

# **Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities**

**(Plan period: 2006–2010)**



**World Health Organization**

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Sustaining Leprosy Control Activities**

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## **Acronyms**

BCG	bacillus Calmette-Guerin
IEC	information, education and communication
MB	multibacillary leprosy
MDT	multidrug therapy
NGO	nongovernmental organization
PB	paucibacillary leprosy
WHO	World Health Organization



## **Executive summary**

The main principles of leprosy control, based on timely detection of new cases and their treatment with effective chemotherapy in the form of multidrug therapy, will not change over the coming years. The emphasis will remain on providing quality patient care that is equitably distributed, affordable and easily accessible. At the moment, there are no new technical tools or information that warrant any drastic changes in the strategy for leprosy control.

However, there is an urgent need to make decisive changes in the organization of leprosy control, in the attitude of health care providers and beneficiaries, and in the working arrangements between all partners.

The main elements of the strategy are as follows:

- sustain leprosy control activities in all endemic countries
- use case detection as the main indicator to monitor progress
- ensure high-quality diagnosis, case management, recording and reporting in all endemic communities
- strengthen routine and referral services
- discontinue the campaign approach
- develop tools and procedures that are home/community-based, integrated and locally appropriate for the prevention of disabilities/impairments and for the provision of rehabilitation services
- promote operational research in order to improve implementation of a sustainable strategy
- encourage supportive working arrangements with partners at all levels.

This strategy will require endorsement and commitment from everyone working towards the common goal of controlling leprosy, to ensure that the physical and social burden of the disease continues to decline throughout the world.

**Brief description of the disease**

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*. It usually affects the skin and peripheral nerves, but has a wide range of clinical manifestations. The disease is classified as paucibacillary or multibacillary, depending on the bacillary load. Paucibacillary leprosy is a milder disease characterized by few (up to five) hypopigmented, anaesthetic skin lesions (pale or reddish). Multibacillary leprosy is associated with multiple (more than five) skin lesions, nodules, plaques, thickened dermis or skin infiltration, and in some instances, involvement of the nasal mucosa, resulting in nasal congestion and epistaxis. Involvement of certain peripheral nerves may also be noted, sometimes resulting in the characteristic patterns of disability. In most cases of both paucibacillary and multibacillary disease, the diagnosis is straightforward, but in a small proportion of cases, suspects without anaesthetic patches require examination by a specialist to look for other cardinal signs of the disease, including nerve involvement and a positive laboratory test (the slit skin smear), if reliably available.

Among communicable diseases, leprosy is a leading cause of permanent physical disability. Timely diagnosis and treatment of cases, before nerve damage has occurred, is the most effective way of preventing disability due to leprosy; effective management of leprosy complications, including reactions and neuritis, can prevent or minimize the development of further disability. The disease and its associated deformities are responsible for social stigma and discrimination against patients and their families in many societies. The mode of transmission of the leprosy bacillus remains uncertain, but most investigators believe that *M. leprae* is spread from person to person, primarily as a nasal droplet infection. The incubation period is unusually long for a bacterial disease, generally 5-7 years. The peak age of onset is young adulthood, usually 20-30 years of age; disease is rarely seen in children less than five years old. While humans are considered to be the major host and reservoir of *M. leprae*, other animal sources, including the armadillo, have been incriminated as reservoirs of infection. The epidemiological significance of these findings is unknown, but is likely to be very limited, except perhaps in North America. Unlike tuberculosis, there is no evidence to suggest that an association exists between HIV infection and leprosy. BCG vaccination is known to have some protective effect against the disease.

# Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities

(Plan period: 2006–2010)

## 1 Introduction

The WHO Strategic Plan for Leprosy Elimination 2000–2005<sup>1</sup> encouraged commitment among endemic countries in dealing with the challenges posed by the disease. The most important component of the strategy was to ensure that leprosy control activities would be available and accessible to all affected individuals at their nearest health facility. (Leprosy control activities include diagnosis, treatment with multidrug therapy (MDT), patient and family counselling, community education, prevention of disabilities/impairments, rehabilitation and referral for complications.) The large-scale implementation of the Strategic Plan increased coverage for leprosy control activities and brought many undetected cases to health facilities for treatment. However, in many endemic countries, the Plan's implementation was slow. In addition, the continued reliance on specialized personnel and institutions inhibited the process of building up the capacity and competence of general health workers to take responsibility for leprosy control in their own area. The Strategic Plan 2000–2005 had as its goal the elimination of leprosy as a public health problem, defined as reduction of prevalence to fewer than one case per 10 000 population nationally. The Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities 2006–2010 is a natural evolution of the Strategic Plan, designed to address the remaining challenges and further reduce the disease burden due to leprosy.

