

# **Report of the Informal Consultation on Stopping Discrimination and Promoting Inclusion of Persons Affected by Leprosy**

**New Delhi  
14-16 November 2017**



**World Health  
Organization**

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## Acronyms

AIDS	acquired immunodeficiency syndrome
AIFO	<i>Associazione Italiana Amici di Raoul Follereau</i> (Italian Association of Friends of Raoul Follereau)
APAL	Association of Persons Affected by Leprosy
ART	antiretroviral therapy
ASHA	accredited social health activist
AT	assistive technology
CBR	community-based rehabilitation
CLAP	Coalition of Leprosy Advocates of the Philippines
DR Congo	Democratic Republic of the Congo
EMIC	Explanatory Model Interview Catalogue
ENAPAL	Ethiopian National Association of Persons Affected by Leprosy
GLP	Global Leprosy Programme
G2D	grade-2 disability
HIV	human immunodeficiency virus
HRC	Human Rights Council
IDEA	International Association for Integration, Dignity and Economic Advancement
IEC	information, education, communication
ILEP	International Federation of Anti-Leprosy Associations
MCR	multicellular rubber
MDT	multidrug therapy
MESH	maximizing employment to serve the handicapped
MORHAN	Movement of Reintegration of Persons Afflicted by Hansen's Disease
MP	Member of Parliament
NGO	nongovernmental organization
NLEP	National Leprosy Eradication Programme (India)
PLHA	person living with HIV or AIDS
SARI	Stigma Assessment and Reduction of Impact
SDG	Sustainable Development Goal
SEARO	WHO Regional Office for South-East Asia
SILF	Sasakawa India Leprosy Foundation
SMHF	Sasakawa Memorial Health Foundation
TLMTI	The Leprosy Mission Trust India
TNF	The Nippon Foundation
UN	United Nations
US\$	United States dollar
WHO	World Health Organization

## Executive summary

### Informal consultation

An Informal Consultation on Stopping Discrimination and Promoting Inclusion of Persons Affected by Leprosy was held in New Delhi from 14 to 16 November 2017.

Participation of 40 delegates with diverse backgrounds, experience and expertise enriched the discussions in the consultation. Persons affected by leprosy brought to the table the challenges faced in daily life and suggested actions to be taken to reduce stigma and discrimination related to leprosy. The national programmes presented actions taken in their respective countries and the gaps in the leprosy programmes to achieve the relevant targets of the Global Leprosy Strategy 2016–2020. New initiatives and experiences from different nongovernmental organizations (NGOs) were shared, which triggered discussion about possibility of replication. Presentations from mental health and disability prevention departments of the WHO South-East Asia Region opened up opportunities for collaboration with other health disciplines to improve quality of care. Experts on social aspects of leprosy informed the delegates about available tools to measure progress in reducing stigma and about initiative to be taken up for achieving zero discrimination.

His Excellency Saber H Chowdhury MP, honorary president of the Inter-Parliamentary Union, gave a detailed account on the way the Lepers Act (1898) of Bangladesh was repealed and explained steps taken for such actions in a parliamentary system.

The participants in general agreed that information about stigma and discrimination related to leprosy needs to be collected in a more systematic manner to assess the magnitude of the problem and to further plan activities to reduce it.

A member of the Movement for the Reintegration of People Affected by Hansen's Disease (MORHAN), Brazil flagged up the issue of stigma caused by the use of 'leprosy' as the name of the disease. MORHAN representatives explained the benefits experienced after Brazil banned leprosy in favour of 'Hansen's Disease'. The participants generally felt that such name change can be considered by national programmes depending on the country context.

### Conclusions

The participants acknowledged the fact that stigma and discrimination related to leprosy still exists at a significant level.

Participants appreciated that the Global Leprosy Strategy 2016–2020 recognized stopping discrimination and promoting inclusion as a core component in the fight against leprosy and identified the target of zero countries with discriminatory laws as one of the principal targets of the strategy.

Assessment and policy instruments and information tools are available to address stigma and discrimination developed by national and international agencies. A Special Rapporteur was appointed by the United Nations High Commissioner for Human Rights showing increased priority for documenting actions taken by states to address all forms of discrimination against persons affected by leprosy and their family members.

Data on incidence of stigma and discrimination are not routinely collected by national programmes and other stakeholders and it is difficult to measure or assess extent of stigma and discrimination against persons affected.

Participants appreciated the efforts of providing a platform for a diverse group of stakeholders such as parliamentarians, national programmes, international organizations and networks of persons affected by leprosy, including experts on mental health and assistive technology and HIV programme to deliberate on stigma and discrimination related to leprosy.

Leprosy is a treatable disease. However social consequences can persist even after medical treatment is completed. These need to be addressed by providing holistic services for the persons affected by leprosy.

## Recommendations

### *National leprosy programmes*

National programmes should be strengthened in order to address issues related to stigma, discrimination and other social issues related with leprosy and take appropriate remedial measures.

A multi-disciplinary and multi-sectoral accountability framework and mechanism should be developed involving relevant ministries, persons affected by leprosy, parliamentarians, nongovernmental organizations, professional bodies, corporate sector and community-based organizations to address issues related to stigma and discrimination.

Meaningful and impactful engagement of persons affected by leprosy should be ensured at all decision-making levels in leprosy programmes.

Any derogatory language and/or expressions in national laws, legislations, policies and documents need to be replaced by dignified language in line with the UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy.

Counselling should be included as an integral part of services employing designated professional or trained peer counsellors.

A community-based surveillance system should be developed to screen for leprosy and its complications and to identify and report on incidences of stigma and discrimination in the community.

Capacity building activities should be undertaken in order to improve knowledge, skills and attitudes of health care staff in providing services to the persons affected by leprosy.

A suitable mechanism should be established to get incidences of discrimination reported (e.g. through a toll-free number) and addressed in a systematic manner and also inform facts about leprosy to the community.

National programmes through a designated qualified focal person should ensure availability of proper documentation and facilitate access to Assistive Technology devices, social entitlements such as pensions, right to welfare measures, etc. for the treated patients in need.

National programmes should reach out to all patients, both residing in the community as well as in colonies.

### *World Health Organization*

WHO should develop a long-term engagement with parliamentarians in elimination of stigma and discrimination working with the Inter-Parliamentary Union to accelerate efforts in amending or abolishing discriminatory laws against leprosy and to take affirmative legislative actions.

WHO should support national programmes in implementing activities to enhance the use of assistive technology to improve functional ability, stop discrimination and promote inclusion of persons affected by leprosy.

WHO should develop guidelines for counselling in collaboration with WHO departments, experts in mental health and the International Federation of Anti-leprosy Associations (ILEP).

### *ILEP and other NGOs*

The extent of disability should be defined depending on functional status of persons affected by leprosy in order to mainstream with other disabilities enabling access to social entitlements at par with persons with disabilities due to other diseases

Assess the magnitude of needs relating to various aspects of the leprosy problem, e.g. instances of discrimination; human rights violations; medical interventions; re-constructive surgery needs; assistive devices; employment opportunities; social entitlements; policies and Government regulations.

Persons affected by leprosy should be engaged in the set-up and/or strengthening of networks of persons affected at global, regional and national levels working towards their greater involvement in the health programmes.

### *Persons affected by leprosy*

Persons affected by leprosy should be allowed to play an active role in planning, implementation, monitoring, evaluation of national programmes, counselling, education and communication, advocacy and service delivery through an institutional arrangement by national programmes

The capacity and leadership of persons affected by leprosy at all levels should be enhanced for more effective participation

The participants strongly recommended that leprosy programmes should adopt a 'rights-based approach' in line with the Sustainable Development Goals (SDGs).



## **1. Inaugural Session**

### **1.1. Inaugural address by the Regional Director**

Dr Poonam Khetrpal Singh, Regional Director of the WHO South-East Asia Region, welcomed distinguished parliamentarians, persons affected by leprosy, national programme managers and experts in the field of leprosy. She highlighted salient features of the Global Leprosy Strategy 2016–2020 Accelerating towards a leprosy-free world and called for concerted efforts from all stakeholders to achieve the targets set in this strategy. She also observed that the informal consultation is very timely and the conclusions and recommendations from the consultation would guide the national programmes in their endeavours to reduce discrimination and its impact on leprosy control. She further informed the participants that 16 countries still have legislations, policies that allow discrimination against persons affected by leprosy, which needs to be amended or abolished. She also mentioned that it is important to eliminate discrimination to eliminate the disease. Annually on average 10 000 new cases with grade 2 disabilities (G2D) are being reported. Patients possibly hide the disease for the fear of discrimination thereby delaying diagnosis and continuing transmission of infection. In her message, the Regional Director thanked the parliamentarians for participation in the consultation process and their efforts in reducing stigma and discrimination against persons affected by leprosy.

### **1.2. Opening remarks by person affected by leprosy**

Mr Kofi Nyarko, representing the International Association for Integration, Development and Economic Advancement (IDEA) Ghana, appreciated the efforts of WHO to bring key stakeholders in leprosy control together for discussing steps to reduce stigma against persons affected by leprosy. Reference was made to his visits to leprosy colonies in Ghana and the Democratic Republic of the Congo (DR Congo). Mr Kofi highlighted the importance of empowerment of persons affected and the need for covering the rural parts of the country. Communities in Ghana and DR Congo were willing to re-integrate the persons affected once they were informed about leprosy. Mr Kofi opined that enhancing awareness on leprosy and mobilizing the communities helps re-integration of persons affected by leprosy.

### **1.3. Welcome remarks by the host country**

Dr Anil Kumar, Deputy Director General (Leprosy) of India, welcomed all participants on behalf of the Ministry of Health and Family Welfare, Government of India. In his remarks he expressed that – sadly – discrimination against the persons affected by leprosy still exists in 2017, even after leprosy is recognized as a curable disease. In India it has been noticed that leprosy case detection campaigns comprising of awareness programme followed by house-to-house visits to detect cases contributed to reduction of stigma against the disease and the persons affected by leprosy.

## 1.4. Key note address

H.E. Saber H Chowdhury MP, Honorary President of the Inter-Parliamentary Union, appreciated WHO for including a separate pillar on 'stopping discrimination and promoting inclusion of persons affected by leprosy' in the Global Leprosy Strategy 2016–2020. Mr Chowdhury stimulated a debate if leprosy should continue to be seen as a chance to charity or to make it a platform to raise on the human rights agenda in public health context.

Mr Chowdhury mentioned that country averages often do not mean much since they do not represent the marginalized. There is a need to switch of attitude as it has been done in the field of disasters; from responding to disasters the actions should focus on disaster prevention/risk reduction. Eliminating discriminatory laws is not sufficient as discrimination might persist even after that. The most important thing would be to facilitate inclusion and focusing on empowerment of women affected by leprosy. The informal consultation shall help defining milestones to measure progress compared to what has been done and synchronize with reaching the set SDGs.

In his capacity of being linked to the Inter-parliamentary forum, Mr Chowdhury offered support to representatives of different WHO Regions and national programme managers.

## 1.5. Objectives and expected outcomes

The objectives and expected outcomes were presented by Dr Erwin Cooreman, Team Leader, WHO Global Leprosy Programme and discussed with all participants. This helped in giving clarity to the participants with regard to the consultation process.

