

Organization of Leprosy Services

1. The Need for Sustainable Leprosy Services

Leprosy will remain a problem for decades to come. Significant numbers of new cases of leprosy will continue to occur; they must be detected at an early stage and given regular and complete treatment with MDT. Some of the new patients will demonstrate evidence of disability at diagnosis, and some will develop disability after diagnosis. In addition, all patients with nerve function impairment (NFI), both those on treatment and those already cured, will be at risk of developing additional impairments. Although leprosy will continue to be a disease of low endemicity, and may even be rare in many areas, leprosy services (diagnosis, treatment, prevention and care of disabilities, rehabilitation) will need to be sustained far into the 21st century (¹).

2. The WHO Elimination Strategy

The WHO elimination strategy possesses two major components—early case-detection, and treatment (by MDT) of all patients. The core elements of the strategy focus on improving community access to MDT by means of the delivery of MDT by the general health services (²), including:

- capacity building to enable all health facilities in endemic countries to diagnose and treat leprosy;
- insuring easy and uninterrupted access to free MDT by improving logistics; and
- motivating people to seek timely treatment by creating increased community awareness of the early signs and by changing the social perception of leprosy (³).

The elimination goal and the activities undertaken to achieve it, especially in the field of advocacy, have contributed greatly to the fight against leprosy. Strategically, it has been an excellent choice. Never before has such a broad and strong commitment to the fight against leprosy been found as during the past decade. This has contributed greatly to the rapid achievement of full

MDT coverage of all registered cases. Moreover, on a global level, patients are diagnosed at an earlier stage of the disease (⁴). Implementation of MDT has contributed to the dramatic reduction of the number of patients registered for treatment and, as a consequence, the case-holding workload of the health staff. However, the number of new cases detected globally has changed very little over the years, demonstrating the need to sustain leprosy services.

3. How May Leprosy Control Activities Be Best Sustained?

3.1 Integration of leprosy control within the general health services

Disease control can be defined as 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 (⁵).

The strategy to achieve control of leprosy consists of four major elements:

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

Implementation of this strategy ideally requires readily accessible, efficient 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. Several integrated programs have shown that leprosy control can be effectively implemented by the general health services (⁶⁻¹³)¹.

¹ A number of articles describing experiences with integration are currently in press, and will appear in a special number of *Leprosy Review* devoted to this topic.

3.2 Basic requirements for sustaining effective integrated leprosy services:

- The government should be committed to sustained leprosy control activities, and there should be a national policy on leprosy control.
- A prerequisite for integration is the existence of an adequately functioning general health service infrastructure ⁽¹⁴⁾. Where this does not exist, the vertical program should be continued for the time being.
- The change from a vertical to an integrated program is far from easy. The process must be carefully planned, and must be appropriate to the local situation. If the process is hurried and staff and patients are not properly prepared, the quality of patient care and the confidence of patients in the services, as well as their willingness to cooperate, will deteriorate. If the process is too slow, it is likely to fail by default ⁽⁶⁾.
- The process of integration must be introduced step-by-step (phasing in place, time and activities) ^(6, 7). Important steps toward realizing this change are sensitization of administrators and health authorities, and sensitization and training of general health staff and former vertical staff ⁽¹⁴⁾.
- Training should be based on clearly defined job descriptions for all categories of workers who have leprosy related tasks.
- Regardless of the level of endemicity in a country, a well-functioning central unit, usually housed in the Ministry of Health, is necessary. The central unit should be responsible for advocacy, policy formulation, technical guidance, technical training, planning, monitoring and evaluation. Moreover, countries should coordinate national and international donor support.
- An uninterrupted supply of anti-leprosy drugs must be guaranteed.
- Most vertical programs have detailed recording and reporting systems. With integration, however, these systems must be simplified to allow for appropriate data collection by peripheral, multipurpose health workers. The numbers of forms, reports or registers should be reduced to the minimum, and be incorporated into an already existing general health management information system.

Only data directly linked to decision-making should be routinely collected.

- The private for-profit health sector will play an increasing role in the provision of leprosy services. This may pose problems, such as treatment by non-standard regimens, incomplete treatment, inadequate instructions to patients and the consequent risk of drug resistance, and increased incidence of disability. National strategies should therefore clearly define the role of the private sector, including training and quality control.
- Non-governmental organizations supporting leprosy control continue to be important partners with governments in integrated leprosy control programs. If donors wish to ensure the establishment of sustainable leprosy services, they must work with and strengthen the national general health services system.
- In integrating leprosy control into general health services, equity and quality of care for leprosy patients should be assured. This implies that the services for leprosy patients (including diagnosis, treatment, rehabilitation, etc.) should provide the same level of quality (not less, but also not more) as do the services for other health problems.
- In order to establish sustainable services, broad ownership of the strategy must be assured, both within the specific leprosy organizations and, equally important, outside ⁽¹⁵⁾. It is important that the various agencies involved in leprosy control collaborate and coordinate their activities, in order to increase their effectiveness.