The main principle of leprosy control is “morbidity control”, i.e. timely detection of new cases, their treatment with effective chemotherapy in the form of multidrug therapy, prevention of disability and rehabilitation. This will not change over the coming years. The emphasis will remain on providing diagnostic and treatment services that are equitably distributed, affordable and easily accessible. At the moment, there are no new technical tools or information which warrant any significant changes in the strategy.

This document presents an overview of the Global Strategy. Together with the more detailed operational guidelines (to be published in the course of 2005) they will enable countries to develop their own country-specific strategy and plans of action.

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<sup>1</sup> World Health Organization. *The final push towards elimination of leprosy: strategic plan 2000–2005* (document WHO/CDS/CPE/CEE/2000.1). Geneva, 2000.

## 1.1 Major achievements of the elimination strategy

The significant achievements in reducing the global burden of leprosy over the last two decades are the result of two important events in the history of the fight against leprosy. The first event took place in 1981, when a WHO Study Group on Chemotherapy of Leprosy recommended the use of multidrug therapy as the standard treatment for leprosy.<sup>1</sup> The success of multidrug therapy led to the second event in 1991, when the Forty-fourth World Health Assembly passed resolution WHA44.9,<sup>2</sup> declaring its commitment to eliminating leprosy as a public health problem by the end of 2000 – i.e. achieving a prevalence of less than one case per 10 000 population.

- Between 1985 and the beginning of 2005, more than 14 million leprosy cases were diagnosed and had completed treatment with multidrug therapy, with very few relapses reported.
- The number of countries reporting prevalence rates above one per 10 000 population has been reduced from 122 in 1985 to nine at the beginning of 2004.
- There has been a considerable increase in coverage of leprosy services in hard-to-reach areas and in underserved populations.
- Since 1995, the drugs required for multidrug therapy have been available free of charge in all endemic countries through WHO.
- There is now increased awareness and political commitment in all endemic countries.
- There is increased acceptance of the idea of integrating leprosy control services into general health services, and this is being implemented as a policy in most countries.

## 1.2 Background and justification

In view of the need to sustain leprosy services for many years to come, there has to be a shift from a campaign-like elimination approach towards the long-term process of sustaining integrated, high-quality leprosy services which, in addition to case detection and treatment with multidrug therapy, also include prevention of disability and rehabilitation. There is an opportunity for this process to build on the gains made by the elimination campaign, such as increased awareness of leprosy, political commitment and the involvement of the general health services.

Even though the leprosy burden has been reduced substantially, new cases of leprosy will continue to appear for the foreseeable future in most of the currently endemic countries. The basic principles for leprosy control beyond the year 2005 will continue to be based on early detection and treatment of leprosy patients. Health services must continue to provide quality services for leprosy control to these communities over a foreseeable period of time. Special expertise in leprosy and its control needs to be maintained at national and subnational levels. Such specialized leprosy units should serve as focal

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<sup>1</sup> World Health Organization. *Chemotherapy of leprosy for control programmes: report of a WHO Study Group* (WHO Technical Report Series, No. 675). Geneva, 1982.

<sup>2</sup> Available online at [www.who.int](http://www.who.int), “Governance” (accessed 8 June 2005).

points for leprosy work, dealing with technical issues and coordinating activities as part of the overall national health plan. However, it is best to have these specialized units integrated within services provided for other endemic diseases. A central unit, usually housed within the Ministry of Health, should be responsible for advocacy, policy formulation, technical guidance, technical training, planning, monitoring and evaluation. Specialized components must also be available within the general health service at intermediate levels for technical supervision, advice, referral services (including those in hospitals) and research. Depending upon local conditions (e.g. the incidence and prevalence of leprosy; the availability and level of training of various categories of health staff), each country or region must decide at which level of the health system such specialized support should be available. In very low-prevalence endemic countries/areas, these units may be the only efficient way of providing leprosy services to the community.

The achievements so far need to be sustained, and there is a need for constant vigilance and surveillance to monitor and deal with relapses and the possible emergence of drug resistance, particularly to rifampicin. In addition, as the disease burden reduces further, it will become increasingly difficult to maintain public and government interest in leprosy control at current levels, especially as there are competing needs from other, more serious health issues.