The general objective was to discuss factors causing stigma and discrimination against leprosy and recommend approaches for stopping discrimination and promoting inclusion.

The specific objectives were to:

- Discuss social mobilization and empowerment interventions to reduce stigma and discrimination and promote inclusion of persons affected;
- Improve understanding on legislations that allow discrimination and recommend steps to abolish them;
- Discuss improving access to service delivery in order to promote Universal Health Coverage and achieving the SDGs.

The expected outcomes of the consultation were:

- Identification of successful approaches for social mobilization and empowerment for stopping discrimination;
- Information shared on discriminatory laws against leprosy and processes to get them amended;
- Steps in improving leprosy services and access to health care identified.

## 2. Global leprosy situation

Dr Cooreman provided an overview of the leprosy epidemiological situation in the world based on the data provided by countries in 2016. A total of 217 968 new leprosy cases were detected, corresponding to a rate of 2.9 per 100 000 population. The registered prevalence was 175 361 or 0.2 per 10 000. More than 60% of all cases are reported by India, followed by Brazil (12%) and the WHO African Region (10%). The long-term trend of cases reported shows a slow decline. In 2016, though, an increase is noticed likely due to operational reasons (impact of case detection campaigns in various countries) rather than an epidemiological change. Disaggregation by region of all key epidemiological indicators was also shared.

Children represented 8.5% of new cases (ranging between 6.4% in the Americas and 9.5% in the Western Pacific Region); some countries reported high proportions of children, reflecting ongoing transmission. The G2D rate varied between 4.6% in the South-East Asia Region and 14.0% in the African Region, with higher rates signaling late case detection. The global G2D rate was 1.75 per million population. Reaching the target of less than one per million by 2020 will require a faster reduction in G2D in the coming years.

Data on leprosy among foreign-born patients have also been collected since 2015. Only a limited number of countries have reported on this indicator. While almost all leprosy cases in developed countries are occurring in foreign-born residents, immigrants or refugees, several developing countries also reported a significant share of foreign-born patients among their patients (e.g. 26% in Argentina, 38% in Chad, 40% in Malaysia and 24% in Thailand).

A summary was also given of the Global Leprosy Strategy 2016–2020, highlighting the importance of Pillar III (“Stop discrimination and promote inclusion”). Drug resistance and its limited impact on leprosy control were briefly discussed in the presentation.

## 3. Stigma, discrimination and inclusion – definitions, conceptual framework and tools for assessment and monitoring

The topic of stigma and discrimination was introduced by Dr Wim van Brakel, stigma expert of the international NGO Netherlands Leprosy Relief.

The definitions on inclusion, stigma and discrimination with reference to current understanding in leprosy control were presented in detail by Dr van Brakel. An intervention model on reducing stigma was explained in the presentation.

Stigma is a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception, or reasonable anticipation of a negative social judgement about a person or a group of persons (Weiss and Ramakrishna). Impairment triggers a negative social judgement which increases the disability experienced by the person or a group of persons. This results in exclusion and contributes to the poverty of the the person affected

and this in turn increases the impairment. The social judgement in certain situations could even be averse if not negative.

'Inclusion' is defined as 'a state when all people freely, openly and without pity accommodate any person [with a disability] without restrictions or limitations of any kind (wikipedia). The SDGs (targeted for 2030) uses the expression 'leaving no one behind' to express inclusion.

The intervention model of stigma describes the situation between two sets of people, i.e. people who are stigmatized (persons affected by leprosy) and those who stigmatize (e.g. community, health workers). Stigma anticipated or perceived in a group of people is called 'anticipated stigma'; in some the stigma gets internalized by patients/affected persons, which is called 'self-stigma'; some face discrimination, which means experiencing stigma in life. Counselling has a place in addressing the self stigma as well as the perceived stigma among the persons affected by leprosy. Empowerment and socio-economic development of persons affected help in addressing the discrimination or stigma experienced by the persons affected by leprosy.

The stigmatizers, on the other end, develop and on occasions express a negative opinion or feeling about leprosy. These negative opinions gradually get transformed into attitudes. Many factors such as fear of contracting the disease or becoming disabled get influenced by the stereotypes prevalent in the community against leprosy or the persons affected. As a result, stigma against the disease gets perpetuated. This could further restrict participation of the persons affected by leprosy in the community which might affect the mental health of the persons affected and could lead to poor quality of life.

Dr van Brakel also presented validated tools that can assess stigma in the community, experienced by persons affected by leprosy and the impact of stigma on mental health and participation of the persons affected by leprosy.

The following tools were discussed:

- Community stigma: Explanatory Model Interview Catalogue (EMIC) stigma scale (perceived stigma in community); Social Distance Scale (respondent attitudes); 5-Question Stigma Indicator (perceived stigma in community);
- Stigma experienced by affected persons; Stigma Assessment and Reduction of Impact (SARI) Scale (anticipated, internalized and experienced stigma, and disclosure concerns); EMIC Stigma Scale (stigma anticipated and experienced by affected persons);
- Impact on mental health: Patient Health Questionnaire 9 (depression assessment);
- Impact on social participation: Participation Scale
- Participation in organisations and projects: Arnstein's ladder of citizen participation.

The presentation concluded with a take home message that stigma is a complex and dynamic phenomenon, and has many common aspects across conditions and cultures. There is a need to visualize, assess different aspects of stigma, and introduce suitable and feasible interventions to achieve measurable impact in reducing stigma against persons affected by leprosy.

#### **4. Stopping stigma and discrimination and promoting inclusion – activities and indicators Global Leprosy Strategy 2016–2020**

Dr V R R Pemmaraju, Technical Officer, GLP elaborated Pillar III of the Global Leprosy Strategy 2016–2020.

Stigma and discrimination against leprosy and the persons affected by leprosy continues to pose challenges in early case detection and compliance to multidrug therapy (MDT). Patients facing discrimination experience loss of wages and social exclusion in the community. The family members are also affected by stigma causing difficulties in their activities of daily living and some suffered depression due to this. In some situations, services to women with leprosy were particularly affected.

The Global Leprosy Strategy 2016–2020 identified ‘Stopping discrimination and promoting inclusion [of persons affected by leprosy]’ as a separate strategic direction and set a global target of reducing the number of laws or legislations that allow discrimination against persons affected by leprosy at global level to zero. Stopping discrimination against persons affected by leprosy is still not high on the programmatic agenda in many national leprosy programmes. Laws that allow discrimination on the basis of leprosy exist in at least six countries at national level and some more are at sub-national level. Involvement of persons affected by leprosy in leprosy services is not a universally followed principle; it happens at national level in some countries (e.g. India’s Technical Resource Group includes the Association of People Affected by Leprosy (APAL) as a member) and at sub-national levels in other countries (e.g. Ethiopian National Association of Persons Affected by Leprosy or ENAPAL). The national leprosy programme in the Philippines has formally entered into a partnership with the Coalition of Leprosy Advocates of the Philippines (CLAP). Leprosy patients experience different treatment in health care settings. Collaboration between national leprosy programmes and other relevant departments and ministries varies but may lead to positive actions in areas such as housing or social support.

The following actions were recommended at global level:

- Promote awareness and compliance with the Human Rights Council Resolution 29/4 (2015);
- Identify global and regional partners to support implementation of activities under Pillar III of the Global Leprosy Strategy 2016–2020;
- Collect and analyse evidence related to stigma and barriers to inclusion and use this to monitor the impact of activities at national level through periodical “surveys”.

The following actions were recommended at national level for stopping discrimination of persons affected by leprosy:

- Facilitate implementation of guidelines for the implementation of Resolution 29/5 of the UN Human Rights Council;
- Programmes shall ensure availability of data/information on stigma related to leprosy;
- Facilitate services integration (health and social) to reduce stigma and reduce barriers to care;
- Review and edit national policy documents to ensure no discriminatory language is used;

- Ensure availability of valuable and effective information-education-communication (IEC) materials to contribute to enhance inclusion;
- Ensure provision of psycho-social support to patients to avoid internalization of stigma and facilitate their inclusion;
- Consider involvement of religious leaders to reduce stigma;
- Promote research in the areas of stigma and discrimination.

The Global Leprosy Strategy 2016–2020 advocates for inclusion of persons affected by leprosy to build quality leprosy services by including the individuals affected and the associations in delivering the services. Educating health staff in reducing the use of stigmatizing language and attitude; specifying roles of persons affected by leprosy in national policies and involving community in designing stigma reduction campaigns help breaking the stereotypes prevalent in the community and elimination of discrimination against persons affected by leprosy.

## **5. Chronology of events in stopping discrimination against leprosy and promoting inclusion of persons affected by leprosy**

Professor Takahiro Nanri, Executive Director of the Sasakawa Memorial Health Foundation (SMHF), explained the principles and activities of The Nippon Foundation (TNF) and SMHF. TNF is the ‘mother organization’ providing technical guidance and financial support to several ‘daughter organizations’ active in various fields. One of these is SMHF, which is mainly dedicated to leprosy control. TNF support for leprosy has allowed WHO to provide leadership in global leprosy control for over four decades. The support included donation of MDT drugs for five years during the roll-out of the MDT programme.

The chronology of activities of TNF and SMHF started from their establishment in 1962 and 1974, respectively. In 2002 Mr Yohei Sasakawa, Chairperson of TNF, was appointed as ‘WHO Goodwill Ambassador for Leprosy Elimination’ and continues to advocate for leprosy in this capacity. He equated the fight against leprosy to the two wheels of a motorcycle, the front wheel being the efforts against the disease and the back wheel to those against discrimination. This message gives equal importance to medical relief and social support.

Annual Global Appeals to End Stigma and Discrimination against People Affected by Leprosy were released by TNF since 2006. These target different stakeholders each year. The first Global Appeal focused on persons affected by leprosy while subsequent appeals rallied diverse stakeholders behind the cause of ending stigma and discrimination against leprosy including Noble Peace Prize winners, religious leaders, medical and nursing professionals, lawyers, young entrepreneurs, etc. To enhance coverage of social support to persons affected by leprosy, the Sasakawa India Leprosy Foundation (SILF) was created in 2006.

TNF and SMHF engaged also with the United Nations Human Rights Council (HRC), for adopting the ‘First Resolution on Elimination of Discrimination against Persons affected by Leprosy and their family members’ in 2008. The second HRC resolution on leprosy was adopted in 2009. The former resolution calls on governments to take measures to eliminate discrimination and requests the

United Nations High Commissioner for Human Rights to include leprosy discrimination in human rights education and awareness rising. In 2010 HRC drafted the “UN Principles and Guidelines on Eliminating Discrimination against Persons Affected by Leprosy and their Family Members”, which was later in the year adopted by the UN General Assembly.

A Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members was appointed in 2017 with a three-year mandate.

## **6. Evidence of effective interventions in reducing stigma and discrimination against persons affected by leprosy**

Dr Pim Kuipers, Adviser of ILEP, presented available evidence of effective interventions for reducing stigma and discrimination. Results of a survey on priorities of persons affected by leprosy covering 265 participants (111 women and 154 men) from 20 different countries were presented. It was revealed that 65% of persons affected enjoy the same political rights as non-affected persons. In terms of right to work, 27% felt that persons affected by leprosy have the same right as non-affected. No or low levels of discrimination was felt on more abstract issues such as citizenship; whereas higher levels of discrimination was experience in practical and personal issues such as marriage or access to social entitlements. The discrimination became more tangible at personal level.

