosy have formed over the years in order to make their voices heard, influence decisions that directly affect their lives, fight the prejudice and discrimination they encounter and regain their right to full and equal participation in society.

International

IDEA (International Association for Integration, Dignity and Economic Advancement); Est. 1994

IDEA has branches in Angola, Brazil, China, DR Congo, Ethiopia, Ghana, India, Japan, Kenya, Mozambique, Nepal, Nigeria, Norway, Paraguay, Philippines, South Korea, Sudan, Taiwan and the U.S.A.

www.idealprosydignity.org/



Brazil

MORHAN (Movement for the Reintegration of People Affected by Hansen's Disease); Est. 1981

www.morhan.org.br/



India

APAL (Association of People Affected by Leprosy); Est. 2006
<http://apalindia.org.in/>



Ethiopia

ENAPAL (Ethiopian National Association of Persons Affected by Leprosy); Est. 1996



Indonesia

PerMaTa (Association for Independence of People Affected by Leprosy); Est. 2007



Philippines

CLAP (Coalition of Leprosy Advocates of the Philippines); Est. 2012



Raising awareness

World Leprosy Day

French journalist and philosopher Raoul Follereau inaugurated World Leprosy Day in 1954. It is commemorated on the last Sunday in January, when governments, NGOs, organizations of persons affected by leprosy and others participate in activities to raise global awareness of leprosy. In India, the anniversary of the martyrdom of Mahatma Gandhi on January 30 is observed as Anti-Leprosy Day, to commemorate Gandhi's selfless efforts and personal involvement in caring for those affected by the disease.

Global Appeal



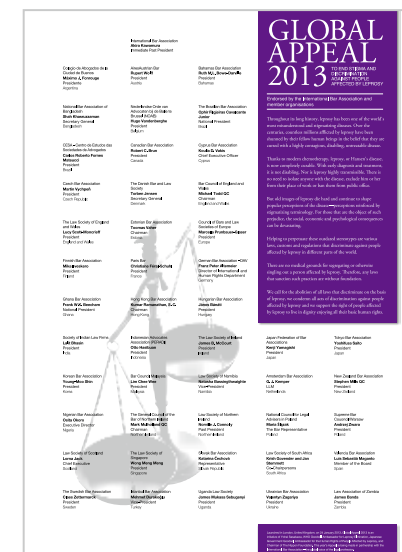
Global Appeal 2015 (Tokyo, Japan)

The Nippon Foundation initiated an annual Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy in 2006, launched on or near World Leprosy Day each year. Global Appeal 2017 is endorsed by the Inter-Parliamentary Union. Past appeals have received the backing of national human rights institutions, faith leaders, executives of leading companies, the World Medical Association, the International Bar Association, the International Council of Nurses and Junior Chamber International, among others.

Think Leprosy Now

In 2015, The Nippon Foundation began a campaign called "Think Leprosy Now", inviting people from different walks of life to contribute short messages promoting greater awareness of leprosy and calling for an end to discrimination.

<http://leprosy.jp/thinknow/?lang=en>



Global Appeal 2013, endorsed by the International Bar Association

Organizations involved in leprosy work

www.searo.who.int/entity/global_leprosy_programme/en/



www.ohchr.org/EN/HRBodies/HRC/pages/hrcindex.aspx



www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/Leprosy.aspx



www.leprosy-ila.org/do.php/Home



www.ilepfederation.org/



World Health Organization (WHO)

Spearheading international efforts against leprosy, the WHO's Global Leprosy Programme (GLP) is based in New Delhi at the WHO's South-East Asia Regional Office. In late August/early September, the GLP releases its annual global leprosy update in the *Weekly Epidemiological Record*. It revises its global leprosy strategy every five years.

UN Human Rights Council

The Human Rights Council is an inter-governmental body within the United Nations system responsible for strengthening the promotion and protection of human rights around the globe and for addressing situations of human rights violations and make recommendations on them. In 2006, the Human Rights Council replaced the former Commission on Human Rights. The Human Rights Council has an Advisory Committee formed of 18 experts that functions as a think tank for the Council.

