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ILEP Technical Guide:
Facilitating the Integration Process
A Guide to the Integration of Leprosy Services
within the General Health System

Contents

Preface	iv
Acknowledgements	v
List of abbreviations	vi
Chapter 1 – Introduction	1
Chapter 2 – Integration: background and case studies	4
Chapter 3 – Overview of the integration process	8
Chapter 4 – Stages and steps in the integration process	13
Stage A – Analysing the situation	13
Stage B – Ensuring the commitment of decision-makers to the principles and process of integration	20
Stage C – Developing a plan of action for integration	21
Stage D – Preparing the health system for the implementation of integrated leprosy services	28
Stage E – Starting the implementation of integrated leprosy services	29
Stage F – Monitoring the implementation of integrated leprosy services	30
Stage G – Evaluating the process of integration	31
Appendix 1 – References and further reading	32
Appendix 2 – An example of distribution of tasks in leprosy control	34
Appendix 3 – An example of a simple stakeholder analysis	36

Preface

Leprosy will continue to be a significant problem beyond the year 2005, even in countries where the 'elimination' target (a prevalence rate of patients on treatment below 1 per 10,000 population) has been reached at country level. New cases will continue to occur, and will need to be detected at an early stage of the disease and submitted to regular and complete treatment with multi-drug therapy (MDT). A significant proportion of patients will already show disability at diagnosis and many will be at risk of developing (further) disability after diagnosis. Leprosy services will have to be sustained for decades to come.

The International Leprosy Association/Technical Forum 2002 report states that 'to guarantee sustainable leprosy services, leprosy control programmes should be integrated in the general health services' (ILA/TF, 2002). The ILEP Medico-Social Commission had already advised in 1989 that MDT implementation should be through the general health services (ILEP, 1989). Integration is also a major component of the WHO leprosy 'elimination' strategy.

Integration means that leprosy control activities become the responsibility of the general health service (i.e. one that is multipurpose, permanent and decentralised), which is as close to the community as possible. The need for integration has been recognised in virtually all leprosy-endemic countries and an increasing number of countries have embarked on the integration of leprosy services. Several countries have shown that integration is feasible and that general health staff can deliver leprosy services effectively.

However, the change from a vertical to an integrated programme is not easy. The process must be carefully planned and must be appropriate to the specific local situation; an over-hurried, ill-planned process of integration may easily result in a deterioration in the quality of leprosy services with dramatic consequences for leprosy patients. In some countries significant problems have been encountered, usually caused by inadequate planning.

Moreover, the same mistakes tend to be repeated in different settings, despite the extensive experience that has been documented and made available in reports and publications. Much more use should be made of the lessons learned during such experiences and this is precisely why these guidelines are published. They are founded on the experience of countries that have gone through the integration process, and aim to help those embarking on or already engaged in the same process. The guide uses a flexible model to describe in a systematic way how integration can be achieved successfully. It is primarily meant for public health managers and decision-makers at national and regional levels, but I hope that it will also be useful for trainers and managers working at other administrative levels or in other programmes.

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List of abbreviations

AIDS	Acquired Immuno-Deficiency Syndrome
CDC	Communicable Diseases Control
DANLEP	Danish Assistance to the National Leprosy Eradication Programme
DFB	Damien Foundation Belgium
IEC	Information, Education, Communication
ILA/TF	International Leprosy Association/Technical Forum
ILEP	International Federation of Anti-Leprosy Associations
KIT	Royal Tropical Institute, The Netherlands
MB	Multibacillary
MDT	Multi-Drug Therapy
MIS	Management Information System
MoH	Ministry of Health
NGO	Non-Governmental Organisation
PHC	Primary Health Care
SWOT	Strengths, Weaknesses, Opportunities, Threats
TB	Tuberculosis
TBL	Tuberculosis and Leprosy
TDR	Special Programme for Research and Training in Tropical Diseases
TLMI	The Leprosy Mission International
WHO	World Health Organization

1 Introduction

Leprosy control and integration

Over the past two decades, the conditions in which leprosy control programmes operate have changed dramatically. The introduction of multi-drug therapy (MDT), together with the global effort to eliminate leprosy as a public health problem have had a substantial impact on leprosy control. Though the number of new patients detected has not changed globally, most are now detected in an early phase of the disease, and the number of patients on treatment has been reduced substantially.