A literature review covering 150 articles was discussed during the presentation. Interventions focusing on general public (stigmatizers) and persons affected (stigmatized) were reviewed. Social contact is the most effective type of intervention to improve stigma-related knowledge and attitudes in the short term. The interventions used approaches, which are information based, building skills, counselling and support to the persons affected. Most of the interventions used two or more strategies to reduce stigma and discrimination.

Evidence from research studies on the following interventions was presented for discussion. Personal contact between persons affected and the public will gradually demystify incorrect information, break the stereotypes and generate empathy. Empowerment of persons affected by leprosy participated in the intervention helped reducing the impact of stigma in the community. Peer counselling helped in improving knowledge, skills and positive attitudes regarding leprosy, restoring a sense of identity, promoting dignity and empowerment and raising awareness about rights. Using the services of peer counsellors is an opportunity of involvement of persons affected.

The evidence from effective stigma reduction interventions suggest to maintain focus on the personal and practical dimensions, personal and social contacts with community members reduces discrimination, counselling and enhancing the role of the persons affected help restoring identity and dignity of the persons affected in the community, further studies are required to consider the ‘drivers and effects’ of discrimination and multiple strategies should be used to make the intervention effective.

## 7. Discrimination against leprosy – status and steps being taken by countries

### 7.1. Bangladesh

Bangladesh is one of the global priority countries and reports more than 3000 new cases annually with a G2D rate among new cases ranging between 8 to 11 percent. The national programme does not have information of any instance that has hampered early case detection, though anecdotal data informed that few cases reported to have hidden the symptoms for fear of getting labelled as persons affected by leprosy. In respect of one case stigma has affected on completion of treatment of that particular patient. A survey conducted by The Leprosy Mission International revealed that 53% of the people surveyed did not know about leprosy and of them 31% considered that it is caused by sin. No instances of discrimination were identified by the national leprosy programme. Persons affected by leprosy live in communities and are not segregated because of leprosy disability or due to the disease. Reports of not getting proper treatment at health facilities were received from a few women patients. MDT is received in leprosy (or tuberculosis (TB)/leprosy) corners set up in *upazila* health centres rather than from the general out-patient department.

Bangladesh repealed the Lepers Act (1898) on 24 November 2011. Since then there is no law that allows discrimination of persons affected by leprosy. All children including those with disabilities have access to schools. Persons with G2D have informed that they face some limitation in interacting with community members. Media or official documents avoid using derogatory language.

The National Leprosy Programme disseminated IEC materials to dispel myths and misconceptions against leprosy in the community and among school children. Innovative activities for stigma reduction involved religious leaders. The network of persons affected by leprosy is still in its development stage and needs support from NGOs active in those areas.

Persons affected by leprosy have less voice and need socio-economic support. The National Leprosy Programme is planning to constitute a national level apex body/organization of people with leprosy and others.

### 7.2. Brazil

Hansen's Disease colonies may have disappeared but social isolation of individual patients with Hansen's Disease still exist in Brazil. The country offers little room for people who are not productive. Health professionals also instill fear to enforce adherence to treatment. Though various laws are in place to prevent and protect against discrimination, they are not always effective. Social media also spread negative attitudes towards Hansen's Disease. The principal approach to counteract this is to educate, inform and empower people against all forms of discrimination (not only against Hansen's Disease).

Change can come from the grassroots to create a movement that may convince top decision makers. Hansen's Disease patients can contribute positively at different levels.



The presenter also proposed to phase out completely the term “leprosy” in favour of Hansen’s Disease (as has happened in Brazil).

MORHAN has initiated several initiatives to promote the human rights of leprosy patients. These include a telephone hotline and an app. It has a formal partnership with religious authorities. Social media are also used to further the cause of Hansen’s Disease patients. In collaboration with the Order of Lawyers of Brazil, a booklet titled “The rights of persons affected by Hansen’s Disease” was published. Several social welfare schemes were launched by the government. Efforts for reunification of children forcefully taken away with their biological parents are done. Stigma fighting activities are now part of the MOH plan.

### 7.3. Ethiopia

Leprosy has been identified as a public health problem in Ethiopia for the past five decades. Ethiopia reached the goal of elimination of leprosy as a public health problem in 1999 and sustained the prevalence at less than one case per 10 000 population. Still 93 districts in the country recorded a prevalence higher than the elimination threshold. In 2016, 3076 new cases were registered. Of them 12% were children suggesting continued transmission in the community; 14% of the new patients presented with G2D.

The attitude of the community towards leprosy patients is rather adverse and people do not prefer to sit with persons affected by leprosy in public transportation. They do not share food from the same plate with the persons affected. Children with leprosy travel to distant villages to continue education fearing stigma in their own village. Persons with a family history of leprosy are not preferred for marriage and similar negative attitudes are observed in the workplace also. Fear of getting disease and deformities are known causes of stigma in Ethiopia.

In media and other documents, derogatory expressions do occur in local languages, i.e. *segadawe* in Amharic, *kurchi* or *juzam* in Oromo. These signify that the disease has misconceptions and also describe that it is incurable. This perpetuates stigma in the community.

*Fetha Nagast*, a traditional code inherited from the king’s times, gives a humanitarian view of the disabling disease. *Fetha Nagast* also allows the separation of a healthy husband from a wife with leprosy by giving her an outfit or dowry. Other laws exist in the country, e.g. persons affected by leprosy cannot function as priest. Similarly one has to be free of leprosy to become a judge because the infection may keep many people away from him.

The leprosy programme is jointly implemented with TB control. Proclamation 568/2007 was issued the Government of Ethiopia covering the Right to Employment of Persons with Disability.

### 7.4. India

India has adopted innovative strategies involving Accredited Social Health Activists (ASHAs) in community surveillance for leprosy suspects. This increased the reach of case finding initiatives to all

villages covered under National Health Mission. Leprosy case detection campaigns initiated in 2016 are continued while tailored campaigns are designed for hard-to-reach areas and hotspots in low endemic districts. These initiatives led to an increase in case detection and reduction of the proportion of new cases with G2D from 4.6% to 3.9%.

The national sample survey conducted in 2010 informed that 3% of the persons affected by leprosy experience self-stigma and jobs were affected to 13% of the patients interacted. No instances of stigma and discrimination were reported in the country either in the community or in healthcare settings. Media has published reports of discrimination: a girl affected by leprosy was forced to discontinue her schooling due to visible deformities and a leprosy patient was denied funeral by the community because of the fear of contracting the disease. Derogatory expressions or use of discriminatory language was not noticed either in the media or in official documentation.

Leprosy services are integrated into general health care. The Leper's Act was repealed in 2016 and laws pertaining to juvenile justice, care and protection were amended providing protection to children affected by leprosy. *Sparsh* leprosy awareness campaigns were carried out to improve community participation. Persons affected by leprosy were involved in leprosy programme steering committees from district to national level.

## 7.5. Indonesia

The leprosy control programme is included in the national priority agenda. Targets with definite timelines were set to reach the goal of elimination of leprosy as a public health problem in all provinces by 2019. As of 2017, elimination of leprosy is achieved in 26 (out of 34) provinces. The strategies include raising community awareness; promoting active community participation; early detection; prompt and complete treatment; increased participation of persons affected by leprosy and the community; and sustained financial support to leprosy programme at various levels of Government.

Stigma reduction/elimination was an important message in leprosy promotive activities. From the information from leprosy programme staff and *Persatuan Mandiri Kusta* (PerMaTa), the network of persons affected by leprosy, no instance of stigma and discrimination against persons affected by leprosy was noticed or registered. Leprosy is not well recognized by the local governments and insufficient involvement of people in the leprosy programme.

By the end of 2017, two networks of persons affected by leprosy are organized: PerMaTa and Tu Mou Tou. These networks are not formally engaged with Government bodies. Network of persons with disabilities like *Pusat Pengembangan dan Pelatihan Rehabilitasi Bersumberdaya Masyarakat* (PPRBM or Centre for Community Based Rehabilitation Development and Training), leprosy diabetes wound care and tobacco victims groups are actively supporting health care in the country. The Indonesia national leprosy programme plans to strengthen communication and collaboration with associations of persons affected by leprosy and use their services in advocating other stakeholders and local governments. The plans also include developing mechanisms to facilitate and monitor participation of persons affected by leprosy.

## 7.6. Nepal

Nepal reports more than 3000 new cases on average every year. In 2016, 3215 new cases were reported; of them, 7% were children and 3% presented with G2D. Instances of stigma were noted in the form of hiding cases in the family, and while taking MDT in a health institute and in some cases as drop out half way while taking MDT. Similarly self-inflicted discrimination was felt among persons affected by leprosy. A television news channel reported of an individual affected by leprosy living in an isolated setting due to the disease. Remedial action was instituted by the national leprosy programme. Isolated leprosy colonies were all mainstreamed through the developmental activities undertaken by the Government of Nepal.

A law exists which states that if a person marries without letting the partner know about the status of any disease s/he is suffering, the partner can propose a divorce. Within the given cultural setting women are more affected under this provision and leprosy is also used as one of the reasons for divorce. From the Government's point of view, this is being reviewed following the feedback from people, civil society organizations and human rights activists. The national leprosy programme has included positive messages to address discrimination and stigma against the disease in their IEC campaigns.

National implementation plan for leprosy programme includes specific interventions to promote gender equity, advocacy campaigns to reduce stigma against leprosy. Inclusion of persons affected by leprosy at different levels in leprosy services and self-care groups were the key interventions in the national strategic plan for addressing issues related to discrimination against persons affected by leprosy in the community. Disability survey by national programme is underway and the results will inform about the disability case load in the country. Partner organizations are implementing interventions to promote empowerment of persons affected by leprosy and access to social entitlements and other welfare measures like pensions and employability for the persons with disabilities.

The national leprosy programme plans to include reporting on discrimination in the community in the routine programmatic reporting through the health management information system, so that the actual extent of the stigma in the community can be more accurately determined. The Nepal national leprosy programme recognizes the presence of networks of persons affected by leprosy in the country. These networks are governed by a Memorandum of Understanding with the local or central government. The network of persons affected by leprosy also closely coordinates with networks of persons with disabilities.

## 7.7. Sudan

Sudan reported 744 cases in 2016 including 98 with G2D and 19 children. Stigma is considered as an attitude of the community which might result in isolation of the person affected by leprosy. It was observed by the national leprosy programme that stigma increased the loss-to-follow-up rate. Discrimination caused hiding of the disease by the members in the community and increased G2D. Most persons affected by leprosy work as farmers or labourers in the farm or with merchants. There is no policy of deporting persons affected by leprosy and they are well employed in the Government

services. Different media platforms were used by Government services and also NGOs to spread awareness about leprosy. IEC materials are produced in Arabic and local dialects for dissemination among people living in the remote areas.

