

# PARTNERSHIP AND POLITICAL COMMITMENT FOR SUSTAINABLE LEPROSY CONTROL BEYOND 2005

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## 1 Introduction

Although leprosy was known to be endemic in many parts of the world for centuries, organized efforts to control the disease in a substantial way were not made by many national governments for a long time. It was mainly national and international non-governmental organizations (NGOs) that provided care for leprosy patients, and this was usually fragmented, institutionalized and localized. Lack of **political commitment** to the cumbersome fight against the stigmatized, chronic and disabling disease, which often required life long treatment with dapsone, was one of the main reasons that governments did not take on responsibility for leprosy control. The introduction of the more effective and relatively short-duration treatment with MDT in the early 1980's and the adoption of the resolution on elimination of leprosy by the World Health Assembly in 1991 have changed this situation. The elimination goal (attaining a prevalence rate of leprosy patients registered for treatment below 1/10,000 population) and its related activities, especially in the field of advocacy, have contributed tremendously to the fight against leprosy. From a strategic point of view the WHO leprosy elimination initiative has been shown to be an excellent choice. Never before have we found such a broad and strong commitment, including the allocation of resources, to the fight against leprosy as during the past 15 years. This commitment of governments, their health services and health workers has been crucial for the achievement of global MDT coverage and the increased effectiveness of leprosy services. In many countries patients are now diagnosed at an earlier stage of the disease.

In addition to political commitment, **partnerships** have played an important role in leprosy control. WHO, national and international NGOs (notably the ILEP members), The Nippon Foundation (TNF), Novartis, Danida, the World Bank, etc have a significant supportive function in partnership with national governments. This support is technical, operational and financial. Partnership can be defined as: Inter-organizational relationships involving activities (beyond that which contracts or authority alone would demand) aimed at achieving shared goals based upon close working relationships. There are more definitions of partnership but they usually include these common themes:

- commitment to shared objectives;
- mutuality, equality and open dialogue;
- sense of trust and respect between the partners;
- mutual obligations and accountability.

Partnership does not mean that partners should agree on all aspects, but it implies that there is a willingness to 'give and take' on both sides so as to reach consensus.

ILEP as a federation is a good example of partnership between organizations that share common objectives. In 2002, a difference in opinion on technical issues and the lack of dialogue within the Global Alliance for the Elimination of Leprosy (GAEL) led to disruption of the previously outstanding partnership between WHO and ILEP that had been exemplary to many other disease control initiatives. Since then, ILEP has continually expressed its strong interest in restoring the collaboration with WHO under the condition that an open dialogue on technical issues would be possible. Although there were partnership problems at the international level, WHO and ILEP members continued their fruitful collaboration in most countries at the national level. However, since last year, a constructive collaboration between WHO and ILEP has been re-established at the international level. This is a very positive development.

## 2 Strategy and indicators for the 'post-elimination' period

Setting a goal for the elimination of an infectious disease only makes sense if it implies a reduction in the incidence of the disease. However, despite a dramatic reduction of the number of leprosy patients registered for treatment, resulting in the achievement of the 'elimination' target in most countries, the number of newly detected cases at the global level has not shown a comparable decline (in fact the decline in case detection as seen at the global level during the last two years can virtually be attributed to the reduction in case detection in India alone):

- the decrease of prevalence is attributable primarily to cleaning registers, shortening the duration of treatment and, in some countries, to improved diagnostic accuracy. It is not a consequence of reduction of the transmission of *Mycobacterium leprae*;
- although incidence rates have been observed to have declined in many settings (examples are Thailand, Vietnam and Myanmar), evidence that the change from dapsone monotherapy to MDT has caused an acceleration of that decline is lacking. In many places, the decline of incidence began before the introduction of MDT, or could be explained equally well by other factors. In other settings, no decline of incidence has been observed despite the routine administration of MDT to all newly detected patients for a number of years.

The expectation that reduction of prevalence to very low levels would lead to a reduction of the incidence within a few years has been shown to be overoptimistic. The original target year of 2000 had to be changed to 2005, but despite the shortened duration of treatment, it will still not be possible for some countries to reach their goal by 2005. Moreover, some countries, although reaching their national goal, still have a significant disease burden at regional or district levels. There are strong indications that transmission is decreasing, but this is a very slow process. Significant numbers of new patients will continue to present for many years to come in countries where the elimination target has been achieved recently. There is now a clear consensus among leprosy workers that it is essential to sustain leprosy control activities also in countries or areas that have reached the elimination target.