Credit: WHO/TDR/Grump

At the same time the context within which leprosy control operates is changing, mainly as a result of reforms in the health sector and because of the increasing attention paid to other diseases such as AIDS, malaria and tuberculosis. Nevertheless, in the coming years it is likely that a substantial number of new patients will be in need of leprosy services. As a result, even though leprosy may continue to be a disease of low endemicity, and may even be rare in many areas, leprosy services - diagnosis, treatment, the prevention and care of disabilities, and rehabilitation - will need to be sustained far into the 21st century (ILA/TF, 2002).

The World Health Organization (WHO) has adopted integration into the general health system as the most appropriate strategy by which to sustain leprosy services. The WHO Expert Committee on Leprosy stresses in its seventh report that integration 'could improve the awareness of the local community, case-finding and accessibility of patients to MDT, and could help to ensure the regularity of treatment' (WHO, 1998). This is consistent with the International Leprosy Association/Technical Forum 2002 report which states that 'to guarantee sustainable leprosy services, leprosy control programmes should be integrated in the general health services' (ILA/TF, 2002). Some years prior to this in 1989, the ILEP Medico-Social Commission had advised that MDT implementation should be through the general health services (ILEP, 1989).

Several countries have already made substantial progress towards the integration of vertical leprosy control programmes into the general health services. Others are just starting. Whatever progress has been made, it is important that the process of integration is facilitated by systematic and comprehensive preparations. As indicated by the ILA/TF, the 'process of change from a vertical to an integrated programme should be carefully planned and adapted to the local situation' (ILA/TF, 2002).

Purpose of this guide

This guide aims to facilitate the process of integrating leprosy services into the general health system. It describes the integration process systematically, using a step-by-step approach and outlining for every phase the rationale behind it and appropriate methodologies for carrying it out. The guide is primarily meant for programme managers and decision-makers in the Ministry of Health and at the regional level.

Chapter 1 introduces the guide and indicates how it should be used. In Chapter 2 the concept of integration is defined and its rationale discussed. Chapters 3 and 4 together constitute the core of the guide and provide the structure of and methodology for the integration process: Chapter 3 offers a general overview of the process, while Chapter 4 describes it in terms of a series of major stages, some being subdivided further into steps. Although some steps within a stage may be addressed in parallel, it is recommended that stages should normally progress in order, as a later stage can only be properly addressed if the earlier ones have been completed. For instance, the development of a plan of action will require the use of information that has been collected and assessed during the situation analysis. Finally, while the guide outlines the reasons why each step is necessary, most emphasis is placed on describing how to carry it out.



Credit: DFB

In many leprosy-endemic countries the process of integration may already be underway, at least in terms of the initial steps. In such cases the guide can be useful in identifying how far the integration process has progressed, whether it has been satisfactory and which steps still have to be carried out or repeated. In sum, the guide can be used as:

- A manual providing information on, and an outline of methods for, the preparation and implementation of the integration process.
- A checklist of the essential steps in the integration process.
- A background document providing practical tools and references for specific aspects of integration.

It should be noted that successful integration requires transparency and commitment. These can only be achieved when all partners are involved and when the process is as participatory as possible; only through transparency can the weaknesses and constraints of leprosy control services be identified and addressed. In a successfully integrated setting, the quality of services will remain at an acceptable level while the advantages of equity, cost-effectiveness and sustainability will also be achieved.

In addition it is crucial to realize that the context in which leprosy control programmes operate is specific to each country, region or state – as a result, this guide should be used flexibly. Although efforts have been made to develop it in such a way that will be useful in different settings, the local context should always be taken into account when planning and implementing integrated services.

Finally, the guide does not intend to describe the general objectives and strategies of leprosy control, such as case-finding, case-holding, the prevention of disabilities and rehabilitation. It assumes that they will basically be the same as before, but that the way in which they are provided will be adapted to an integrated setting.

2 Integration: background and case studies

What is meant by integration?

In most countries where leprosy is endemic, activities aimed at controlling the disease began as vertical programmes. A vertical programme is organised separately from other health services, from the national level down to the operational level, and has its own specialised staff and clinics.

The underlying principle of integration is equity: optimal health care, including that for leprosy patients, consists of *general*, *continuous* and *comprehensive care*. *General* health care means that a patient receives care for a broad spectrum of common health problems, contrary to the care offered by vertical services which only provide care in relation to specific health problems. *Continuous* health care implies the constant (daily) accessibility of services, in contrast to the intermittent availability of vertical services (which may operate monthly clinics, for example). *Comprehensive* health care means that the patient is cared for by health workers who know the personal history and (family) background of the patient. Such care can only be provided by multipurpose, permanent and decentralised health services.