Sudan does not have any laws or policies in practice that discriminate persons affected by leprosy. Self-care sessions and other prevention of disabilities initiatives were introduced by the programme to mainstream the persons affected by disabilities due to leprosy. Religious leaders played a very constructive role in disseminating facts about leprosy and reducing stigma against it. The talks in the mosques during the prayer times helped people to understand the need for getting examined for leprosy and continuing treatment to get cured. Persons affected by leprosy were involved in the communities that govern leprosy programme at national, state and local level. Revolving small funds were made available for persons affected by leprosy particularly with disabilities and some women affected by the disease.

All the activities are synergized and focused to reduce stigma, discrimination, lepro-phobia and isolation of the persons affected by leprosy.

## 7.8. Tajikistan

The Government of Tajikistan expressed its commitment to the principles of global cooperation in overcoming the consequences of the global crisis, reducing poverty, reducing the burden of the disease, thereby emphasizing the priority of public health issues in the country's politics and economy.

It should be noted that leprosy has never been widespread in Tajikistan. Disease occurrence was reported sporadically. In general the prevalence of leprosy is higher in Khorog city and some districts of Gorno-Badakhshan Autonomous Region (Vanj, Ishkashym, Shugnansky). There were officially 48 people (all former patients) living with leprosy in Tajikistan.

Among the key achievements of the country is detection of communicable diseases through outbreak investigations and adequately responding. The main challenges related to leprosy include early diagnosis, stigma and discrimination of the leprosy patients and their families and communities.

Addressing the mentioned challenges involves conducting a situational analysis in order to identify gaps, develop recommendations on early diagnosis of leprosy, and target medical personnel, families and communities for reducing stigma and discrimination. It will also be useful to conduct educational activities at the health care facilities, schools and communities.

Tajikistan shares the dream that “everyone can lead healthy and productive lives, regardless of who they are and where there live” and would work to let it come true.

## **8. Integrating leprosy in national disability prevention and mitigation policies and strategies**

This topic was elaborated by Ms Nikita Sara of The Leprosy Mission Trust India (TLMTI).

Deformities in leprosy cases affect the image of leprosy and impact implementation of leprosy activities in the field. Integration of leprosy services into general health services improves coverage and results in earlier detection, reduction in number of persons becoming permanently disabled and consequently further reduction of stigma against the disease. Integration of leprosy in national disability policies will ensure that leprosy patients will not develop disabilities or conditions that cause secondary damage. It will also help in improving the quality of life of persons affected by leprosy and in protecting their human rights. Integrated community-based health promotion initiatives and campaigns for persons with disabilities will enhance opportunities to the persons affected by leprosy for accessing social entitlements and welfare measures. These steps are expected to bring down the number of legislations to zero that discriminate against persons affected by leprosy.

In case of India, the National Policy of Persons with Disabilities 2006 lays specific emphasis on prevention of disabilities especially where the disability is caused by illness, calling for measures for prevention of the disease and improving mass awareness. It lays focus on mechanisms of early detection to reduce the impact of disability. It talks about counselling and medical rehabilitation such as corrective measures (surgery, assistive devices). The National Policy calls for a specific focus on rural areas so that disability-related services are made accessible to all in need. The National Policy mentions expanding District Disability Rehabilitation Centres and roping in ASHAs in disability-related health services at the grassroots level especially for the marginalized sections of the society. Section 25 (Health care) endows authority to the respective governments at state level to develop schemes and programmes for prevention of disabilities, screening of children at risk on yearly basis and training of health professionals. Though the provisions were made in the absence of a definite timeframe, it would be challenging to get the schemes implemented by the State Governments.

The UN Principles and Guidelines for elimination of discrimination against persons affected by leprosy and their family members encourages governments, relevant UN bodies, national organizations, specialized agencies and national human rights institutions to formulate and implement policies and measures concerning persons affected by leprosy and their family members.

TLMTI provides disability care services through 14 leprosy referral hospitals, community-based projects and working with community based organizations. TLMTI engages with policy makers for amending the People with Disabilities Act and repealing discriminatory laws against leprosy.

## **9. Laws and legislations that discriminate on the basis of leprosy**

This topic was elaborated by Mr John K George, Coordinator of ILEP-in-India.

Leprosy is one of the diseases wherein the problem of discrimination is as old as the disease itself. There is a dire lack of evidence as instances of discrimination are not properly recorded or reported.

Expressions such as ‘contagious’ or ‘incurable’ perpetuate discrimination. Though MDT had a notable impact on the disease burden, it did not have much impact on discrimination against the disease or the persons affected by leprosy. Several laws allow discrimination and adversely influence prevention and treatment. Investments are being made by both the Government and NGOs to represent them and advocate, demand and even fight for their rights.

ILEP supported research to study discriminatory laws across various regions of the world. Seventy-nine such laws were enlisted at national level. In India 119 similar laws and legislations at national and sub-national level have been identified. Some policies and laws affect migration of people or promote separation and segregation during the process of migration. India and Brazil contributed significantly to the number of discriminatory laws. Indonesia reported no discriminatory law against leprosy. It was found that 50% of the laws have been repealed or amended as of 2017. UN organizations, International NGOs and the Inter-parliamentary Union have a crucial role in addressing the issue regarding discriminatory laws against leprosy.

The focus should be on creating an enabling environment for the persons affected by leprosy. Effective media campaigns will be of great help in spreading awareness about leprosy and need for repealing the discriminatory laws. Intensive media engagement could help reaching the messages to all concerned at appropriate levels for triggering corrective actions. There is an immediate need to collect information and generate evidence on prevalence of discrimination.

Derogatory references to the disease and its related situations, the jargons such as ‘leper’, ‘incurable’, ‘separation’, ‘contagious’ should be removed from the legal documents and policy or position papers. Multidisciplinary teams should be formed to holistically address issues related to stigma and discrimination. Multi-pronged approaches that aim at empowering people/communities; sensitizing custodians of law and educating masses are key interventions to be taken up forthwith intensively to address discrimination of persons affected by leprosy and their family members.

## **10. Repealing of leprosy legislation – Bangladesh experience**

H.E. Saber H Chowdhury, MP of Bangladesh and Honorary President of the Inter-Parliamentary Union, described the procedures followed in the parliamentary system for getting bills passed and acts repealed or amended. The Lepers Act (1898) as per Bangladesh Constitution was adapted from British Raj days. The opening lines for the act call for segregation of the persons with leprosy. According to this, persons affected by leprosy could be arrested even without a warrant or warning. Leprosy patients were prohibited to eat in restaurants, travel in public transport or get employed. This completely goes against the principle that “everybody is equal before law”. The Leprosy Mission Bangladesh organized meetings with persons who experienced leprosy and its sequelae, medical conditions and social restrictions. Feeling the pulse of the community and averseness to discuss about leprosy in the Parliament, Mr Chowdhury opted for introducing a private member bill. The move was challenged with lot of resistance from fellow parliamentarians. Through a series of meetings lobbying with all parliamentarians, the human rights commission helped in getting the bill accepted and a committee was formed. The environment was favourable. The then Minister for Health was a doctor and the Prime Minister considered it a humanitarian bill. With their support the Lepers Act (1898) was repealed in November 2011 in the Bangladesh Parliament.

The lessons learnt from Bangladesh will be useful for other countries where such attempts of repealing discriminatory laws are in progress. Ownership of the bill by Members of Parliaments is elementary and support from Ministries of Health and Social Justice or Law are essential. There needs to be good coordination between them. Supportive NGOs need to work in a coordinated manner for generating evidence and garner support from all Members of Parliament to get the discriminatory laws amended.

Amending or abolishing a law is only a step in the process of ending discrimination and more follow up work needs to be undertaken. Building awareness and dismantling the existing mechanism needs time and sustained efforts to see that discrimination is put to an end.

On behalf of the Inter-Parliamentary Union, Mr Chowdhury assured support to any national programme to provide guidance on the process of getting discriminatory laws repealed or amended. The Inter-Parliamentary Union has a membership of 177 national parliaments across the world which includes more than 40 000 parliamentarians.

## **11. Improving political commitment for the elimination of discrimination against leprosy – Perspectives of members of parliament**

The session was introduced by H.E. Yakub Khan MP whose parliamentary constituency consists of a highly endemic leprosy area in East Java, Indonesia. He acknowledged that stigma and discrimination is present in the society, which leads to unnecessary psychological burden on patients and their families. While supporting the efforts of the central government, he believes that action at the local level is also very important. The role of local governments, religious leaders, teachers and other community actors cannot be underscored.

H.E. Saber Chowdhury shared the perspective of members of parliament and the need to form a coalition of important stakeholders. Buy-in of parliamentarians is crucial as they can contribute in four ways (“four P’s”): (i) people: parliamentarians are constitutionally mandated representatives of the people and draw their power from them; (ii) pronouncement: what a parliamentarian says (or does) influences debate and discussion; (iii) policy: articulating policies is important but needs to be backed up by legislation. The role of parliamentarians is to enact new and repeal or amend existing laws and monitor that laws are implemented subsequently; (iv) purse (funds): state budgets and allocations to various areas are to be approved in national or regional parliaments. He further highlighted that action results from commitment, which itself is raised by ownership. As honorary president of the Inter-Parliamentary Union, he highlighted the body’s role in engaging parliamentarians from India, Brazil and Indonesia.

Salient points emerging from the discussion included the pressure on bureaucrats to take action when a MP is engaged. Social media are also very helpful in disseminating messages including the viewpoints on leprosy of MPs. While leprosy can be considered a humanitarian issue, generally cutting across party lines, support of the treasury bench will lead to faster passing of parliamentary processes. Engaging with MPs can be undertaken through formal and informal channels, through standing committees as well as caucuses, through hearings of key stakeholders, through meetings



with community members during constituency visits. MPs are also sensitive to campaigns, even protests, held on issues considered important by people.

## **12. Leprosy colonies and social integration process and barriers faced in accessing health care and welfare measures**

### **12.1. Experience of discrimination in Ghana**

Mr Kofi Nyarko presented on activities undertaken in re-uniting people with their families and communities in his country. In 2004, IDEA-Ghana established a programme to reunite families in line with the UN Principles and Guidelines which encourage reuniting families separated because of leprosy. Ghana IDEA members visited the home places and families of persons affected by leprosy and educated them about leprosy. Meeting the village chief was paramount along with the community members in this process. After preparing the ground for reuniting, the village chief along with a family member brought the individual separated from the family due to leprosy back to the village and to the family.

The persons affected by leprosy who were reunited with their families were very happy and felt more dignified in a welcoming community. For some this day came after several decades, many after 20 or 30 years living in leprosy colonies; several passed away unable prior to any chance of reunification. By the end of 2017, all Ghanaian persons (723) were re-united with their families, leaving eight foreign (from Burkina Faso, Côte d'Ivoire and Niger) residents in colonies. When the people return to the community, the village chief helps them in (re-)acquiring farmland and the community supports them in getting the lives settled. All such individuals are registered in the Livelihood Empowerment Against Poverty programme and receive approximately US\$ 18 as secured income. This also helps persons affected to pay premiums to healthcare as all other citizens.

In recent years, all leprosy patients are treated in the National Health Insurance Scheme. Returning to one's family with the support of the community is considered as a major step in inclusion of persons affected by leprosy.