International Leprosy Association (ILA)

The International Leprosy Association (ILA), founded in 1931, is a professional society of physicians, scientists, and individuals and organizations, working to understand and relieve the problems associated with leprosy. From its inception, the primary goal of the ILA has been to provide up-to-date, medically and scientifically accurate information about the disease. The key event in its calendar is the International Leprosy Congress, which the ILA currently organizes every three years. The congress brings together scientists, researchers, health personnel, partner organizations and individuals affected by leprosy to interact, discuss and share the latest developments in the leprosy world.

International Federation of Anti-Leprosy Associations (ILEP)

Founded in 1966, the International Federation of Anti-Leprosy Associations (ILEP) is a federation of anti-leprosy NGOs supporting medical, scientific, social and humanitarian activities for the relief and rehabilitation of persons affected by leprosy. Working with the WHO, ministries of health, governments, foundations and other NGOs, ILEP's 15 members operate in 67 countries.

ILEP members

AIFO (Associazione Italiana Amici di Raoul Follereau), Italy; ALM (American Leprosy Missions), United States; ALRA (Austrian Leprosy Relief Association), Austria; DAHW (German Leprosy and Tuberculosis Relief Association), Germany; DFB (Damien Foundation Belgium), Belgium; FAIRMED, Switzerland; Fontilles, Spain; FRF (Fondation Raoul Follereau), France; LEPPA, United Kingdom; NLR (Netherlands Leprosy Relief), Netherlands; Ordre de Malte, France; SMHF (Sasakawa Memorial Health Foundation), Japan; SLC (Leprosy Relief Canada), Canada; TLMI (The Leprosy Mission International), United Kingdom.

Novartis Foundation

Novartis Foundation pioneers innovative health care approaches that have a transformational impact on the health of the poorest populations. Diseases that are the focus of its efforts include cardiovascular disease, malaria and leprosy. In the field of leprosy, Novartis pursues a strategy of early diagnosis and treatment, development of new diagnostic tools, contact tracing and preventative treatment, and strict epidemiological surveillance. Since 2000, Novartis Foundation has donated multidrug therapy (MDT) through the WHO, ensuring the free supply of MDT to all registered leprosy patients.

The Nippon Foundation

Established in 1962, The Nippon Foundation is one of the largest not-for-profits in Asia. Since 1975, it has been the principal donor to the WHO's Global Leprosy Programme, and between 1995 and 1999 it underwrote the free distribution of MDT worldwide. Recognizing that leprosy is a social as well as a medical issue, the foundation has also focused on tackling the stigma and discrimination associated with the disease. The Nippon Foundation's chairman, Yohei Sasakawa, has served as WHO Goodwill Ambassador for Leprosy Elimination since 2003 and as Japanese Government Goodwill Ambassador for the Human Rights of Persons Affected by Leprosy since 2007. A sister foundation, Sasakawa Memorial Health Foundation, is a key partner in anti-leprosy work.



WHO Goodwill Ambassador for Leprosy Elimination

As WHO Goodwill Ambassador, Yohei Sasakawa is a frequent visitor to leprosy-endemic countries, where his activities include the following:

- To meet with government leaders and health officials and see that leprosy has an appropriate place on the health agenda.
- To promote greater awareness and understanding of leprosy via press conferences and media interviews.
- To make field trips, meet with health workers and see the work they do.
- To hear directly from persons affected by leprosy about the issues they face, and see the conditions they live in.
- To speak out against stigma and discrimination.

The activities of the Goodwill Ambassador are covered in his bimonthly newsletter published since 2003.

www.smhf.or.jp/e/ambassador/index.html



www.novartisfoundation.org/



www.nippon-foundation.or.jp/en/what/projects/leprosy/



www.smhf.or.jp/e/hansen/



Leprosy heritage

There is now a growing movement to preserve the history and heritage of leprosy for the valuable lessons that can be passed on to future generations about discrimination and prejudice, dignity and human rights. Sasakawa Memorial Health Foundation and the International Leprosy Association have collaborated on the *International Leprosy Association—History of Leprosy* website. The website includes a database on leprosy history, lists of places and locations associated with leprosy, and testimonies of people affected by the disease.

<http://leprosyhistory.org/>



What can parliamentarians do?