Integration means that the general health service assumes responsibility for leprosy control activities. This will include case-finding, treatment, the prevention of disabilities and rehabilitation, all of which are implemented at the health services delivery level, but it also includes policy making and planning, training, supervision and the identification of referral arrangements. It is therefore essential that capacity for the latter elements of leprosy control is retained at the intermediate and national level. The local context will determine how these functions are integrated.



Credit: DFB

Why integration?

For decades leprosy control activities were undertaken by specially trained and highly dedicated and motivated individuals. National authorities responsible for health services tended to depend on local and international organisations to support the programmes. However, the introduction of effective treatment in the form of MDT brought about significant changes in the management of leprosy as a disease. It also prompted the use of public health approaches for the organisation of leprosy services, reflecting the need to make MDT services more widely accessible, cost-effective and sustainable. At the same time, it was recognised that society's negative perception of the disease and of the persons affected needed to be changed.

The integration of leprosy control activities within existing general health services in endemic countries is now recognised as the best approach to bring about these changes. General health services are relatively widely distributed and close to the communities they serve, and integration will improve MDT coverage and be more cost-effective and sustainable. It may also be expected that the age-old stigma attached to the disease will be reduced as persons affected by leprosy begin to use the general health service alongside other members of the community. This of course does not mean that all supportive components will disappear; it will be important to maintain an effective network of supportive and referral services within the health system to support peripheral general health workers in maintaining an acceptable quality of service.

What have been the experiences with integration?

Efforts to integrate leprosy services have been made in several countries. In some, the process has been relatively successful and has produced satisfactory results in terms of case-finding and the quality of services delivered. In others, integration has faced obstacles and constraints. The following case studies illustrate two recent experiences, and these have been incorporated in the model that is described in Chapters 3 and 4.

Case study 1: Integration in Jigawa State, Nigeria – Building commitment among staff for the integration of leprosy services¹

Jigawa State is situated in the north of Nigeria and is divided into 27 districts. Leprosy is still a significant public health problem in Jigawa; case detection rates for 1999 and 2000 were respectively 5.5 and 1.9 per 10,000. It has a combined leprosy and tuberculosis control programme. Before integration, MDT clinics were conducted about once a week by vertical leprosy staff in 75 out of the 368 health facilities.

In 1996, the State Tuberculosis and Leprosy Control Programme Team tried to integrate leprosy control in order to enhance the accessibility and sustainability of the services. In the same year training was given to the general health staff of the Primary Health Care (PHC) units, but to limited effect. Only about 25% of the trained general health staff attended the MDT clinic sessions and less than 10% participated actively. These disappointing results were caused by a number of factors: fear of contracting the disease, the stigma of leprosy, the lack of incentives such as allowances and motorcycles which were normally given to vertical leprosy staff, and a reluctance among vertical leprosy staff to hand over responsibilities. Even when, in 1997, a special bill by the State Council was formulated indicating that leprosy patients should be treated like other patients in all health facilities in Jigawa State, there was no significant change in the participation of general health staff in leprosy services.

In 1999, a new opportunity emerged through the start of a Leprosy Elimination Campaign and a renewed effort was made to create commitment among general and vertical health staff for the integration process. As preparation for this process, the State Tuberculosis and Leprosy Control Programme Team held a special meeting with all leprosy-trained staff. This meeting indicated that most were not in favour of integration because they feared losing their status and incentives, including their motorcycles. Their fears were mainly due to a lack of knowledge concerning their future role, but these concerns were nevertheless taken seriously and discussed. Furthermore, their new responsibilities - to give technical support to the general health workers and to monitor the programme - were emphasised during the discussions.

Once the vertical staff had accepted their new roles, it was agreed that current MDT clinics would be 'handed over' to the general health staff. During the training of the general health staff a lot of effort was put into trying to reduce their fear of leprosy and to strengthen the idea that leprosy is an 'ordinary' disease.

This time the integration process was much more successful. The total number of PHC clinics providing MDT services increased to 264 out of 368 (72%) by 2000. With this development, the responsibility for routine leprosy services was devolved to the peripheral general health workers, while technical advisory tasks continued to be carried out by specialised (leprosy and TB) staff at the intermediate level.

¹ Summarised from Namadi, Visschedijk and Samson (2002).

Case study 2: Integration of leprosy services in Tamil Nadu, India²

When MDT was introduced in Tamil Nadu in 1983, leprosy services were provided through a network of 102 vertical leprosy control units managed by medical and paramedical staff numbering 3,000 and covering a population of 56 million. When in 1996 an analysis by the State Department of Health showed that provision of leprosy services through a vertical system was no longer cost-effective, a committee headed by the Director of Medical and Rural Health Services was established. This committee, consisting of various stakeholders, formulated a plan for the integration of leprosy services. In addition to cost-effectiveness, the committee based their decision on the expectation of improved sustainability of leprosy services and improved access through a network of more than 30,000 PHC workers.