### **12.2. Experience in India**

Mr Narsappa Vagavathali presented on 'barriers faced in accessing healthcare and welfare measures' in the process of social integration of persons affected by leprosy and discrimination faced by persons affected by leprosy. In accessing health care, APAL members have observed various challenges. At times, persons affected by leprosy did not get admission in general hospital wards. Ulcer care for leprosy is done by untrained hospital support staff such as sweepers. It is difficult for persons affected by leprosy to access care for other health problems including hypertension, diabetes or cataract.

Discrimination in the community has also been reported through the media including denial of dignified funeral rights. Villagers refused to extend support to a family where a person affected by leprosy died in the village. Media also highlighted instances of depriving persons affected by leprosy



of social entitlements including food rations through public distribution systems; or entry into temples and other religious institutions. Food supply was denied for some patients who have lost their finger prints due to absorption of fingers as part of severe disease.

If land ownership is given to the people in leprosy colonies, the process of integration will be faster. Gradually the number of persons with disability is reducing in colonies. Barriers faced by persons affected by leprosy are mainly due to:

- lack of leprosy-specific services;
- denial of general health services;
- difficulties in getting social and welfare services due to stigma and discrimination

## **13. Social marketing and economic rehabilitation experiences in addressing stigma**

### **13.1. Experience in Nepal**

Mr Amar Bahadur Tamalsina shared the experience of the Nepal branch of IDEA which was formed in 1998 and is part of IDEA's global network. This network provides a common platform for all people affected by leprosy. It aims to restore their dignity through mainstreaming them into the society.

For patients with severe deformities, special occupational therapy is created while less deformed patients can more easily set up businesses. However, due to stigma, there is significant hesitation to buy products from or consume food produced by people affected by leprosy, much more than similar items provided by people with (non-leprosy) disabilities. The role of self-stigma should not be underestimated. Leprosy affected persons without visible deformities who disclose their status are the exception. People affected by leprosy have often a short-term vision: they focus on immediate benefits rather than sustainability. Their access to information is for various reasons also inadequate.

Identifying champions and engaging them in advocacy has proven to be successful in Nepal.

### **13.2. Experience with social marketing in India**

Mr K K Mathews shared the business model of MESH, an organization to promote social marketing in India. MESH stands for 'maximizing employment to serve the handicapped'. This is a voluntary organization in India that aims to address stigma through fair trade. It markets products made by persons affected by leprosy or with disabilities. Affected persons are trained and supported (e.g. in designing) to produce items that MESH will buy and further sell according to the principles of fair trade. As such it provides opportunities for social and economic inclusion. Stigma is being addressed by reducing the need to beg (which creates a negative image in the society), by providing employment with dignity; and by providing a regular income to individuals (and communities) so they have more power to make their own decisions. Especially women have got greater control over

family spending, which in turn has led to better education of their children. Successful businesses have been expanding thereby involving people who were not affected by leprosy which led to further bringing down barriers in the community. Leprosy affected persons owned their businesses and engaged with the rest of society as business people, not as (former) patients.

## **14. Community-based rehabilitation**

### **14.1. Model of Ethiopia**

Mr Tesfaye Tadesse of ENAPAL reported that Ethiopia reports on average 3000 new cases annually. There are still a number of 'leprosy villages' where persons affected by leprosy are living segregated from the general community. The problems faced by them were also compounded by socio-economic issues and deep rooted stigma against the disease. ENAPAL was founded in 1966. It focuses on leprosy and the issues of persons affected by leprosy. The need was identified to address the deteriorating services in leprosy hospitals. ENAPAL has a membership of approximately 20 000 persons affected by leprosy from seven regions in the country. Activities include training and creating awareness on early signs of leprosy in the general community to improve early case detection. Health extension workers, leaders and members of ENAPAL, school communities and community leaders were trained. The persons affected by leprosy and community members living in the leprosy villages were trained on self-care and management of affected limbs and eyes. The training on early detection was mainly done to health extension workers from selected high burden areas and similar trainings were conducted to school communities aimed at spreading awareness and improving voluntary reporting of cases with skin patches.

ENAPAL also provides support for stay for persons affected by leprosy receiving rehabilitation care and assistive technology devices. ENAPAL in collaboration with the National Leprosy Programme and partner organizations developed flipcharts and IEC materials – with pictures and messages in local language – for improving self-care and reducing the impact of deformities on daily life. Reaching out to women as a separate group was another special activity undertaken by ENAPAL: women interested in embroidery were trained to create self-employment and restore dignity. In the area of income generation, a multi-purpose employment project was started involving a large number of persons affected by leprosy.

In areas of advocacy, ENAPAL spearheaded campaigns such as World Leprosy Day and public rallies and mass awareness campaigns were conducted including mayors of respective municipalities. Panel discussions and campaigns were also conducted using public discussion platforms and media were conducted to discuss role of community, other partners and areas for improvement of leprosy services in the community.

### **14.2. Community-based rehabilitation in India**

The Italian Association of Friends of Raoul Follereau (AIFO) started its work in partnership with NLEP in India in 1962. Dr M V Jose of AIFO mentioned that initially the work was started as a support to leprosy organizations and gradually evolved into provision of treatment with MDT covering one

district (Chittoor in Andhra Pradesh). Support to the National Leprosy Eradication Programme (NLEP) was expanded to modified districts of NLEP and placement of District Technical Support Teams to strengthen district-level programme implementation and NLEP coordinators and consultants at state leprosy programme level.

During this phase, community-based rehabilitation (CBR) was started in Mandya district (Karnataka). The CBR project covered 2.7 million people of the district, including 21 152 persons with disabilities. Of them, 472 persons were affected by leprosy. The CBR unit implemented activities to raise awareness among the general public. The activities contributed to detection of 4600 new leprosy cases with leprosy over a period of ten years in the district.

### **14.3. Restoring dignity to the persons affected**

Dr Vineeta Shankar, Executive Director of SILF mentioned that her organization is dedicated to the task of mainstreaming leprosy affected and cured persons through economic and social empowerment. It also aims in changing social attitudes and behaviour through creating greater awareness. The agency works towards ending stigma and restoring dignity of people cured of leprosy by integrating them into the mainstream society, i.e. build resilience through social and economic empowerment; and create an enabling environment, thereby ensuring equal social, economic and culture opportunities.

For its livelihood and education projects, SILF works directly with APAL. Involving them at all levels instills a sense of ownership, though sometimes at the expense of efficiency. All efforts, including those specifically for awareness raising and advocacy, have resulted in a much better integration of leprosy affected people in the social and political space. Colony dwellers have acquired property titles; all patients received identity cards that are also required to access entitled social benefits; hygienic situation has improved through construction of individual toilets and repairing drinking water facilities. The word “leprosy” was intentionally dropped from the name of several colonies.

Women constitute a special focus, leading to leadership roles taken up by women in the social, economic and health and wellbeing arena.

Important challenges still remain: professional or peer counseling is absent in health facilities; there is inadequate focus on rehabilitation; leprosy is not explicitly or properly defined in disability schemes; various social welfare schemes to which people affected by leprosy are entitled remain beyond reach; leprosy affected people are often not adequately organized to raise up to a higher level of leadership.

The discussion that followed revealed that dignity is defined in a different way in different contexts. While leprosy colonies are often the only option in India and considered as a “home”, such colonies are never called “home” in an African context. Though considered as disgraceful, it is not possible to eliminate begging completely as the alternative livelihood option needs to be supplemented for a more decent living. There is a dearth lack of data, emancipatory research in the area of stigma and discrimination is very much desirable.

## 15. Working with other programmes

### 15.1. Access to assistive technology for leprosy patients and former patients for disability prevention and mitigation

The session was introduced by Dr Patanjali Nayar, Regional Adviser, Disability Prevention, Injuries and Rehabilitation, SEARO.

Disability is the result of the interaction between the person and the environment (ICF: International Classification of Functioning, Disability and Health - WHO). As per WHO estimates, 15% of the world's population is affected by one or other forms of disabilities; 98% of the children with disabilities can not get formal education and the problem is more severe in girls with disabilities. Elderly people with disabilities also suffer from discrimination and disempowerment in the community. In summary, the persons with disabilities in childhood and elderly population and females get excluded and thereby lose opportunities for daily living and are deprived of good quality of life.

Though the disabilities are caused by impairments and conditions caused by different diseases, people are disabled in and by their environment. Environmental factors are important, either as barriers, or as facilitators. For example, technology is an environmental factor, a facilitator or a barrier. From human rights perspective, additional measures need to be taken to support people with disabilities for improving access to health services and social entitlements. In a disease such as leprosy, stigma and discrimination compound the problem and discrimination needs to be eliminated along with provision of other services. Some of the disabilities impinge activities of daily living and even essential activities like eating and maintaining hygiene of the body. Rehabilitation and assistive technologies can help people with disabilities to participate in the society on the equal basis with others (Convention on the Rights of Persons with Disabilities).

The UN defines rehabilitation as “all measures for reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualization”.

Assistive products maintain or improve functioning and thereby promote well-being for people with disabilities caused by health conditions such as stroke, cancer, diabetes, leprosy and a few other diseases. It is in fact a subset of health technology that refers to assistive products and related systems and services. The assistive products enable people to live independent, productive healthy and dignified lives. These improve participation in social and professional lives and enable them to compete in the market with those without disabilities. Damage to nerves leading to loss of autonomic, sensory and motor sensations, damage to nasal tissue and inflammation of iris and ciliary are the main primary impairments. These lead to ulcers, paralysis of muscles and contractures, loss of vision and collapse of nasal septum affecting activities of daily living. The fear of getting such deformities after contracting leprosy is considered as the main cause of stigma against leprosy. Assistive technology (AT) changes the equation in favour of the person by changing the environment and neutralizing the adverse impact caused by the environment.

AT facilitates overcoming challenges faced by the people with disabilities and facilitates day-to-day activities. The socio-economic benefits provided helps in reducing direct health and welfare costs, i.e.

reduction of hospital admission costs and state benefits. By improving functioning, the community is benefited with an enabled workforce and stimulates economic growth. The people feel enabled and can overcome the stigma to some extent. In many situations, it also helped improve productivity and contributed to economic growth of the family and the community. A variety of AT appliances and tools are available for improving function and capabilities of the person affected by leprosy, i.e. specialized microcellular (MCR) footwear, grip-aids to hands to improve pinch and grip functions, permanent prosthesis and plantar metatarsal pads are available. It is for the Government departments and NGOs working in leprosy programmes to identify the persons affected with disabilities due to leprosy in need of AT devices and help them access the devices.

Challenges persist in improving the reach of AT devices to the people affected by leprosy due to stigma against the disease, costs of the devices and coverage of the programme. It is prudent to note that people with disabilities have the same needs as others in terms of healthcare. The problem lies in the fact that the healthcare professionals are not skilled enough to provide healthcare for the people with disabilities. It is also observed that people with disabilities are denied healthcare or treated badly in the healthcare system. Half of the people with disabilities cannot afford health care. The people with disabilities are more likely to suffer 50% catastrophic health expenditure.

## **15.2. Mental health Issues – persons affected by leprosy**

The topic was introduced by Dr Nazneen Anwar, Regional Adviser, Mental Health, SEARO.