3.3 Referral services and specialized support

Integration means that day-to-day patient management, recording and reporting will become the responsibilities of general health staff. However, integration does not mean that specialized elements need disappear from the health service. On the contrary, specialized components 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 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, and whether this should be combined with specialized components for other diseases.

3.4 Combined vertical control programs

Combination of several vertical control programs, such as those for leprosy and tuberculosis, is not the same as integration within the general health services. Combination of two vertical programs into a single vertical program increases cost-effectiveness, because supervision, training, and patient management for both diseases can be implemented by the same personnel, thus reducing the costs of salaries, transport and facilities. The same advantages apply to integration, but with integration the gains are greater. In addition, a combined vertical program is subject to most of the limitations of a vertical leprosy program. Therefore, integration of leprosy control within the general health services is preferable to combination with another vertical program. (¹⁶).

3.5 Leprosy control in areas of low endemicity

In situations in which case-detection rates are low, a focused approach is appropriate, whereby services are provided mainly in selected general health facilities in the area in which leprosy still occurs. The skills of health workers will mainly be limited to suspecting leprosy (¹⁷). Referral 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.

3.6 Health sector reforms

Because leprosy control is implemented within the health sector of a country, the services provided are highly dependent on changes in this sector. In many countries over the past several years, the health sector

has been dominated by so-called health sector reforms (HSR), which have become the umbrella, under which a wide variety of changes and developments in the health sector have been brought together (^{18, 19}). HSRs have profound consequences for disease control programs, such as leprosy control. However, the strategy of HSR is consistent with that of leprosy control, because integration is also a central element of the strategy of most HSRs. On the other hand, the drive of health sector reforms to decentralize decision-making and financing may have an impact on the sustainability of leprosy services: because leprosy is a relatively rare disease, district health authorities may reallocate resources to more pressing health problems (¹⁵). This constitutes a challenge for national leprosy control programs and leprosy NGOs, which, in order to be effective, must appreciate the relative importance of leprosy and the need for appropriate control strategies. The resources devoted to leprosy must be in balance with those required for other, often much more serious, public health problems.

Recommendations. In order to guarantee sustainable leprosy services, leprosy control programs should be integrated within the general health services. The process of change from a vertical to an integrated program should be carefully planned, and must be adapted to the local situation. A prerequisite for integration is the existence of an adequately functioning general health service infrastructure. Timely training of general health staff and former vertical leprosy staff is important; it should be based on clearly defined job descriptions for all categories of workers who will have leprosy-related tasks. An uninterrupted supply of anti-leprosy drugs must be guaranteed. Recording and reporting of data must be simplified to allow for appropriate data collection by peripheral, multipurpose health workers.

Where case-detection rates are low, a focused approach is appropriate, whereby services are provided mainly in selected general health facilities in the areas in which leprosy still occurs. The skills of health workers will be limited mainly to suspecting leprosy. Referral facilities should confirm the diagnosis and begin treatment. Continuation of treatment could be delegated to the

peripheral health facility serving the community in which the patient resides. The resources devoted to leprosy must be in balance with those required for other, often much more serious, public health problems.

4. How Can Appropriate and Effective Training Be Developed for All Grades of Staff Involved in Leprosy Control?

Health-related activities should be undertaken by adequately trained workers at the most peripheral level of the health service as possible. In most leprosy endemic countries these are usually paramedical workers. Paramedical general health care providers play a central role in delivering cost-effective health interventions; they are easier to employ in rural areas, and usually communicate better with the patients. These workers must be adequately trained for their tasks, well-supervised, provided with logistical support, and linked with well-functioning district health services for referral.

Depending on the patient load, a tailor-made leprosy-control strategy will have substantial consequences for the specific level of expertise required. In areas of high endemicity, peripheral general health staff should be capable of diagnosing and treating leprosy under the technical supervision of specialized workers who are stationed at the intermediate level. This category of specialized staff will usually have responsibility for 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. Continuation of treatment is another task that can be implemented at the most peripheral level. 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 responsible for a population of 200,000–500,000. The centers that treat complications of leprosy and provide rehabilitative surgical services will be even more centralized.

Training programs should be both formal and informal, applying appropriate methods, including interactive learning and con-

tact with patients, and should be based on the tasks assigned to the specific category of workers. In addition to the degree of endemicity of leprosy, the distribution of tasks will depend upon other local conditions, such as health service coverage, availability and level of education of the different categories of staff, etc.