In February 1997, just before the start of integration, the entire PHC system got involved in an intensive health education and case detection campaign conducted all over Tamil Nadu. This provided an entry point into leprosy work for PHC staff. Later, 22,667 medical and paramedical PHC staff were trained in leprosy and in the prevention of disabilities. Patient cards and registers were simplified and staff were taught to use a simplified monitoring system. Information, education and communication (IEC) materials were designed and produced to create awareness of the changes in service delivery. MDT regimen boards were displayed in primary health centres.

In October 1998 a study was conducted to evaluate the process and impact of integration. This study found that most personnel, including a significant proportion of former leprosy workers, had accepted integration in principle. In addition, essential indicators of leprosy performance during pre- and post-integration periods were compared in six selected districts. The study found that overall the average number of new cases had not changed significantly. Furthermore it showed that voluntary reporting was significantly higher in the post-integration period, which was attributed to the increased accessibility of leprosy services to the rural residents. The study recommended that well-defined referral systems and linkages should be established and that the knowledge, skills, attitude and motivation of workers should be strengthened by identifying training needs and by organising such training. It also noted that the level of awareness in the community regarding leprosy needed to be enhanced.

² Summarised from Department of Community Health, Vellore (2003).

3 Overview of the integration process

In this document the integration process has, more or less arbitrarily, been divided into seven stages (A-G) as follows. After an **analysis** of the current situation (A), **commitment** for integration has to be obtained from the major decision-makers (B). Next a **plan of action** for the preparation and implementation of integrated leprosy services has to be developed (C). After a period of **preparing** the health system (D), the general health services can start to **implement** integrated leprosy services (E). The implementation has to be carefully **monitored** (F) and after a few years the whole integration process should be **evaluated** (G).

Each stage consists of a number of steps, and an overview of both is given in Table 1. Each stage is represented by a section in the table. The first column of the table gives the steps involved for that stage. The second column lists the main issues to be considered while the third column gives examples of specific concerns. The methodology for undertaking each stage is described in Chapter 4.



Credit: Wellcome Trust Research Labs, Blantyre

Table 1 – Stages and steps in the integration process

Steps	Issues to be considered	Specific concerns
A. Analysing the situation		
A1. Analysing the epidemiological situation	<ul style="list-style-type: none"> • What is the current leprosy problem? • What is the expected situation in 5-10 years? 	<ul style="list-style-type: none"> • Ascertaining the exact magnitude of the leprosy problem. • Reliability of data.
A2. Analysing current leprosy services	<ul style="list-style-type: none"> • What is the state of current leprosy services (including patient-related and support services)? • What are the weaknesses and strengths of current leprosy services? • What is the current human resource capacity for leprosy services? 	<ul style="list-style-type: none"> • Availability of clear job descriptions and allocation of tasks among different health workers. • Availability of information on health seeking behaviour. • Sufficient attention given in the analysis to programme management (training, supervision, monitoring). • Clear description and analysis of the required financial resources.
A3. Analysing the health system and the degree of integration of leprosy services	<ul style="list-style-type: none"> • To what extent is the leprosy control programme already integrated? • Are there constraints within the general health service which are relevant to the integration of leprosy control? 	<ul style="list-style-type: none"> • Adequacy of the general health service in terms of population coverage. • Adequacy of the general health service in terms of human resource capacity. • Factors such as user fees that may hamper accessibility.
A4. Analysing the stakeholders	<ul style="list-style-type: none"> • Who are the relevant stakeholders? • What are their positions towards integration? • How should their commitment be secured? 	<ul style="list-style-type: none"> • Estimating the commitment of vertical leprosy staff and general health workers. • Attitude of donors/NGOs towards integration. • Community support for integration. • Patients' willingness to accept integration.
B. Ensuring the commitment of decision-makers to the principles and process of integration		
	<ul style="list-style-type: none"> • Who are the decision-makers? • Through which process can they be informed and convinced of the need for integration? • How can explicit commitment to integration be obtained? 	<ul style="list-style-type: none"> • Getting the key decision-makers involved. • Ascertaining how genuine is their commitment to integration. • Clarity of the concept of integration. • Stability of political situation. • Support from donors.