Multifaceted interactions are noted while discussing mental health issues experienced by persons affected by leprosy. Prevalence of mental health issues is higher among persons affected by leprosy. It remains a hidden phenomenon and has been found to be beyond the reach of healthcare systems. Leprosy and mental health conditions experience dual or rather compounded stigma. Having been shunned by the family, community and family members, leprosy patients face a high risk of developing psychiatric disorders. Long duration of illness and physical disability also increase the risk of psychiatric disorders. It is prudent to note that depression is the most common psychiatric disorder among people affected by leprosy. Depression and chronic stress have been associated with immune deficiency and possibly lead to a shift in the type of cellular immune response to pathogens. Depression reinforces the feelings of social exclusion and interferes with activities of daily living and reduces social interaction. In severe cases depression can push a person towards suicide.

Mainly due to lack of skills of healthcare workers in taking history, mental health issues go unidentified in most persons affected by leprosy. The signs and symptoms of concurrent mental health conditions and substance use disorders are not well elicited and documented. This resulted in a wide gap between what is needed and what is being offered.

Leprosy as a priority medical condition does not figure in the recommendations on mental health problems and in Guidelines on mental health issues. Very little research is done in this area. As a result, information on how to screen for mental health issues, how to manage persons affected by leprosy with mental health problems and possible interaction of anti-leprosy drugs and medicines used for treating mental health conditions.

Integrated care for persons with leprosy and mental health issues is helpful as it improves satisfaction levels of the persons affected, treatment compliance and optimal use of resources. It is prudent to identify leprosy as a medical condition with important mental health needs. Developing an integrated framework addressing leprosy and mental health issues facilitates providing holistic care for the persons affected. Leprosy treatment guidelines should include processes for screening, diagnosis and management of mental health and substance use disorders among persons affected by leprosy. An algorithm will help health workers to screen persons affected by leprosy for mental health issues. It will be useful to collect and document more information on mental health issues related to leprosy. Counselling at the time of diagnosis for persons affected by leprosy and their family members would be a useful for preventing and managing concurrent mental health and leprosy issues.

### **15.3. Lessons learnt from people living with HIV/AIDS movement in social mobilization and rights-based approach**

The topic was introduced by Ms Mona Balani of the HIV/AIDS Alliance India.

The history of HIV/AIDS has a similar story for leprosy in terms of the stigma faced by the persons affected. A female sex worker was diagnosed as the first case of HIV in India (in 1986) and followed by diagnosis of many cases. The epidemic pattern was the same as in other countries and it was more seen in high risk population who were “divergent” in nature and not conforming to “acceptable” societal norms, e.g. commercial sex workers, men having sex with men, injecting drug users. Mother-to-child transmission of infection, transfusion of unsafe blood and use of infected syringes were also identified as modes of transmission.

Between 1986 and mid-1990ies, HIV infection grew rapidly and cases were reported from every part of the country. It also caused quite a bit of discussion on how it happened and what has caused and the number of deaths and so on. Denial of presence of HIV for some time affected the progress on implementing the control programme. The inhibitions and taboo associated to talk about sex has adversely affected advocacy and communication about factual situation of HIV infection in the communities. A national programme was launched aiming at collecting information on the number of cases and communication to public about HIV. Estimates of five million persons infected and living with HIV or AIDS (PLHA) created a sense of fear, confusion and anger. PLHA and the persons associated with them faced stigma and discrimination in hospitals, society, families and by everyone in general. The Indian Network of People Living with HIV was formed in 1997. The movement got further support when the celebrities came out to provide support against stigma and discrimination.

Discriminatory instances happened such as children affected by HIV being thrown out of school and denying treatment for PLHA. Discrimination turned sometimes into ugly events (e.g. stoning of women). Between 2000 and 2010 the HIV/AIDS control programme achieved great results of expanding the reach of services to most of the infected persons with anti-retroviral treatment (ART) and preventive services to stop vertical transmission. Community-based organizations were involved to support HIV control activities from awareness raising to collecting information to increasing the reach of services to fight discrimination against PLHA and their families. The HIV and AIDS (Prevention and Control) Bill was passed in 2012 and was further amended in 2017, which ensures

reach of ART, preventive services and access to health care for other ailments. The protection mandated in the Bill also was extended to the fields of employment, healthcare services, educational services, public facilities, property rights, holding public office, and insurance.

Lessons that can be taken from HIV communities for strengthening participation of persons affected by leprosy in leprosy programmes were discussed during the presentation. The following were enlisted during the presentation:

- Invest in the affected communities – the returns are far greater;
- Believe in the fact the affected communities are best placed to know and inform what will work for them and how;
- Do not look at the affected communities as mere recipients of services;
- The stand-alone bio-medical model to public health does not work – there is a need to think and work holistically;
- The affected communities are not a homogenous group – they do not bind together because of an illness but because together they believe that they can make a difference.

## 16. Human rights and leprosy

The session was led by Mr Mathias Duck, Chairperson, ILEP Panel of men and women affected by leprosy.

*“Human rights are natural, fundamental and inalienable. They predate human existence, they are God given rights to human beings and as such these rights are transcendental and abstract as distinct from State conferred rights. Therefore, if human rights are natural, all human beings irrespective of any disease or impairment, race, or whatsoever should be accorded same right without discrimination”*

(Evarestus Lilibeth, attorney and person affected by leprosy)

The UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members is a very comprehensive guidance document. Crucial is in how far it is being put into practice. A questionnaire based on this document was circulated as part of a research project to know the experience of stigma of persons affected by Hansen’s disease. Responses from 265 countries were analyzed. The analysis indicated continued occurrences of discriminatory practices related to residence of the person affected, employability or marriage and access to public spaces including religious institutions, hospitals or schools. The responses also referred to the use of discriminatory language in communication and in the policy documents.

The participation of ‘state’ is minimal in the elimination of discrimination of persons affected. Participation of persons affected is not a routine practice in national leprosy programmes. Recurrent themes in different countries related to discrimination include abandonment of persons affected by their families or inability to access public transport.

Mr Duck's presentation was concluded with the following points:

- Discriminatory practices and language are still largely part of the experience of persons affected;
- There is little or no evidence as to the state's involvement in the elimination of discrimination against persons affected;
- Participation of people affected is still limited.

Good examples of reducing stigma and improving human rights of persons affected and getting the state more involved and committed are happening when affected persons are organized, e.g. the chapters of IDEA in Brazil (MORHAN), Ghana, India (APAL), Nepal, Nigeria and other countries, Ethiopia (ENAPAL), Indonesia (PerMaTa), China (HANDA), Paraguay (Felehansen), Philippines (CLAP) and several others.

The presenter voiced the issues raised and recommendations made by the ILEP Panel of women and men, as summarized in Box 1.

<b>Issues and recommendations related to stigma and discrimination against persons affected by leprosy</b>
<b>1. Participation and empowerment</b> <ul style="list-style-type: none"><li>➤ Research about meaningful and impactful participation and empowerment of persons affected among ILEP members and persons affected.</li><li>➤ Creation of local panels of persons affected to advise ILEP members and country programmes.</li><li>➤ Organization of national workshops about stigma and discrimination.</li><li>➤ Enable people affected to propose research topics and to be research partners.</li></ul>
<b>2. Communication with and among persons affected</b> <ul style="list-style-type: none"><li>➤ Translate important documents and information into local languages.</li><li>➤ Develop mechanisms or platforms for communication (facebook, app, newsletter, video, radio, television, toll-free number, etc.).</li></ul>
<b>3. Knowledge of situation and voice of people affected, especially women and children</b> <ul style="list-style-type: none"><li>➤ Mapping concerns of people affected, especially women and children.</li></ul>

Concrete steps, actions and mechanisms that increase meaningful and impactful participation of persons affected are the way forward. All stakeholders were solicited to be part of the process of empowering the community of persons affected by leprosy. There is an increasing need to discuss and decide on the language. MORHAN has recognized that changing the terminology from leprosy to Hansen's disease was fundamental in their achievements.



## 17. Group work

The Informal Consultation had participation of people from different backgrounds. Parliamentarians from leprosy endemic countries, persons affected by leprosy from different countries, leprosy programme managers, social activists and experts in the field of leprosy doctors and WHO staff were among the participants. Two groups were formed with participants from different backgrounds to discuss on the following topics:

- Status of discrimination against persons affected by leprosy and their family members; information on laws or policies that allow discrimination against leprosy;
- Steps to be taken to mitigate discrimination and abolish laws that discriminate on the basis of leprosy.

The terms of reference were drawn to get acceptable understanding on issues like definition of stigma and measurable indicators for discrimination. The experience and expertise of individual members enriched the discussions. Information available from research studies in reducing stigma and discrimination against persons affected by leprosy was referred extensively during the group work. The discussion covered ways of collecting information on discrimination in the absence of a systematic reporting mechanism. The group recommended indicators to assess or monitor a reduction (or surge) in discrimination against leprosy.

The key points discussed were:

- (i) collecting information on discrimination faced by persons affected and their family members;
- (ii) instances of discrimination (community, healthcare settings, educational institutions, workplaces, religious places, other settings);
- (iii) status of implementation of the UN Principles and Guidelines;
- (iv) factors allowing discrimination on the basis of leprosy (laws/legislations at international, national and sub-national level, policies, procedures, community practices);
- (v) models for assessing stigma and discrimination (indicators to measure status and progress in mitigating discrimination; research activities; media reporting cases, other).

The group also deliberated on the efforts made by countries in implementing the UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members and enact legislations or laws that allow discrimination against leprosy.

The presentations from both groups were consolidated in the following text. Participation of persons affected by leprosy enriched the discussions with accounts of experiences of discrimination. Salient points emanating from the group discussions are summarized. Experiences from the persons living with HIV in organizing communities and influencing policies were given useful insights to the participants in deciding on the recommendations. The presentations from both the groups are summarised below.

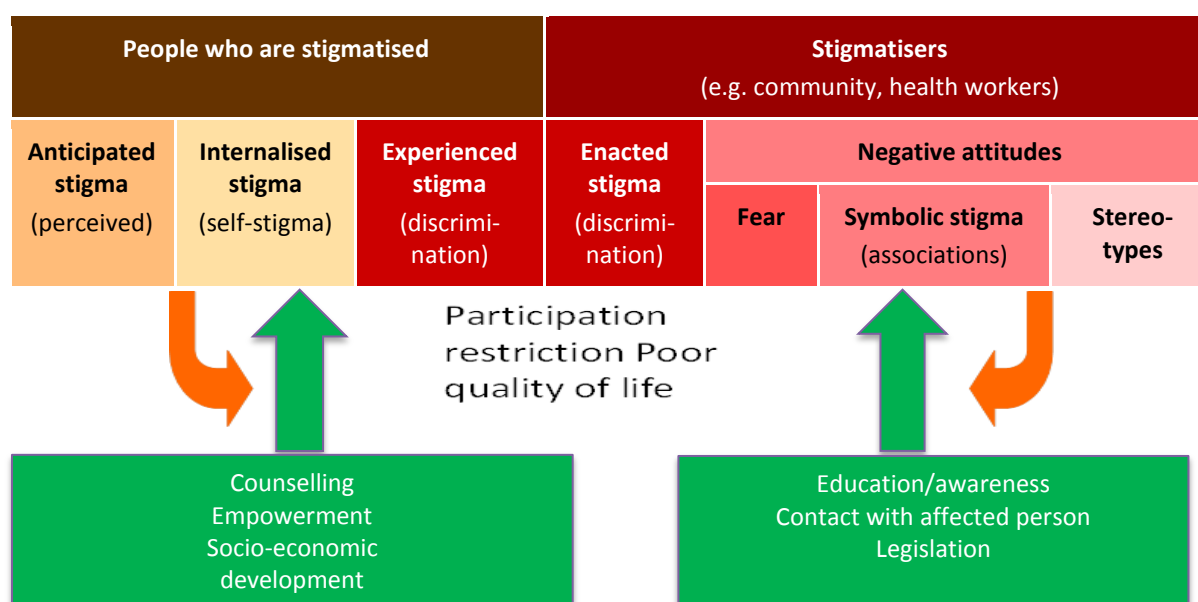
## Understanding of stigma

Stigma refers to attitudes and beliefs that lead people to reject, avoid or fear those they perceive as being different. Discrimination is understood from any action, inaction, document or behaviour, which results in a differential treatment of an individual or a specified group, minority or community that is negative in both or either its consequence and impact. While stigma is an attitude or belief, discrimination is behavioural because of those attitudes or beliefs. Stigma is a dynamic phenomenon. It is a process of devaluing a person.