There is, however, a considerable risk that political commitment will diminish in countries where the elimination target has been achieved. Politicians, including ministers of health and other decision makers, often interpret 'elimination' as 'eradication'. This misconception has been strengthened by messages that leprosy will disappear naturally after achieving a 'prevalence' rate of 1/10,000 or that 'by 2005 leprosy will be confined to the history books', and by terminology such as 'final push strategy'. Such an interpretation of the elimination goal may result in situations where governments may not feel the need to allocate the resources for sustaining leprosy services after the elimination target has been reached. It is important that decision-makers are convinced that 'elimination', though an important milestone in the long march towards a world without leprosy, is not an end to leprosy control activities.

Without political will and support public health programs cannot be successful. However, this does not mean that public health related managerial decisions should be made on the basis of political criteria only. In selecting public health priorities we must find the right balance between technical and political priorities and targets in order to attain a successful process. The elimination target has been very effective in obtaining political commitment and, consequently, in improving leprosy services, but over the last few years the elimination target has become more and more a political target rather than an epidemiological or program quality target. For many the indicator (the prevalence of patients registered for treatment) has become the goal itself, and the actual goal (reduction of the leprosy incidence) has fallen out of sight. In fact, the prevalence of patients on the MDT register is not the most appropriate indicator to reflect the progress towards elimination of leprosy (i.e. reduced transmission and incidence). Both the WHO TAG (for the 'post-elimination situation') and the ILA Technical Forum have identified new-case detection as the preferred indicator. This is also consistent with the indicators used for other infectious diseases (e.g., tuberculosis). This indicator should preferably be used in conjunction with the proportion of newly detected patients with disability grade 2. The treatment completion rate is an important indicator of the effectiveness of patient management. These indicators are also useful for self-evaluation by health

workers as they can be easily translated into their major responsibilities: find patients before they have developed disabilities and cure them. Another relevant indicator is the proportion of children among new cases. A large proportion is a sign of recent transmission of the infection. The recently published global WHO leprosy control strategy 2005 – 2010 has included these indicators among those recommended for monitoring and evaluation of leprosy control activities.

In addition to the arguments for more appropriate indicators, there are well-founded reasons, scientific, political and strategic, to seriously consider whether the concept and terminology of '(post) elimination' should continue to be applied after the target year 2005. The elimination campaign has been the subject of hot dispute. The elimination goal and its justification have been discredited to a great extent by the scientific community (ILA Technical Forum, ILA Congress; 2002) as well as by the independent GAEL evaluation (2003). Moreover, it will be very difficult to obtain political commitment for a disease that is officially declared as eliminated (as a public health problem). In addition, important partners such as the ILEP members have rejected this confusing kind of terminology. It will, however, not be easy to find terminology that is as appealing to the target audience as the terminology used for the elimination campaign.

In view of the need to sustain leprosy services for many years there has to be a shift from the campaign-like elimination approach towards the long-term process of sustaining integrated, quality leprosy services which, in addition to case detection and treatment with MDT, also include prevention of disability (PoD) and rehabilitation. There is an opportunity for this process to build on the gains made by the elimination campaign, such as the increased awareness for leprosy, the political commitment and the involvement of the general health services. It is of vital importance that the recently published global WHO strategy for leprosy control 2005 – 2010 has identified the sustainability of leprosy control activities through integration as its major strategic component.

### **3 Towards sustainable leprosy control**

Disease control is defined as the reduction of the incidence and prevalence of the disease, and of the morbidity and mortality resulting from the disease to a locally acceptable level, as a result of deliberate efforts. Continued intervention is required to maintain the reduction.

The leprosy control strategy has four major elements:

- early case detection,
- adequate chemotherapy (MDT),
- prevention of leprosy related impairments, and
- rehabilitation.

Ideally implementation of this strategy requires accessible, cost-effective and sustainable health services that cover the population fully, and are accepted by the community and the patients. This strategy implies that leprosy control activities should be implemented by the general health services, and there is a broad consensus on the need to integrate leprosy services into the general health system. WHO, ILEP and ILA see this as the most realistic strategy to sustain cost-effective leprosy services. Integration is also a central element of the health sector reforms. Integration not only improves accessibility to treatment, but also reduces the stigma and discrimination faced by persons affected by leprosy. If donors wish to ensure the establishment of sustainable leprosy services, they must work with and strengthen the national general health services system.