The crucial problem is that a larger number of staff will have to be trained (also because of the high turn-over of staff), whereas, at the same time, it is obvious that some of them may never see a single patient. As the number of contacts between health workers and leprosy patients diminishes, fewer staff members will attain skills in case management and leprosy control. In terms of cost-effectiveness, the frequency, duration and the cost of training must be adapted to this situation.

Specific courses on leprosy for general health workers are not cost-effective in areas of low endemicity. Therefore, incorporating leprosy control into the curricula of medical faculties and paramedical schools (e.g., as part of the instruction in dermatology and communicable diseases) is essential for both the successful operation of leprosy control as an integral part of the general health services, and sustaining leprosy expertise within the health services⁽²⁰⁾. Courses dealing specifically with leprosy may still be required for supervisors and training of trainers.

Each leprosy-endemic country should have at least one center of expertise for management of the complicated patients and training of specialized staff. This need not be a special leprosy hospital, but may well be an adequately equipped general (university) hospital⁽¹⁷⁾.

General health staff with responsibilities for leprosy-related activities should preferably be trained in their own country. Because of increasing integration of leprosy control programs, the need for international training for leprosy will decrease, except for the training of highly specialized experts in management of leprosy control, clinical leprosy, reconstructive surgery, etc. At the international level, some centers of excellence should be maintained for the training of leprosy specialists in the various disciplines and research. Such institutions could diversify according to local capacity and needs⁽²¹⁾.

Donor agencies could play a supportive role in the production and distribution of appropriate health learning materials.

Technical supervision is an essential element in human resource management and development, and remains a cornerstone of integrated leprosy control programs. Technical supervision implies continuous guidance, support and on-the-job training. This motivates staff and prevents loss of skills. The contents of the on-the-job training should be consistent with the contents of the national manual and the formal training courses. Identifying strong and weak spots in the supervised institution and its staff members, listening to feedback and trying to remove obstacles are important tools with which to enhance the program.

Recommendation. Training of staff involved in leprosy control should be based on the tasks assigned to the specific category of workers. In addition to the degree of endemicity of leprosy, the distribution of tasks will depend upon other local conditions, such as health service coverage, and the availability and level of education of the different categories of staff. Leprosy should be included into the curricula of medical faculties and paramedical schools.

5. What Is the Evidence that IEC Interventions Can Change the Knowledge, Attitudes and Behavior of the Public with Regard to Leprosy—Especially with Regard to Self-reporting, Reduction of Stigma and Compliance? Which Methods Are Most Cost-effective?

Information, education and communication (IEC) is defined as a set of activities based on the process of communication and learning that is designed to improve the health behavior of the populace. In the case of leprosy, IEC activities aim to dispel the social stigma of leprosy, and to seek the participation of the community in facilitating early self-reporting⁽²²⁾. IEC messages focus on the cause of leprosy, early signs and symptoms, the need for treatment in order to be cured, the availability of free drugs at the nearest general health facilities, and that disability can be prevented. An equally important part of

IEC activities is education of the patients and their relatives regarding compliance with treatment, prevention of disability and self-care.

Many different IEC methods are used for public education, and there is not a clear consensus as to which are the most effective:

- talks to communities, community leaders, etc.;
- radio and TV messages;
- street dramas, puppet shows, posters, and pamphlets;
- talks at schools, clinics, etc.;

Is it realistic to expect that massive spreading of information will eventually change people's attitudes and behavior with regard to leprosy? There is evidence that educational approaches, especially participatory approaches, result in increased knowledge, change of behavior and reduction of stigma⁽²³⁻²⁵⁾. It has also been reported that mass-media campaigns using dynamic and entertaining media messages have an impact in shifting attitudes⁽²⁶⁾. Successful health education depends on using a few messages of proven benefit, repeatedly and in many forums⁽²⁷⁾. The BBC media campaign in India in 2000 contributed strongly to reduction of the stigma and to early self-reporting of patients⁽²⁸⁾. However, other reports suggest that IEC activities were much less effective than had been expected^(29, 30). Moreover, increased knowledge of leprosy does not always generate a positive change of attitude towards patients or earlier self-reporting⁽³¹⁻³⁴⁾. Therefore, studies should be carried out to evaluate the impact of IEC activities, and to identify the methods that are most cost-effective under different conditions.

Stigma continues to exist at various levels in many countries. The isolation of vertical leprosy control programs may encourage rejection of sufferers from the disease, whereas integration of leprosy control into the general health services may have a positive educational effect on the community towards reduction of the stigma.

Recommendation. There is evidence that IEC activities, especially participatory approaches, result in increased knowledge,

change of behavior and reduction of stigma. Studies should be carried out to identify the methods that are most cost-effective under different conditions.