Discrimination occurs in the family, community, educational facility, healthcare setting, workplace, place of worship or other setting. The impact of disclosure towards family or community members is different. Though discrimination is generally frowned upon, from a community perspective it originated as a social protection mechanism to safeguard the family and the community.

Figure 1 shows an intervention model of stigma.

Fig. 1: *Intervention model of stigma*



Globally, there are likely several discriminatory laws and/or practices and it is time all the policies, laws and legislations are compiled and documented. This implies that discrimination of affected persons may actually be very common. This calls for two sets of actions, i.e. collecting information on instances of discrimination and defining processes to revise/amend/repeal societal practices, policies, laws and legislations that allow discrimination against is elementary to eliminate discrimination.

## Collecting information on instances of discrimination

The group discussed the processes of reporting discrimination against persons affected by leprosy and found that there are no mechanisms in place to recognize or report. The groups strongly recommended that reporting should be encouraged through a dedicated point, with prerequisite

steps to ensure confidentiality. The processes followed in collecting information on prevention of sexual abuse might also be used as an example for discussion. Committees need to be created at district level which can take responsibility to address discrimination against persons affected by leprosy and their family members.

Health worker or persons responsible for treatment can be authorized to collect information about occurrence of discrimination while speaking with persons affected by leprosy. This option should be extended to also to persons affected by leprosy who have been cured. In India ASHAs could also collect information in the society and occasionally at family level and report any forms of discrimination to health workers, counsellors or designated persons.

The group during discussions also suggested that making a toll-free number available might improve the opportunities for persons affected by leprosy and those experiencing discrimination to report their experiences.

With regard to measuring the levels of discrimination, the following indicators were proposed, i.e., Social Participation Score, Community Stigma Score (e.g. five-question indicator or social distance scale), number of cases of discrimination reported (through tele calling/ counselor), media reports/articles, score of stigma experienced by people affected by leprosy (e.g. SARI Scale). The need for standardizing these scores at national level was emphasized by the experts in the group.

The following mechanisms were suggested to measure change in discriminatory practices: sentinel surveillance which can collect information and provide feedback, periodic surveys to monitor trends, 'MeToo' campaign. Social media campaign may be effective in amplifying positive (or negative) stories of discrimination. This will also help in garnering political commitment.

While discussing the ways of mitigating stigma and discrimination the following steps were considered by the group.

Tele-counselling facility accessible to persons affected was one of the options suggested to manage discrimination. The position of United Nations Special Rapporteur is considered as an opportunity to discuss discrimination at the global platform and advocate to Member States to address issues related to UN Principles and Guidelines to eliminate discrimination against persons affected by leprosy and their family members.

At the community level, communications should be developed to raise awareness about leprosy and include leprosy in the curriculum of students aiming at changing the mindset of the people. This gradually is expected to break prejudices and reset the stereotypes. The group also recommended scanning the documents related to policies, laws and other national documents to detect derogatory words or expressions about leprosy and advocate for replacing them with dignified terminology.

The group recommended research studies to design or objectively assess stigma reduction initiatives. Studies to investigate and assess involvement of persons affected by leprosy are encouraged by the group.

The group discussed about laws that allow discrimination against persons affected by leprosy. It was generally agreed that in presence of such discriminatory laws efforts to eliminate discrimination against persons affected by leprosy must continue. The group recommended that WHO and all

national programmes should make an inventory of discriminatory provisions, laws and policies at national and at sub-national levels which should be disseminated to relevant stakeholders. National programme managers and respective ministries dealing with social justice, equity, law enforcement need to be oriented on the current leprosy situation and informed that such discriminatory laws are obsolete. The need for repealing or amending such laws should also be emphasized. Policy makers (including law makers) need to be sensitized and the advocacy initiatives need to be sustained. Coalitions need to be formed including persons affected by leprosy, NGOs working in the field of leprosy, parliamentarians and national programme officials and experts from the ministry of law and social justice need to be formed to make concerted effort to get the discriminatory laws repealed/amended. The Inter-Parliamentary Union may provide a platform for meetings of parliamentarians to discuss repealing discriminatory laws against leprosy.

## **18. Closing session**

### **18.1. Conclusions**

The participants acknowledged the fact that stigma and discrimination related to leprosy still exists at a significant level.

Participants appreciated that the Global Leprosy Strategy 2016–2020 recognized stopping discrimination and promoting inclusion as a core component in the fight against leprosy and identified the target of zero countries with discriminatory laws as one of the principal targets of the strategy.

Assessment and policy instruments and information tools are available to address stigma and discrimination developed by national and international agencies. A Special Rapporteur was appointed by the UN High Commissioner for Human Rights showing increased priority for documenting discrimination against persons affected by leprosy.

Data on stigma and discrimination are not routinely collected by national programmes or other stakeholders. As a result it is difficult to measure or assess extent of stigma and discrimination against persons affected.

Participants appreciated the efforts of providing a platform for a diverse group of stakeholders such as parliamentarians, national programmes, international organizations and networks of persons affected by leprosy, including experts on mental health and assistive technology and HIV programme to deliberate on stigma and discrimination related to leprosy.

Leprosy is a treatable disease. However social consequences can persist even after medical treatment is completed. These need to be addressed by providing holistic services for the persons affected by leprosy.

## 18.2. Recommendations

### *Recommendations to national leprosy programmes*

National programmes should be strengthened in order to address issues related to stigma, discrimination and other social issues related to leprosy and take appropriate remedial measures.

A multi-disciplinary and multi-sectoral accountability framework and mechanism should be developed involving relevant ministries, persons affected by leprosy, parliamentarians, NGOs, professional bodies, corporate sector and community-based organizations to address issues related to stigma and discrimination.

Meaningful and impactful engagement of persons affected by leprosy should be ensured at all decision-making levels in leprosy programmes.

Any derogatory language and/or expression in national laws, legislations, policies and documents need to be replaced by dignified language in line with the UN Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members.

Counselling should be included as an integral part of leprosy services and should be undertaken by professional counsellors, peer-counsellors or persons duly trained in providing counseling services.

A community-based surveillance system should be developed to screen for leprosy and its complications and to identify and report on incidences of stigma and discrimination in the community.

Capacity building activities should be undertaken in order to improve knowledge, skills and attitudes of healthcare staff in providing services to the persons affected by leprosy.

A suitable mechanism should be established to get incidences of discrimination reported and addressed in a systematic manner and also inform facts about leprosy to the community, e.g. through a toll-free telephone helpline.

National programmes through a designated qualified focal person should ensure availability of proper documentation and facilitate access to Assistive Technology devices, social entitlements such as pensions, right to welfare measures, etc. for the treated patients in need.

National programmes should reach out to all patients, both residing in the community as well as in colonies.

### *Recommendations to WHO*

WHO should develop a long-term engagement with parliamentarians in the elimination of stigma and discrimination, thereby working with the Inter-Parliamentary Union to accelerate efforts in amending or abolishing discriminatory laws against leprosy and to take affirmative legislative actions.

WHO should support national programmes in implementing activities to enhance the use of assistive technology to improve functional ability, stop discrimination and promote inclusion of persons affected by leprosy.

WHO should develop guidelines for counselling in collaboration with WHO departments, experts in mental health and ILEP.

### *Recommendations to ILEP and other NGOs*

The extent of disability should be defined depending on functional status of persons affected by leprosy in order to mainstream with other disabilities enabling access to social entitlements at par with persons with disabilities due to other diseases.

The magnitude of needs relating to various aspects of leprosy should be assessed, e.g.:

- ✓ instances of discrimination
- ✓ human rights violations
- ✓ medical interventions,
- ✓ reconstructive surgery needs
- ✓ assistive devices
- ✓ employment opportunities
- ✓ social entitlements
- ✓ policies and Government regulations

Persons affected by leprosy should be engaged in the set-up and/or strengthening of networks of persons affected at global, regional and national levels working towards their greater involvement in the health programmes.

### *Recommendations for persons affected by leprosy*

Persons affected by leprosy should play an active role in planning, implementation, monitoring, evaluation of national programmes, counselling, education and communication, advocacy and service delivery through an institutional arrangement by national programmes

The capacity and leadership of persons affected by leprosy at all levels should be enhanced for more effective participation

The participants strongly recommended that leprosy programmes should adopt a 'rights-based approach' in line with the SDGs.

# Annex 1

## Programme

Day 1: Tuesday 14 November 2017	
09:00 – 10:00 hrs	<b>Inaugural address</b> – Dr Poonam Khetrapal Singh, Regional Director <b>Opening remarks by persons affected by leprosy</b> – Mr Kofi Nyarko, IDEA Ghana <b>Welcome address by host country</b> – Dr Anil Kumar, Deputy Director General (Leprosy), India <b>Keynote address</b> – H.E. Saber H. Chowdhury MP, former President, Inter-Parliamentary Union <b>Objectives and expected outcomes of the Informal Consultation</b> – Dr Erwin Cooreman, Team Leader, WHO GLP <b>Introduction of participants</b>
10:00 – 10:30 hrs	Coffee/Tea Break
10:30 – 11:00 hrs	<b>Global leprosy situation</b> – Dr Erwin Cooreman, Team Leader, GLP
11:00 – 11:40 hrs	<b>Stigma, discrimination and inclusion – definitions, conceptual framework and tools for assessment and monitoring</b> – Dr Wim van Brakel, NLR
11:40 – 12:00 hrs	<b>Stopping stigma and discrimination and promoting inclusion – activities and indicators Global Leprosy Strategy 2016–2020</b> – Dr VRR Pemmaraju, Technical Officer, GLP
12:00 – 12:30 hrs	<b>Chronology of events in stopping discrimination against leprosy and promoting inclusion of persons affected by leprosy</b> – Professor Takahiro Nanri, Executive Director SMHF
12:30 – 13:00 hrs	<b>Evidence on effective interventions in reducing stigma and discrimination against persons affected by leprosy</b> – Dr Pim Kuipers
13:00 – 14:00 hrs	Lunch break
14:00 – 15:00 hrs	<b>Discrimination against leprosy – status and steps being taken presentation by national programmes</b> – Bangladesh; Brazil; Ethiopia
15:00 – 16:00 hrs	<b>Discrimination against leprosy – status and steps being taken presentation by national programmes</b> – India; Indonesia; Nepal
16:00 – 16:30 hrs	Coffee/Tea Break
16:30 – 17:30 hrs	<b>Discrimination against leprosy – status and steps being taken presentation by national programmes</b> – Sudan; Tajikistan; Philippines