The key will be to integrate all the essential components of leprosy control activities into the available primary health care system. This should include the utilization and strengthening of integrated referral facilities to deal with leprosy complications and issues related to chronic care. Such a strategy will need careful planning and may require different approaches at the national and subnational levels within the same country, depending upon the local leprosy burden and the availability of appropriate health infrastructure.

Therefore, in close consultation with Member States, WHO regions and partners, a Global Strategy has been developed with the aim of sustaining leprosy control activities wherever leprosy exists. This will help to uphold the gains made by the elimination strategy and reduce the disease burden further in all endemic countries.

## **2 Current situation**

WHO regularly collects data on registered prevalence and new case detections from the various WHO regions and countries. It is known that these data are affected by several operational factors and changes in the methodology for case detection, treatment and registration procedures.

### **2.1 Global**

Over the last two decades, the global case-load has fallen by almost 90%. At the beginning of 2004, only about 0.46 million patients were registered for treatment and during the year 2003 about 0.5 million new cases were detected globally (Table 1).

**Table 1. Leprosy situation by WHO region at the beginning of 2004 (not Europe)**

WHO region	Registered prevalence at beginning of 2004 (per 10 000)	Cases detected during the year 2003 (per 100 000)
Africa	51 233 (0.8)	47 006 (7.2)
Americas	86 652 (1.0)	52 435 (6.2)
South-East Asia	304 296 (2.0)	405 147 (26.5)
Eastern Mediterranean	5 780 (0.1)	3 940 (0.8)
Western Pacific	10 449 (0.1)	6 190 (0.4)
<b>Total</b>	<b>458 428</b>	<b>514 718</b>

Global reported annual detection reached a peak of 804 000 in 1998, then levelled off at around 750 000 before falling to around 621 000 during 2002 and 515 000 during 2003 (Table 2).

**Table 2. New cases detected 2001-03, by WHO region (not Europe)**

WHO region	Number of new cases detected during year:		
	2001	2002	2003
Africa	39 612	48 248	47 006
Americas	42 830	39 939	52 435
South-East Asia	668 658	520 632	405 147
Eastern Mediterranean	4 758	4 665	3 940
Western Pacific	7 404	7 154	6 190
<b>Total</b>	<b>763 262</b>	<b>620 638</b>	<b>514 718</b>

Table 3 shows leprosy prevalence at the beginning of 2004 and case detection during 2003 for the nine countries where the prevalence of leprosy cases registered for treatment is still above the elimination target of 1 per 10 000 population, according to the latest available information. Together, they represent about 88% of the new cases detected during the year 2003, and 84% of registered cases at the beginning of 2004. These countries are: Angola, Brazil, Central African Republic, Democratic Republic of the Congo, India, Madagascar, Mozambique, Nepal and United Republic of Tanzania.

**Table 3. Countries yet to reach the elimination target at the beginning of 2004**

Country	Number of cases registered at the beginning of 2004 (Rate/10 000)	Number of cases detected during 2003 (Rate/100 000)
Angola	3 776 (2.8)	2 933 (22.1)
Brazil	79 908 (4.6)	49 206 (28.6)
Central African Republic	952 (2.6)	542 (14.7)
Democratic Republic of the Congo	6 891 (1.3)	7 165 (13.5)
India	265 781 (2.4)	367 143 (34.0)
Madagascar	5 514 (3.4)	5 104 (31.1)
Mozambique	6 810 (3.4)	5 907 (29.4)
Nepal	7 549 (3.1)	8 046 (32.9)
United Republic of Tanzania	5 420 (1.6)	5 279 (15.4)
<b>Total</b>	<b>382 601</b>	<b>451 325</b>

## 2.2 WHO regions

### 2.2.1 African Region

The annual rate of new-case detection has increased over recent years in several countries in the Region (Angola, Democratic Republic of the Congo, Madagascar, Mozambique and United Republic of Tanzania). This may reflect efforts to expand leprosy control activities, in particular in areas previously disturbed by security concerns. Certain countries may need special efforts to establish leprosy control activities in areas with civil wars.

### 2.2.2 Region of the Americas

Data from the Region are difficult to interpret because of the expansion of health services and differences between countries in case-definition and registration policies. Brazil contributes most to the disease burden in this Region. Though prevalence has been reduced substantially during 2004, the case-detection trend has shown no decline in Brazil for several years.

### 2.2.3 South-East Asia Region

The region accounts for the major burden of leprosy globally. There is evidence for recent declines in case-detection rates in the Region: in India, Bangladesh and Myanmar, but not in Indonesia. The case-detection trend in Indonesia has been static for the past three years.