Whenever IEC is planned, the following issues should be considered:

- MDT services delivered by well-trained staff should be available in the area before IEC activities can be implemented;
- because the leprosy problem is decreasing, a trade-off must be made in each country between the magnitude of the problem and the inputs required for raising public awareness. Combination of IEC for leprosy with IEC for other diseases is more cost-effective and, moreover, does not set leprosy apart from other health problems;
- cooperation with other sectors such as the Ministry of Education or the Ministry of Information. A concerted approach will gain in efficiency and effectiveness;
- inclusion of IEC techniques in training curricula for all levels of staff. Health workers must be taught communication skills with the aim of establishing effective communication with the patient, his family and his neighbors;
- inclusion of guidelines on IEC in the national manual, and development of simple and practical instruction manuals to be used in the field. This will strongly facilitate effective IEC;
- application of the WHO communications tool box. This is useful for developing local IEC materials (35);
- IEC activities should consist of the most appropriate mix of various elements (e.g., personal selling, advocacy, advertising, printed materials, community mobilization, point-of-service promotion). The use of individual elements will depend upon available resources, both financial and managerial, as well as the specific audience or behavioral outcome that is being elicited (36).

6. Special Initiatives

In 1995, WHO introduced Leprosy Elimination Campaigns (LECs) and Special Action Projects for the Elimination of Leprosy (SAPEL) as special initiatives to accelerate progress towards the elimination of leprosy as a public health problem.

6.1 What role can LECs play in promoting sustainable services?

The main objective of LECs is to detect leprosy patients who have remained undetected, and to cure them with MDT. LECs are indicated in areas with a perceived large number of "hidden" patients. The major elements of LECs are training of general health staff, community education, passive case-finding and treatment. LECs are intended to be one-time activities, enabling every peripheral health center to provide MDT services (37). LECs have been widely implemented in different ways, and have increased public and professional awareness regarding leprosy and its treatment. Hundreds of thousands of patients have been detected and placed on MDT during LECs (38). Also, in some countries, LECs have contributed to the integration process (39,40).

However, a number of risks are involved. Especially if LECs are modified to include active case-finding surveys, as has been done in many countries, they may harm the development of effective and sustainable leprosy services (41). Those suspected of leprosy are directed to report to campaign teams, sometimes at makeshift venues such as huts or schools (40), supporting the misconception that leprosy is a disease apart from other diseases, which must be diagnosed and treated by special services. It harms the people's confidence in the general health staff, which is essential for self-reporting of new cases, compliance with treatment and early reporting of NFI.

Case-detection may decrease temporarily during the first years after an LEC, as will the prevalence, once the patients found in the course of the LEC have completed their treatment. The backlog may gradually build up again, after which case-detection and prevalence may increase. Repeated LECs might prevent this development (42). However, accessibility, compliance with treatment, monitoring, drug supply, and prevention of disabilities can be more effectively realized by permanently available general health services than by repeated, short-term campaigns (41).

Integration of leprosy services within the general health system, including the establishment of supervision, monitoring and uninterrupted drug supply, is the best strategy to bring sustainable services closer to the

patients. In conformity with their original aims, LECs can be a valuable element of this strategy. In order to establish effective leprosy services, case-finding in LECs must be based on self-reporting to the general health staff, and should include the diagnosis and management of nerve function impairment^(41, 43).

Recommendation. LECs should be implemented as an element of the process of integration. In order to establish effective integrated leprosy services, case-finding in LECs must be based on self-reporting to the general health staff, and should include the diagnosis and management of NFI.

6.2 What can be done if there is no health care infrastructure?

WHO designed Special Action Projects (SAPEL) to address unavailability of MDT services among special population groups living in difficult-to-access or under-served areas, including ethnic minorities, nomads, refugees, etc. The basic approach of SAPEL was the development of innovative, situation-specific strategies for diagnosis and delivery of MDT, including capacity building of local health workers or volunteers, and promotion of community awareness and participation. Linkages of WHO with other partners, including NGOs, in the planning and implementation of activities have been encouraged, with a view to replicating the strategies in other under-served populations. By the end of 2001, of 92 approved projects in 30 countries, 73 had been completed, and approximately 12,500 patients had been reached in a target population of 33 million. The identified solutions included flexible MDT delivery to border-crossing nomads by heads of clans, reduction of defaulting among slum dwellers by involvement and training of private practitioners, support of military personnel in areas of insecurity, etc.,⁽³⁾.

Many SAPEL projects can be conceived of as health systems research projects, in which a problem is identified and a specific solution defined and tested. Although the number of cases detected is relatively small, the SAPEL initiative has been valuable in demonstrating how countries may identify approaches to expand leprosy services to under-served populations. These

activities should be combined, wherever possible, with other special initiatives to address other health problems.

Recommendation. In leprosy endemic areas in which there is no health infrastructure, innovative, situation-specific strategies for diagnosis and delivery of MDT should be developed. This kind of activity should be part of the overall framework of the integrated leprosy services.

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