Day 2: Wednesday, 15 November 2017	
09:00 – 09:30hrs	<b>Integrating leprosy in national disability prevention and mitigation policies and strategies</b> – Ms Nikita Sarah, Head - Advocacy & Communication, The Leprosy Mission Trust India.
09:30 – 10:00 hrs	<b>Laws and legislations that discriminate on the basis of leprosy</b> – Mr John Kurian George, Coordinator, ILEP in India
10:00 – 10:30 hrs	<b>Repealing of Leprosy Act – Bangladesh Experience</b> – H.E. Saber H Chowdhury MP, Honorary President, Inter-Parliamentary Union
10:30 – 11:00 hrs	Coffee/Tea Break
11:00 – 12:30 hrs	<b>Improving political commitment for elimination of discrimination against leprosy – Perspectives of Members of Parliament</b> Moderator: H.E. Saber H Chowdhury, MP
12:30 – 13:30 hrs	Lunch break

13:30 – 14:00 hrs	<b>Discrimination – Leprosy colonies and social integration process and barriers faced in accessing health care and welfare measures</b> Experience in Ghana – Kofi Nyarko, IDEA Ghana Experience in India – V Narsappa, APAL India
14:00 – 14:30 hrs	<b>Social marketing and economic rehabilitation experiences in addressing stigma</b> Experience in Nepal – Amar Bahadur Tamalsina, IDEA Nepal Experience in India – KK Mathews, MESH India
14:30 – 15:00 hrs	<b>Community-based rehabilitation and Partnership with national leprosy programmes –</b> Tesfaye Tadesse, ENAPAL, Ethiopia; Dr MV Jose, AIFO, India
15:00 – 15:30 hrs	Coffee/Tea Break
15:30 – 15:45 hrs	<b>Collaborative approaches in strengthening leprosy control and access to health care</b> Experience in the Philippines – Dr Francisco Onde, CLAP, The Philippines
15:45 – 16:00 hrs	<b>Restoring dignity to the persons affected by leprosy</b> Experience in India – Dr Vineeta Shankar, SILF
16:00 – 16:30 hrs	<b>Access to assistive technology for leprosy patients and former patients for disability prevention and mitigation</b> – Dr Patanjali Nayar, Regional Adviser, Disability prevention, injuries and rehabilitation
16:30 – 17:00 hrs	<b>Mental health Issues – persons affected by leprosy</b> – Dr Nazneen Anwar, Regional Adviser, Mental Health

Day 3: Thursday 16 November 2017			
09:00 – 09:30 hrs	<b>Lessons learnt from people living with HIV/AIDS movement in social mobilization and rights-based approach</b> – Ms Mona Balani, Programme Officer, India HIV/AIDS Alliance		
09:30 – 10:00 hrs	<b>Human rights and leprosy</b> – Mathias Duck, ILEP Panel of Men and Women affected by leprosy		
10:00 – 10:30 hrs	Coffee/Tea Break		
10:30 – 12:30 hrs	<p style="text-align: center;"><b>Group work</b></p> <table border="1"> <tr> <td> <p><b>Group 1</b></p> <ul style="list-style-type: none"> <li>Status of discrimination against persons affected by leprosy and their family members; Information on laws, policies that allow discrimination against leprosy</li> <li>Steps to be taken to mitigate discrimination and abolish laws that discriminate on the basis of leprosy</li> </ul> </td><td> <p><b>Group 2</b></p> <ul style="list-style-type: none"> <li>Barriers experienced by persons affected by leprosy in accessing health care and in society</li> <li>Actions for greater involvement of persons affected by leprosy in their social integration and in healthcare</li> </ul> </td></tr> </table>	<p><b>Group 1</b></p> <ul style="list-style-type: none"> <li>Status of discrimination against persons affected by leprosy and their family members; Information on laws, policies that allow discrimination against leprosy</li> <li>Steps to be taken to mitigate discrimination and abolish laws that discriminate on the basis of leprosy</li> </ul>	<p><b>Group 2</b></p> <ul style="list-style-type: none"> <li>Barriers experienced by persons affected by leprosy in accessing health care and in society</li> <li>Actions for greater involvement of persons affected by leprosy in their social integration and in healthcare</li> </ul>
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12:30 – 13:30 hrs	Lunch break		
13:30 – 15:00 hrs	<b>Feedback from groups</b> Moderators: National Programme Managers India and Indonesia; Dr Wim van Brakel, ILEP Technical Commission; Mr Tesfaye Tedesse		
15:00 – 15:30 hrs	Coffee/Tea Break		
15:30 – 16:30 hrs	<b>Conclusions and closing</b>		



## Annex 2

### List of participants

#### ***Focal persons from National Leprosy Programmes***

1. Dr Md. Shofiqul Islam  
Deputy Director (MBDC) & Programme Manager (Leprosy)  
Directorate General of Health Services,  
Mohakhali, Dhaka  
People's Republic of Bangladesh
2. Dr Anil Kumar  
Deputy Director General (Leprosy)  
Ministry of Health and Family Welfare  
New Delhi  
India
3. Dr A K Puri  
Additional Director General (Leprosy)  
Ministry of Health and Family Welfare  
New Delhi  
India
4. Mr K V S Rao  
Director  
Department of Empowerment of Persons with Disability  
Ministry of Social Justice and Empowerment  
New Delhi  
India
5. Dr K S Baghotia  
State Leprosy Officer  
Directorate of Health Services  
Government of Delhi  
New Delhi  
India
6. Dr Mohammad Daud  
Director  
Leprosy Control Division  
Ministry of Health  
Kathmandu  
Nepal
7. Dr Md. Salah El Tahir El Samani  
Federal Ministry of Health  
Khartoum  
Sudan
8. Mr Taye Letta  
Federal Ministry of Health  
Addis Abeba  
Federal Democratic Republic of Ethiopia
9. Dr Tifanny Tiara Pakasi  
Head of Leprosy Section  
Ministry of Health  
Jakarta  
Indonesia
10. Dr Ade Erma  
Finance and Planning  
Ministry of Health  
Jakarta  
Indonesia
11. Dr Munira Karimova  
Deputy Director  
City Clinical Infectious Diseases Hospital  
Dushanbe  
Tajikistan

#### ***Persons affected by leprosy***

12. Mr V Narsappa  
President  
Association of People Affected by Leprosy  
Hyderabad  
India
13. Mr Kofi Nyarko  
IDEA Ghana  
Accra  
Ghana

14. Sr Francisco Faustino Pinto  
MORHAN  
Conselheiro do Conselho Nacional de  
Saúde, Brasília  
Brazil

15. Mr Francisco D Onde\*  
Coalition of Leprosy Affected People  
Jagobiao, Mandaue City, Cebu  
The Philippines

16. Mr Amar Bahadur Timalisina  
Kathmandu  
Nepal

17. Mr Mathias Duck  
Chair, ILEP Panel of women and men  
affected by leprosy  
Geneva  
Switzerland

18. Mr Paulus Manek  
Head  
PerMaTa  
Jakarta  
Indonesia

19. Mrs P K Jayashree  
Goodbye Leprosy Trust India  
Bengaluru  
India

#### ***Members of Parliament***

20. H.E. Saber H. Chowdhury MP  
Honorary President  
Inter-Parliamentary Union  
Dhaka  
Bangladesh

21. H.E. Pritam Gopinath Munde MP \*  
Honorable Member of Lok Sabha  
New Delhi  
India

22. H.E. V Maitreyan MP \*  
Honorable Member of Rajya Sabha  
New Delhi  
India

23. H.E. Ayub Khan MP  
Member of House of Representatives  
Jakarta  
Indonesia

#### ***WHO TAG Member***

24. Mr Tadesse Tesfaye Haile  
ENAPAL  
Addis Ababa  
Ethiopia

#### ***Experts***

25. Dr Wim Van Brakel  
Head, Technical Department  
Netherlands Leprosy Relief  
Amsterdam  
The Netherlands

26. Ms Mona Balani  
Programme Officer  
India HIV/AIDS Alliance  
New Delhi  
India

27. Dr Willem (Pim) Kuipers  
Project Officer  
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#### ***Local Participants***

28. Dr Vineeta Shanker  
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29. Mr K K Mathew  
Chief Manager  
MESH  
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| <p>30. Mr B Vijayakrishnan<br/>Fontilles India<br/>Secunderabad<br/>India</p> <p>31. Mr John Kurien George<br/>Fairmed/Emmaus Swiss-India<br/>Gurugram<br/>India</p> <p>32. Dr Mary Verghese<br/>Director<br/>The Leprosy Mission Trust India<br/>New Delhi<br/>India</p> <p>33. Ms Nikita Sarah<br/>The Leprosy Mission Trust India<br/>New Delhi<br/>India</p> | <p>38. Dr Alexandre Tiendrebeogo<br/>Regional Adviser (Neglected Tropical Diseases)<br/>Regional Office for Africa</p> <p>39. Dr Md. Jamsheed Ahmed<br/>Regional Adviser (Neglected Tropical Diseases)<br/>Regional Office for Southeast Asia</p> <p>40. Dr Patanjali Dev Nayar<br/>Regional Adviser (Disabilities, Injury Prevention and Rehabilitation)<br/>Regional Office for South-East Asia</p> <p>41. Dr Nazneen Anwar<br/>Regional Adviser (Mental Health)<br/>Regional Office for South-East Asia</p> <p>42. Dr Rashmi Shukla<br/>Focal person for leprosy<br/>WHO Country Office for India</p> |
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**Observer**

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| <p>34. Professor Takahiro Nanri<br/>Executive Director<br/>Sasakawa Memorial Health<br/>Foundation<br/>Tokyo<br/>Japan</p> | <p>43. Ms Indu Gulhar<br/>Executive Assistant<br/>Global Leprosy Programme<br/>Regional Office for South-East Asia</p> |
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*\*invited but unable to attend*

**WHO Secretariat**

35. Dr Erwin Cooreman  
Team Leader  
Global Leprosy Programme  
Regional Office for South-East Asia
36. Dr Laura Gillini  
Medical Officer  
Global Leprosy Programme  
Regional Office for South-East Asia
37. Dr V R R Pemmaraju  
Technical Officer  
Global Leprosy Programme  
Regional Office for South-East Asia

An Informal Consultation on Stopping Discrimination and Promoting Inclusion of Persons Affected by Leprosy was held in New Delhi from 14 to 16 November 2017. Forty delegates with diverse backgrounds, experience and expertise enriched the discussions. Persons affected by leprosy brought to the table the challenges faced in daily life and suggested actions to be taken to reduce stigma and discrimination related to leprosy.

Representatives of national programmes presented actions taken in their respective countries.

Key recommendations from the consultation included counselling and reporting of incidences of discrimination. Efforts should be continued to inform facts about leprosy to the community.

The participants strongly recommended that leprosy programmes should adopt a 'rights-based approach' in line with the Sustainable Development Goals .



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