#### 2.2.4 Eastern Mediterranean Region

Prevalence and new-case detection trends show that leprosy is no longer an important health problem in most of the countries of this Region. However, leprosy services have been seriously disrupted by civil unrest in several countries: e.g. Afghanistan, Somalia and southern and western parts of Sudan.

#### 2.2.5 Western Pacific Region

Leprosy has declined in most of the countries in this Region. China, Philippines and Viet Nam continue to report 1 000 or more new cases annually.

### 2.3 Major challenges

- To continue progress towards the goal of  $\leq 1$  case per 10 000 population in those countries which have yet to reach it.
- To maintain quality of services in integrated systems and in low-endemic situations.
- To strengthen surveillance, drug supply logistics, information, education and communication (IEC), job-oriented capacity-building for general health workers and an efficient referral network.
- To assess the magnitude of the disability burden due to leprosy and develop appropriate tools and procedures to address issues related to prevention of disability and rehabilitation in integrated settings.
- To expand coverage of leprosy control activities in underserved/marginalized communities and areas.
- To further reduce stigma and discrimination against affected persons and their families and promote correction or deletions of outdated legislation.
- To reduce the gender imbalance seen in new case detection in some programmes.
- To build effective partnerships based on mutual trust, equality and unity of purpose.
- To ascertain the appropriate level of priority for leprosy relative to other more serious health and developmental challenges faced by the communities.
- To ensure an appropriate level of priority in the allocation of external resources in the context of a shift in priorities and resources to other challenges.

## 3 Basic concepts and guiding principles of the Global Strategy

### 3.1 Leprosy control activities

Disease control means reduction of the incidence and prevalence of the disease, and of the resulting morbidity and mortality, to a locally acceptable level as a result of deliberate efforts. Continued intervention is required to maintain the reduction. Leprosy control activities delivered by the health system include diagnosis, multidrug therapy, patient and

family counselling, community education, prevention of disabilities/impairments, rehabilitation and referral for complications.

A direct translation of the word “services” may create confusion in some languages, as the term “leprosy services” may be wrongly interpreted as vertical leprosy programmes. Where this problem occurs, an alternative term may be used, such as “anti-leprosy activities”.

### **3.2 Key issues**

- Opportunity to reduce disease burden by means of case-finding and treatment, BCG vaccination and improved socioeconomic conditions.
- Appropriate level of priority for leprosy relative to other, more serious health and developmental challenges faced by communities.
- Appropriate level of priority to be ensured with respect to external resources in the context of a shift in priorities and resources to other challenges.

### **3.3 Guiding principles**

- Early case detection and provision of multidrug therapy remain the cornerstone of leprosy control.
- An integrated approach using general health staff.
- Continued political commitment and adequate resources for leprosy control.
- Strong community acceptance, involvement and participation.
- Provision of high-quality leprosy control activities that are easily and equitably accessible to all, including referral services for complications and chronic care.
- Consensus and willingness to work together among all partners.
- The Global Strategy should maintain the momentum provided by the Strategic Plan 2000-2005, and reduce disease incidence in endemic communities. Particular attention should be given to the nine countries still having a high disease burden.
- The Global Strategy calls for continued national commitment and resources, backed by international agencies, to ensure that leprosy services are sustained.
- The Global Strategy will succeed only if it is accepted by consensus and supported by a strong collaborative spirit of partnership between affected communities, national governments and international and local nongovernmental organizations.
- Given the heterogeneity of the leprosy situation in the world, the Global Strategy will encourage national governments to develop appropriate country-specific goals and targets and effective plans of action to ensure accessibility, timely case detection and completion of treatment. National authorities are encouraged to adapt the Global Strategy to suit their epidemiological situation,

their own commitment, availability of resources and the capabilities of existing local health systems.

### **3.4 Goal**

The goal of the Global Strategy is to reduce further the burden of leprosy and to provide access to quality leprosy control services for all affected communities, following the principles of equity and social justice.

### **3.5 Main objectives**

- Provide high-quality services for all persons affected by leprosy.
- Improve cost-effectiveness by integrating and/or decentralizing ongoing leprosy control activities within the existing local health infrastructure, including referral facilities and monitoring components.
- Sustain political commitment and increase collaborative activities with all partners at the global, national and regional levels.
- Enhance advocacy efforts in order to reduce stigma and discrimination against persons and families affected by leprosy.
- Strengthen the monitoring and supervision components of the surveillance system.
- Build capacity among health workers in the integrated setting.

