

# **Guidelines for strengthening participation of persons affected by leprosy in leprosy services**



**World Health  
Organization**

Regional Office for South-East Asia

# Guidelines for strengthening participation of persons affected by leprosy in leprosy services

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## Executive summary

The involvement of persons affected by leprosy in key activities of leprosy services has long been considered essential. Yet it has received scant attention by those delivering the services. There has been a lack of awareness among policy makers about the importance of including those individuals for whom the services are designed, as well as recognition of the significant contributions that people who have experienced leprosy have made to their communities and the world. However, during the last decade it has increasingly been recognized that people who have personally experienced the disease are important partners in their treatment. Ensuring that persons affected by leprosy are the central focus of the programme will have profound implications for the way that services are planned, delivered and evaluated.

These guidelines have been developed in consultation and active partnership with persons affected by leprosy. The change from a provider-centred approach, to an individual-centred one aimed at shared responsibility and shared decision-making is not simple; it requires greater commitment to and significant adjustment in programme structure and service delivery. It also recognizes that the family members of the person affected by leprosy also play an important role in assisting the individual in their daily lives and in addition help in the delivery of leprosy services. Through this re-orientation, the benefits could be enormous, with significant qualitative improvements in leprosy service and empowerment of persons affected by leprosy.

Several strategic issues have been identified, which have been classified as either primary or operational. The primary issues are stigma and discrimination; equity, social justice and human rights; and gender. The operational issues are information, education, communication; advocacy; counselling; training and capacity building; referral; prevention of disability; rehabilitation; and planning and management including monitoring of services; resource mobilization; research, and monitoring and evaluating the process of facilitating the involvement of persons affected by leprosy.

The central theme of the guidelines is to recognize the expertise of individuals who have had the disease and, through partnership, enable these individuals to support in the delivery of leprosy services. Efforts should be made to promote opportunities for each individual to realize ways in which they can be involved in leprosy services. This will ultimately lead to individuals affected by leprosy having equal access to quality services and being respected in their roles as contributing members of society.

It is essential for programmes to foster partnership with persons affected by leprosy and their families, and for civic groups to provide the means for capacity building through training and support, so that people affected by leprosy can effectively participate in leprosy services.

Facilitating the participation of persons affected by leprosy is not simple. It is essential to document the process and results, provide feedback on lessons learned, and disseminate the results to a wider audience to expand the process.

## **Definitions and terminology**

In the context of these guidelines, the term “persons” and “individuals” refers to all people currently under treatment for leprosy and individuals cured from leprosy. People no longer receiving treatment should not be referred to as “patients” outside of the medical setting.

It is important to always refer to individuals using the term “person” first. For example, say “a person affected by leprosy” or “a person affected by Hansen’s disease”. This is preferred to “leprosy-affected person” since using the term “person” first emphasizes a common humanity and makes leprosy secondary. When referring to a person affected by leprosy in other languages the concept of “person” first should be followed and appropriate translation made accordingly taking into account the local situation.

Offensive terms such as “leper” or the equivalent in any language or dialect should not be used.

Labels such as “victim,” “sufferer”, and descriptions such as “deformed”, or acronyms such as “PAL,” or “LAP” that do not recognize an individual as separate from the disease should not be used.

## **Acronyms**

IDEA	International Association for Integration, Dignity and Economic Advancement
IEC	information, education and communication
ILEP	International Federation of Anti-Leprosy Associations
NGO	nongovernmental organization
POD	prevention of disability
SMHF	Sasakawa Memorial Health Foundation
UNHRC	United Nations Human Rights Council
WHO	World Health Organization

## Introduction

*“Leprosy is not merely a disease, but a challenge to fellowship . . . There are things that speak to man with ancestral voices, demanding from the enlightened today the redress of the ancient wrongs of the dark past, and leprosy is one of them . . .”* Professor T.N. Jagadisan, India, editor, author, teacher and social worker who personally faced the challenges of leprosy.

The stigma associated with leprosy, which has prevailed in virtually every culture and has resulted in discrimination, stereotypes, labelling, and ultimately the exclusion of individuals affected by leprosy from equal participation in society. Adoption by the UN General Assembly on 21 December 2010 of the resolution on Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members was a milestone.

In June 2010, the World Health Organization conducted an historic meeting in Manila to formalize *Guidelines for strengthening the participation of persons affected by leprosy in leprosy services*. Half of the identified experts were individuals who had personally experienced the challenges of leprosy. The guidelines attempt to help programme managers identify areas where persons affected by leprosy can be involved and suggest relevant strategies to involve individuals to improve and strengthen leprosy services in endemic countries.

Actions directed at strengthening the involvement of persons affected by leprosy should become an integral part of the greater effort directed at the disabled in general which includes other disadvantaged persons also.

Of the 14 issues identified, three are considered primary: stigma and discrimination; equity, social justice and human rights; and gender. The remaining 11 are operational: information, education, communication; advocacy; counselling; training and capacity building; referral; prevention of disability; rehabilitation; planning and management;

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