Integration means that day-to-day patient management, recording and reporting become the responsibilities of general health staff. However, integration does not mean that special expertise needs to disappear from the health service. On the contrary, this (non-vertical) expertise must be available within the general health service at the central and intermediate levels for planning and evaluation, provision of training, technical supervision, advice, referral services (including those at hospitals) and research. Depending upon local conditions (e.g., the endemicity 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 expertise should be made available. In areas of relative **high endemicity**, peripheral general health workers should be capable of diagnosing and treating leprosy under the technical supervision of specialized (= not vertical) health workers who are positioned at the intermediate level. This category of specialized staff will usually have responsibility for other diseases in addition to leprosy. In settings of **low endemicity**, the ability to suspect leprosy and refer the patient to a health unit capable of diagnosis and initiation of treatment is the most important skill required for peripheral general health workers. These referral centers (e.g., a district hospital and/or selected health centers) should verify the diagnosis and start the treatment of the patient. Continuation of treatment could be delegated to the peripheral health facility serving the community in which the patient resides. The community should be informed, and the general health staff of the peripheral health facility should be trained in diagnostic skills and case management. In areas with small patient loads, management of nerve damage will have to be concentrated in health facilities serving a larger population -- e.g., a district hospital. Centers treating the complications of leprosy and providing rehabilitative surgical services will be even more centralized.

Improved access to quality leprosy diagnosis and case management will remain the cornerstones of the future leprosy control strategy. However, in view of the need for leprosy services for many years to come there has to be a change from the campaign-oriented elimination strategy towards the long-term approach of sustaining integrated quality leprosy services. These services, in addition to case detection and treatment with MDT, also include PoD and rehabilitation. The table summarises the major changes involved in the shift towards the post-2005 strategy.

*Table: What will change?*

<b>From:</b>	<b>To:</b>
Campaign oriented elimination	Sustainable control
Case detection and MDT	Case detection, MDT, PoD and Rehabilitation
Numerical target	Quality targets
Prevalence	New case detection and treatment completion
Unbalanced partnership	Equal partnership

#### **4 Role of partners**

The government should be committed to sustained integrated leprosy control activities, and there should be a national policy on leprosy control. Regardless of the level of endemicity in a country, a well-functioning central unit with leprosy expertise, usually housed in the Ministry of Health (MoH), is necessary. The central unit should, in close collaboration with other departments, be involved in advocacy, policy formulation, technical guidance, planning and the monitoring and evaluation of the integrated program. This unit will not necessarily be a unit specifically for leprosy but could have responsibilities and tasks for many other diseases.

WHO, NGOs and other agencies supporting leprosy control continue to be important partners with governments in integrated leprosy control programs. The role of the partners in the short to medium-term will focus on strengthening the national capacity to improve coverage and provide quality leprosy services. It is important that the partners collaborate and coordinate their activities to increase their effectiveness. The government, particularly the MoH, should coordinate national and international donor support to the country. Effective donor coordination is an important requirement for a consistent and uniform implementation of program activities throughout the country. All partners should know how their resources are utilized, and should therefore be involved in the planning and evaluation process. It is necessary that the MoH and its partners, including WHO and ILEP Members, reach consensus on the strategy, plans of action and budgets. This will be strongly facilitated by organizing joint program reviews by the MoH and all partners.

Besides NGOs and international multilateral and bilateral organizations, there are also government departments other than the MoH that have to be involved in sustaining effective leprosy services, such as education, social welfare, finance, communications and publicity, etc. A great deal of collaboration and coordination is required between the various departments, NGOs and other partners. At the national level the coordination should primarily fall under the MoH.

It is important that WHO continues to provide technical leadership at the international level and participates in the partnership at the country level. The partners must agree on the major strategic issues for the fight against leprosy after the year 2005 and on the specific role of each partner in this strategy. ILEP is a prominent international partner for WHO, along with TNF and Novartis. It is important that the excellent collaboration that existed before 2001 will be restored. It has been a major step forward that WHO has taken the initiative to develop the new Global Strategy for 2006 - 2010 in close consultation with their international partners, including ILEP. This will strongly contribute to sustaining effective leprosy services in the future.

#### **References:**

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