## **4 Sustaining leprosy control activities**

**Sustainability** is the capacity of a programme to maintain quality and coverage of services at a level that will provide continuing control and further reduction of a health problem at a cost that is affordable to the programme and the community.

### **4.1 Reasons to sustain leprosy control activities**

- Achievements made to date must be protected.
- New cases will continue to occur, requiring diagnosis, treatment and care.
- There is a need for monitoring to detect reactions and relapses and prevent the emergence of drug resistance and resurgence.
- There are many people suffering from the consequences of leprosy and/or at risk of developing reactions and leprosy-related impairments.

### **4.2 Activities to sustain leprosy control**

In order to sustain the health benefits of leprosy control, “high-quality leprosy control activities” should include the following.

- Creating community awareness for self-reporting, IEC and capacity-building in health services:
  - timely diagnosis at peripheral health facilities – simple cases with anaesthetic patches, both paucibacillary and multibacillary
  - referral of other suspected cases for further examination.
- Patient management:
  - free multidrug therapy, given in a user-friendly and flexible manner
  - effective counselling and IEC for patients and family members
  - recognition and management of complications
  - referral for care of complications, when necessary
  - correct handling of suspected relapses
  - prevention of disability and self-care (including acceptably designed footwear) for those with nerve damage
  - involvement in community-based rehabilitation programmes
  - referral for specialist rehabilitation interventions, if indicated.
- Equity and social justice:
  - people affected by leprosy treated in all health facilities like other patients
  - respect for privacy and confidentiality
  - advocacy and information for the public to reduce stigma and discrimination
  - inclusion in any government provision for the disabled (e.g. disability pensions).

#### **4.3 Mechanisms for sustaining leprosy control activities**

- Integration into existing basic/general health services that are well supported by a referral network providing services for other diseases/conditions as well.
- Building capacity and competence among health care providers through education at medical/paramedical schools, motivation, on-the-job training and retraining and technical supervision. Increase awareness among the community and build up capacity through IEC and community involvement.

#### **4.4 Importance of integration in relation to sustainability**

In the context of sustaining leprosy services, integration means active involvement of general health services in leprosy control activities. The general health services will take full responsibility for leprosy control in their areas, as part of their routine day-to-day activities. However, the nature of care and the category of staff involved will vary from

country to country, depending on the structure and resources of the general health services.

The rationale behind this approach is that the general health services are widely distributed and have close and frequent contact with the local community, and involving them in leprosy control will improve case-finding, case-holding and the awareness of the local community about the disease. Apart from the costs needed to train the general health workers for their new tasks, over time the operational cost of an integrated programme is expected to be much less than that of a specialized, single-purpose leprosy programme.

Integration will improve efficiency and effectiveness, optimize the use of resources, promote greater equity, reduce stigma and discrimination and ensure long-term sustainability.

#### **4.5 Activities which should be integrated**

- All leprosy related tasks and functions, which should be performed within the existing primary health care system at all times, avoiding segregation or special places or services for leprosy as far as possible.
- All management and support activities, e.g. planning, information systems, training and supervision.
- All organizational components, e.g. referral services, community support and awareness activities, and sharing of other resources.
- Promotion of basic and operational research in order to improve understanding of leprosy and its control.

## **5 Strategic issues**

### **5.1 Epidemiological situation**

#### **5.1.1 Countries that have not yet achieved the elimination target**

Countries that have not yet achieved the elimination target will need to continue their efforts to reduce the disease burden in the next few years, as recommended in the strategy laid down in this document. The countries that have included the elimination target in their long-term planning beyond 2005 can continue to pursue this target, including the use of “prevalence” as a major indicator in addition to those mentioned in Section 6 below. Several of these countries are facing severe challenges, in particular security problems in many of the African nations. These countries should also recognize the need to sustain leprosy services in the future, as the disease will continue to occur in appreciable numbers for many years after the elimination target has been achieved.

#### **5.1.2 Low-endemic countries**

In situations where very few new cases are still occurring, e.g. in some countries in the Eastern Mediterranean and Western Pacific regions, maintaining the full spectrum of expertise to manage the disease at the peripheral level may be impractical, unsustainable

and costly. Referral facilities with specialized leprosy care should be provided at the next level up, in order to cover a large area and thus be more cost-effective.