Steps	Issues to be considered	Specific concerns
C. Developing a plan of action for integration		
C1. Formulating objectives and targets	<ul style="list-style-type: none"> • What are the objectives of the integration process? • How can these objectives be translated into relevant targets? 	<ul style="list-style-type: none"> • Clarity of objectives to all stakeholders. • Setting realistic targets.
C2. Formulating a strategy for the integration process	<ul style="list-style-type: none"> • How should the process of integration be carried out? 	<ul style="list-style-type: none"> • Clarity and robustness of strategy.
C2.1. Building commitment amongst health staff	<ul style="list-style-type: none"> • How can commitment among health workers be ensured? 	<ul style="list-style-type: none"> • Sustained interest of health staff.
C2.2. Strengthening human resource capacity	<ul style="list-style-type: none"> • Which categories of staff should perform the different tasks relating to leprosy control? • How should capacity be strengthened? • How can vacancies for positions in the integrated setting relating to leprosy control be filled? 	<ul style="list-style-type: none"> • Identification of leprosy control tasks for different levels within the health service. • Level of education and experience of general health staff. • Adaptation of vertical staff to general health care setting.
C2.3. Ensuring adequate technical supervision	<ul style="list-style-type: none"> • How can technical support be maintained in an integrated setting? 	<ul style="list-style-type: none"> • Adequacy of the supervision structure. • Continuation of technical support to general health workers providing leprosy services.
C2.4. Adjusting the management information system	<ul style="list-style-type: none"> • Which indicators and targets are to be used for monitoring integrated leprosy control services? • When and how will they be measured? 	<ul style="list-style-type: none"> • Robustness and simplicity of the monitoring system. • Existence of parallel information systems.

Steps	Issues to be considered	Specific concerns
C. Developing a plan of action for integration (cont.)		
C2.5. Ensuring adequate drug supply and logistical support	<ul style="list-style-type: none"> • How will the drug distribution system work in relation to MDT and other drugs? • How will transport systems cope in the new setting? 	<ul style="list-style-type: none"> • Functionality of drug supply system. • Maintenance of guaranteed transport facility.
C2.6. Communicating the changes to the public, patients and other relevant groups	<ul style="list-style-type: none"> • How can it be ensured that patients and communities are willing to report to the general health services and that stigma is reduced? • What media should be used? • How can information be provided to other relevant groups such as traditional healers and the private sector? 	<ul style="list-style-type: none"> • Lack of awareness of integrated services. • Continuation of stigma.
C3. Developing a work plan, budget and time frame	<ul style="list-style-type: none"> • What concrete activities have to be planned and how will they be financed? 	<ul style="list-style-type: none"> • Production of a clear plan with budget.
C4. Selecting indicators to monitor the integration process	<ul style="list-style-type: none"> • Which indicators and targets are to be used for monitoring the integration process? • When and how will they be measured? 	<ul style="list-style-type: none"> • Robustness and simplicity of indicators.
C5. Finalising the plan	<ul style="list-style-type: none"> • Do the decision-makers and other important stakeholders agree with the plan for integration? • Is there sufficient financial support to start the process? 	<ul style="list-style-type: none"> • Strength of stakeholders' commitment to integration. • Adequacy of financial resources for implementing integrated leprosy services.

Steps	Issues to be considered	Specific concerns
D. Preparing the health system for the implementation of integrated leprosy services		
<p>All preparatory activities as planned in stage C are now carried out. These relate particularly to step C2, in which a strategy for the integration process will have been formulated.</p>	<ul style="list-style-type: none"> • How can implementation proceed promptly after training? • Are all staff adequately trained in, and committed to, the delivery of leprosy services following the preparatory stage? • Are the MIS and technical support in place? • Are all logistics and drugs in place for the delivery of integrated leprosy services? • Have the general public, including patients, been adequately informed about the forthcoming changes? 	<ul style="list-style-type: none"> • Loss of momentum if this stage takes too long.
E. Starting the implementation of integrated leprosy services		
	<ul style="list-style-type: none"> • Have all the steps in stage D been completed? 	
F. Monitoring the implementation of integrated leprosy services		
	<ul style="list-style-type: none"> • How can early results be used to enhance commitment to integration? • Does the information collected indicate a need to make adjustments to the integrated services? • Is there a need for health systems research? 	<ul style="list-style-type: none"> • Reliability of information. • Possible opportunities to act upon the information collected.
G. Evaluating the process of integration		
	<ul style="list-style-type: none"> • Have the objectives been achieved? • Do the objectives or strategies need to be adjusted? • What lessons can be learned? 	<ul style="list-style-type: none"> • Responsibility to organise and fund evaluations.