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	*Associazone Italiana Amici di Raoul Follereau* (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