To make the programme more efficient, these referral facilities have to be integrated into the existing referral facilities supporting general health services e.g. departments of dermatology, neurology, (orthopaedic) surgery, etc. Proper referral facilities should be identified at district/provincial/state levels to support peripheral health workers in diagnosis and management. Supervision of activities at the peripheral level should be the responsibility of general health supervisors.

## **5.2 Difficult/disaster situations**

Some countries face difficulties on account of social unrest and/or military operations. All health care functions become difficult to perform in such situations. There exist guidelines to tackle such difficulties during national and man-made disasters. Leprosy control activities may have to be performed using such approaches.

## **5.3 Operational issues**

### **5.3.1 Improving the quality of services**

Each programme may have to define its own standards for quality of care, taking into consideration the capacity and competence of the general health staff and the availability of resources. This should be reflected by the targets set for quality indicators (see Section 6 below).

The quality of care can only be as good as the quality of technical supervision provided by the programme. In addition, the availability of strong backup from an effective referral system will improve the quality of care provided by the integrated services.

### **5.3.2 Free multidrug therapy**

Early case detection and treatment with multidrug therapy will remain the key elements of the Global Strategy in the foreseeable future. There will therefore be a continuing need to maintain the quality and distribution of multidrug therapy at the global level, as well as in endemic countries. Since 1995, thanks to a generous donation from the Nippon Foundation and Novartis, WHO has become the world's leading supplier of multidrug therapy (MDT) drugs, free of charge. An increasing number of countries now rely upon WHO as the sole source of high-quality drugs for their leprosy elimination programmes. Novartis has committed itself to continuing the free supply of MDT drugs beyond 2005. The number of countries using WHO-supplied multidrug therapy has grown to over 100. Apart from the major endemic countries receiving regular shipments of MDT drugs every year, other lower-endemic countries have requested emergency supplies from WHO.

### **5.3.3 Good registration practices**

These should include:

- adherence to WHO/national guidelines on treatment duration
- regular updating of the treatment register at primary health care level

- providing a choice of appropriate visiting schedules based on the needs of the patient, and taking the environment and available services into consideration
- routine counselling, defaulter retrieval and follow-up
- no reregistration (recycling) of any old case as a new case.

#### **5.3.4 Building capacity and competence within integrated programmes**

A key strategy for improving and sustaining leprosy services is to involve peripheral general health workers and community health volunteers in leprosy control tasks down to the village level. Simplified guidelines for general health workers should be made available in all health facilities providing leprosy services. Medical and paramedical training institutions for health workers in endemic countries should include leprosy in their curriculum, so that the new generation of workers will be able to sustain leprosy control services in the future.

#### **5.3.5 Improving community awareness and involvement**

The major theme of community awareness activities will be to provide accurate information about the disease, its curability and availability of services at the nearest health facility. The objective of such IEC efforts should be to encourage self-reporting of new cases and to reduce stigma and discrimination against affected individuals and their families. Most programmes have been using various communication approaches, including the mass media. Although there are claims for their effectiveness, there is limited published evidence to support this. There is some evidence that interpersonal communication is still the best way of conveying correct messages about leprosy.

#### **5.3.6 Monitoring, supervision and evaluation**

The amount of data that an integrated programme can provide for leprosy is limited, since it has to collect data and report on other diseases as well. Therefore, data collected for leprosy should be the basic minimum and should be an integral component of the monthly reporting formats used by the local health services, e.g. monthly mortality and morbidity reports (see Section 6 below).

However, special monitoring exercises may be carried out periodically to validate case-detection and quality-of-care indicators, as part of routine supervision or by independent teams on a sampling basis.

### **5.4 Equity and social justice**

#### **5.4.1 Leprosy and human rights**

The basic human rights include: right to life, dignity of the person, equality before the law and freedom from inhuman or degrading treatment. These have been incorporated into constitutional rights by many nations. The main human rights issues for leprosy-affected persons are dignity of the person and equal access to adequate treatment.

The effectiveness of multidrug therapy in curing leprosy and intense advocacy activities in recent years have brought positive changes in public attitudes towards persons affected by leprosy in many communities. However, the stigma associated with leprosy has not

disappeared completely in many countries. In some countries, the impact of discrimination is particularly severe among female leprosy patients. Any legal or statutory measures that are likely to compromise the rights of an individual affected by leprosy to employment, in his/her own country or elsewhere, should be abolished.

#### **5.4.2 Gender**

Although leprosy may affect relatively more males than females in some populations, this is not universally true. All programmes should ensure that all members of the community have easy and equitable access to leprosy services.