1. Understand the current leprosy situation

Familiarize yourself with the following:

- The leprosy situation in your country (including number of new cases, number of registered cases, ratio of child and female cases, endemic districts).
- The economic and social situation of persons affected by leprosy and their families.
- International human rights instruments that states are party to (such as the Universal Declaration of Human Rights, International Covenant on Civil and Political Rights, International Covenant on Economic, Social and Cultural Rights, and Convention on the Rights of Persons with Disabilities).
- The UN resolution on elimination of discrimination against persons affected by leprosy and their family members, and the Principles and Guidelines
- Your country's past policies toward leprosy.
- Current leprosy policies and related programs implemented by your country.
- Efforts made by national and local governments, private organizations and associations to preserve the history of leprosy in your country.

2. Take an interest in leprosy

- Visit hospitals, sanatoria and colonies and talk with people affected by leprosy and their families.
- Include leprosy issues in your election pledges.
- Ask questions in Parliament about issues relating to leprosy.
- Join a committee dealing with leprosy. (If such doesn't exist, encourage a related committee to take up the issue.)
- Join a parliamentary forum/caucus on leprosy. (If such doesn't exist, get involved in setting one up.)



Forum of Parliamentarians to Free India of Leprosy

In December 2012, at the initiative of Mr. Dinesh Trivedi, MP, the former Union Minister of Railways, and others, a Forum of Parliamentarians to Free India of Leprosy was established. Some 50 parliamentarians from across party lines announced they were joining. Members agreed that both in Parliament and in their respective constituencies, they would work to protect the rights of persons affected by leprosy and their families, help in the restoration of their dignity and in the improvement of their welfare and living standards.

3. Develop an appropriate legal system

- Carry out a survey to see whether the existing legal system reflects the spirit of the UN resolution on elimination of discrimination against persons affected by leprosy and their family members, and the Principles and Guidelines.
- If discriminatory laws and regulations exist, work to abolish or amend them.
- Establish comprehensive laws to guarantee the rights and living standards of persons affected by leprosy and their families (including special allowances and scholarships for persons affected by leprosy and their families).

Discriminatory legislation

There are still countries that have laws that discriminating against people on the grounds of leprosy. The International Federation of Anti-Leprosy Associations knows of almost 50 such laws. Legislation that increases the stigma of leprosy makes it harder for individuals and their families to participate fully in society. Many of these laws date back to a time when segregating people with the disease was seen as the best way to protect the public. There is no medical justification for such laws today. Some countries, notably Brazil and Japan, have introduced new legislation to compensate those whose freedoms were curtailed under past policies and practices.

4. Monitor the activities of government and related organizations

At the minimum, target the following areas:

- Implementation status of the UN resolution and Principles and Guidelines
- Contents of government-formulated policy on leprosy
- Contents and status of programs to be implemented by the government (including those related to health, human rights, social security, advocacy)
- Whether or not the human rights commission is functioning properly at national and regional level.
- Whether or not the necessary personnel are in place to implement the above.
- Contents and implementation status of budgets for implementing programs relating to leprosy.
- Whether or not persons affected by leprosy and their families are afforded appropriate opportunities to participate in the process of formulating, implementing and evaluating these programs and policies.

5. Promote international cooperation

- Regularly exchange information about leprosy issues with parliamentarians in other countries and build cooperative relationships.
- Seek to have leprosy raised at conferences sponsored by the United Nations and other international organizations.

Leprosy as a disability issue

In June 2015, at the 8th annual conference of states parties to the Convention on the Rights of Persons with Disabilities, Disabled Peoples' International hosted a side event, "Voices of People Affected by Leprosy" at which persons affected by leprosy from India and the United States spoke. This was the first time that the issue of leprosy had been raised at the conference.



1. Understanding the current leprosy situation

- ☐ Are you familiar with the leprosy situation in your country (including number of new cases, number of registered cases, ratio of child and female cases, endemic districts)?
- ☐ Do you have data on the economic and social situation of persons affected by leprosy and their families?
- ☐ Are you aware that leprosy is also a human rights issue and that states are party to international human rights instruments (such as the Universal Declaration of Human Rights, International Covenant on Civil and Political Rights, International Covenant on Economic, Social and Cultural Rights, and Convention on the Rights of Persons with Disabilities) that have a bearing on this issue?
- ☐ Are you familiar with the UN resolution on elimination of discrimination against persons affected by leprosy and their family members, and related Principles and Guidelines?
- ☐ Did you know that the last Sunday in January is World Leprosy Day?
- ☐ Are you familiar with the contents and history of your government’s past policies toward leprosy?
- ☐ Are you familiar with the contents of current leprosy policies and related programs implemented by the government?
- ☐ Are you familiar with efforts made by national and local governments, private organizations and associations to preserve the history of leprosy in your country?