#### **5.4.3 Reaching special population groups**

It is important to reach patients living in difficult-to-access areas or special situations, or those belonging to underserved and marginalized population groups, since the most crucial element of the leprosy control programme is to reach every patient. Special initiatives should be aimed at finding people living in difficult areas or situations who are in need of treatment and, secondly, to ensure that they complete multidrug therapy. Innovative and practical strategies involving mainly operational solutions need to be developed in order to provide leprosy services for these patients. If a project operates in situations where the health infrastructure is weak or does not exist, there is a special need for strategies which promote self-reliance and self-help, and which involve the community and grassroots organizations so that the activities can be sustained.

#### **5.4.4 Leprosy in urban areas**

While the basic strategy for controlling leprosy in urban and periurban areas of all categories is similar to the strategy in rural areas, rapid industrialization and the increasing density of migrant populations in slums pose operational challenges.

Coordination between government and nongovernmental organizations, as well as local health authorities, dermatologists and general practitioners, should be encouraged; particularly to ensure that leprosy services are provided by all agencies and all new cases are treated with multidrug therapy.

### **5.5 Patient care**

#### **5.5.1 Referral services and long-term care**

Referral services to provide technical support and hospital facilities are essential in an integrated programme. The referral network must be part of the integrated system, providing referral services for other diseases and conditions in the area, e.g. district hospitals or medical colleges. The basic requirements are the availability of adequately trained staff and the necessary infrastructure. Referral services involving appropriate specialities will play a useful role in providing the necessary care.

One frequently neglected aspect is the provision of services for long-term care for patients suffering the sequelae of nerve damage, for example chronic foot ulcers or chronic leprosy reactions. These will need, besides medical and surgical interventions, support from proper counselling services.

### **5.5.2 Prevention and management of impairments and disabilities**

The current situation with regard to the number of persons living with leprosy-related disabilities and impairments may need reassessment, particularly at national level. In addition, programmes should ensure that persons affected by leprosy have access to services provided by other programmes dealing with other disabling diseases or conditions.

Interventions aimed at preventing disabilities/impairments from occurring and/or worsening include early detection and effective management of leprosy-related reactions and nerve damage; proper counselling on self-care; participation of household members in home-based care; development and use of locally produced and culturally and aesthetically acceptable protective footwear and other appliances.

### **5.5.3 Rehabilitation**

All societies are basically organized for nondisabled lifestyles, and expect disabled individuals to change, rather than making an effort to reorganize themselves to accommodate their disadvantaged members. The concept of rehabilitation encompasses issues that are directly linked to the socioeconomic situation of the country, and issues related to poverty, inequality and sustainable development. It is therefore important that society should include persons affected by leprosy in ongoing programmes for rehabilitation of other disadvantaged members of the community. Many projects have demonstrated the positive benefits and cost-effectiveness of using community-based rehabilitation approaches to deal with this issue.

## **5.6 Research**

The Global Strategy will need input from ongoing and future research studies being conducted globally, in order to improve the quality and quantity of the tools and procedures available for leprosy control. The priority areas for research are prevention and management of nerve-function impairment and reactions, improving chemotherapy, developing and improving diagnostics to identify individuals in the community who are at high risk of developing leprosy and operational research to improve the sustainability and integration of leprosy services.

## **5.7 Partnership**

Partnership is a joint working arrangement in which independent partners cooperate to achieve a common goal.

The term cooperation includes: planning, implementation, sharing information and equally sharing risks and rewards. The aim is to improve performance, avoid duplication, improve cost-effectiveness and prevent conflicts of ideology. The expected outcome is the delivery of high-quality services for persons affected with leprosy.

Partnerships are based on mutual trust, respect and understanding. They should be seen as a process of working together with the governments of the endemic countries to reach the common goal of sustaining high-quality leprosy control services for the affected communities. This will avoid duplication and wastage of resources and will therefore increase the effectiveness of the programme at all levels.

## 6 Indicators for monitoring and evaluation

Indicators are tools for measuring the magnitude of the leprosy problem and progress towards achieving the objectives of the programme. They can be used to set targets for the quality of the programme (e.g., the proportion of patients with grade 2 disabilities among new cases as an indicator for the quality of case detection; treatment completion rate as an indicator for quality of patient management). In view of the different situations in the various countries, the targets for quality should be country-specific and based on recent trends.

### 6.1 Main indicators for monitoring progress

1. Number and rate per 100 000 population of new cases detected per year.
2. Treatment completion/cure rate.
3. Registered prevalence: for those countries yet to reach the elimination target, prevalence of registered cases will continue temporarily to be an indicator till the target has been reached (see Section 5.1.1 above).

#### 6.1.1 Number and rate of new cases detected per year

The nature (e.g. type, grade of disability, etc) and number of new cases detected in a given area are mainly influenced by four factors:

- effectiveness of IEC activities in promoting awareness and self-reporting
- health workers' competence to make an accurate and timely diagnosis
- quality of monitoring and supervision by programme managers
- completeness of programme coverage, ensuring that all inhabitants are reached.

In order to ensure quality of new case detection, programmes should ensure that:

- case-finding is mainly focused on promoting self-reporting, with appropriate clinical examination and history-taking to avoid wrong diagnosis and reregistration
- case definitions are adhered to, as per national guidelines
- previously fully or partly treated cases are not registered as new cases – partly treated cases should be given treatment.

All national programmes should collect and report this information, distinguishing paucibacillary and multibacillary leprosy and child/adult patient (important for the calculation of MDT drug requirements).

### 6.1.2 Treatment completion/cure rate<sup>1</sup>

The two most important components of the leprosy control programme are:

1. timely detection of new cases
2. ensuring that all new patients who start multidrug therapy complete the full course of treatment within a reasonable period of time.

A satisfactory treatment completion rate is indicative of efficient case-holding, counselling and patient satisfaction with the services. Completion of treatment means that a paucibacillary leprosy patient completes six monthly doses of PB-MDT within nine months and a multibacillary leprosy patient completes 12 monthly doses of MB-MDT within 18 months.

All national programmes should undertake cohort analysis for treatment completion rates for both paucibacillary and multibacillary leprosy. A reported unsatisfactory treatment completion rate indicates that the programme manager/supervisor should find more detailed information on the treatment outcome of the reporting clinic/district in order to identify appropriate corrective action, including use of accompanied multidrug therapy as an option for certain category of patients who are unable to visit the health facility regularly.

### 6.2 Additional indicators for case detection

The following indicators may be collected as part of special monitoring exercises to evaluate the programme and to calculate MDT drug requirements.

1. Proportion of new cases presenting with grade 2 disabilities/impairments at the time of diagnosis.
2. Proportion of child cases among new cases.
3. Proportion of multibacillary cases among new cases.
4. Proportion of female patients among new cases.

### 6.3 Indicators for patient management and follow-up

The programme may collect the following indicators periodically on a sample basis, as part of an integrated supervision process.

1. Proportion of new cases verified as correctly diagnosed.
2. Proportion of treatment defaulters.
3. Number of relapses.
4. Proportion of patients who develop new/additional disability during multidrug therapy.

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<sup>1</sup> Calculating the “cure rate” would require that the patients complete the recommended treatment and in addition undergo an examination to confirm absence of exacerbation or occurrence of new lesions. This would require more detailed examination of the patient and a longer follow-up period. For practical purposes, treatment completion rate can be used in the field as a proxy indicator for cure rate.

## **7 Leprosy surveillance system**

### **7.1 Reporting system**

The existing simplified global information system should be adapted to be consistent with the indicators mentioned in Section 6.

### **7.2 Programme review**

WHO will draw up guidelines to assist programme managers in determining priorities with regard to sustainability of leprosy control activities, and to suggest what specific actions might be taken. The review guidelines as developed under the elimination strategy are still valid and will, after some modifications, also be important for the strategy to sustain leprosy control activities. Programme reviews will continue to be organized and coordinated by the WHO global leprosy programme in selected endemic countries, and are based on information which can be collected by health staff under field conditions. Every leprosy programme is subjected to a periodic review by its manager and by WHO.

### **7.3 Drug supply database**

WHO has developed an information database for monitoring the whole flow of drugs from the supplier to the recipient country. Spreadsheets and database management systems have also been produced as an aid to preparing the periodic reports, wherever computer facilities are available at the country level.

## **8 Expected outcomes by 2010**

- Further reduction of disease burden to very low levels.
- Improved quality of diagnosis, case management and registration practices and good management information system.
- Sustainable leprosy services in all endemic countries.
- Easy and equitable access to quality services through general health services, including an efficient integrated referral network.
- Adequate tools and resources for prevention of disability and rehabilitation.
- Strengthened partnerships and collaborative working arrangements with all partners.

We can expect a world with a reduced burden of leprosy, reduced stigma and discrimination, activities based on the principles of equity and social justice, and strong partnerships based on equality and mutual respect at all levels.

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