2. Taking an interest in leprosy

- ☐ Do you have opportunities to talk with persons affected by leprosy?
- ☐ Have you made a public commitment to address leprosy issues?
- ☐ Since becoming a lawmaker, have you ever asked for a briefing on leprosy from the relevant government department in charge?
- ☐ If your answer to the above is no, do you intend for ask for a briefing at some point?
- ☐ Would you be interested in creating a mechanism for newly elected legislators to receive a briefing on leprosy?
- ☐ Has your Parliament ever taken up the issue of leprosy?
- ☐ Do you know which parliamentary committee is responsible for leprosy?
- ☐ Do you know whether the relevant committee takes up the issue of leprosy on a regular basis?
- ☐ Are you a member of such a committee?
- ☐ If you are not a member of the appropriate committee, would you consider joining in future?
- ☐ Are you a member of a parliamentarians’ group on leprosy?
- ☐ If you are not a member, would you consider joining in the future?
- ☐ If a group does not exist, would you consider forming one?

3. Developing an appropriate legal system

- ☐ Does the existing legal system run counter to the spirit of the UN resolution on elimination of discrimination against persons affected by leprosy and their family members, and the Principles and Guidelines?
- ☐ Are there laws and regulations that run counter to the spirit of the UN resolution on elimination of discrimination against persons affected by leprosy and their family members, and the Principles and Guidelines?
- ☐ If yes, are there moves to abolish or amend these laws and regulations?
- ☐ Have you sufficiently verified whether or not laws and regulations at regional and local government level are contrary to the spirit of the UN resolution on elimination of discrimination against persons affected by leprosy and their family members, and the Principles and Guidelines?
- ☐ Is there a comprehensive law that guarantees the rights and living standards of persons affected by leprosy and their family members?
- ☐ If such legislation exists, was sufficient opportunity given to persons affected by leprosy and their family members to express their opinions in the process of the law being formulated?
- ☐ If such legislation does not exist, are there plans to draw up such?
- ☐ How well known are these relevant laws and drafts to persons affected by leprosy and their family members?

4. Monitoring the activities of government and related organizations

- ☐ Do any schemes (e.g. special assistance, scholarship funds) exist specifically for persons affected by leprosy and their family members?
- ☐ Has the government compiled a national report to tackle issues surrounding leprosy?
- ☐ If so, is Parliament or the relevant committee deliberating on such a report?
- ☐ Is Parliament or the relevant committee periodically scrutinizing the contents of government policy toward leprosy?
- ☐ Does Parliament or the relevant committee receive reports from government organizations on the status of implementation of programs related to leprosy?
- ☐ Does Parliament or the relevant committee regularly request information from persons affected by leprosy and their families?
- ☐ Does Parliament or the relevant committee regularly obtain information on leprosy issues via external experts and public hearings?
- ☐ Is Parliament or the relevant committee appropriately monitoring the implementation status of the UN resolution and the Principles and Guidelines?
- ☐ Is Parliament or the relevant committee monitoring whether the national human rights commission is working to improve the situation of persons affected by leprosy?
- ☐ Is Parliament or the relevant committee monitoring whether the necessary personnel are in place to promote the rights of persons affected by leprosy and their families?
- ☐ Is Parliament or the relevant committee monitoring whether the government has secured a sufficient budget to implement the above programs and whether these programs are being properly enforced?
- ☐ Is there an opportunity for persons affected by leprosy and their families to give their views during the process of formulating budgets on policies that relate to them?

5. Promoting international cooperation

- ☐ Do you exchange information and views with your counterparts in other countries on leprosy issues? If not, are you willing to develop contacts with lawmakers in other countries about these issues?
- ☐ In order to protect the human rights of persons affected by leprosy and their families and in order to see that the UN resolution and Principles and Guidelines are properly implemented, are you willing to cooperate, if required, with the UN Human Rights Council and the Office of the UN High Commissioner for Human Rights?
- ☐ In order to guarantee the rights of persons affected by leprosy and their families, are you seeking to have leprosy issues to be taken up at conferences organized by the UN and other international organizations?

REFERENCE MATERIALS

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