Availability of records and reports in health facilities under Integrated Leprosy Services of India

M. A. ARIF
Netherlands Leprosy Relief, U-9, Green Park Extension, New Delhi 110 016, India

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Introduction

With the advent of multi-drug therapy (MDT), the National Leprosy Control Programme (NLCP) of the Government of India was re-designated as a National Leprosy Eradication Programme (NLEP) in the year 1983. In the early 1990s, the NLEP adopted the goal of elimination of leprosy by the year 2000 (the goal has now shifted to December 2005). This programme started as a 100% centrally sponsored scheme of the Government of India, with a vertical infrastructure, i.e. all the staff employed by the programme were specially trained in leprosy and were working for leprosy control only. In high endemic areas, leprosy services were provided through specially identified and temporary service delivery points, which were known as drug distribution points (DDPs). It is interesting to note that, because of stigma, these DDPs were not attached to general health care centres and services were, in some instances, provided under a tree! In moderate and low endemic areas, leprosy services were provided through World Bank-supported Mobile Leprosy Treatment Units (MLTUs).

Tremendous achievements were made in the programme with regard to accessibility and service delivery. With the successful implementation of the programme, the prevalence rate of leprosy dropped from 57/10,000 population in the year 1983 to around 5/10,000 by the year 2000. With the decreasing caseload, running a vertical programme was considered not cost effective. The second phase of the World Bank project started in the year 2001. One of the main objectives was to provide assistance for restructuring leprosy control activities, so that they would be offered through the general health care.

Integration of leprosy into general health care (GHC) services

For the process of integration to go smoothly, GHC staff were involved by including them in four modified leprosy elimination campaigns (MLECs), between 1997 and 2003. It was presumed that all the GHC staff would be capable of handling leprosy cases independently after the MLEC training. However, these training sessions were more for confirmation of
suspect cases by the Medical Officers of the primary health centres, for conducting surveys by
GHC staff, for suspecting cases and referring them for confirmation and for IEC activities,
rather than for handling leprosy cases independently and maintaining records and reports at
GHC centres. Leprosy services are now available through general health care staff in centres
known as Primary Health Centers (PHCs), which cater for a rural population of 100,000,
additional PHCs (for 25-30,000 population) and through sub-centres (for every 5000
population). Gradually, the erstwhile vertical structure is being dissolved and non-medical
supervisors and paramedical workers are attached to PHCs.

The majority of the GHC staff have started to provide leprosy services independently or at
some location dependent on attached vertical staff (now considered part of GHC staff).
Quality of services is variable, and in some centres has yet to be improved. To support
integration, and to improve quality of services, District Technical Support Teams (DTSTs)
have been placed in problem states and districts in India. Though the GHC staff was
sensitised for integration, it was accepted as a duty-bound obligation rather than a welcome
change. In some states, they have not accepted the change even now. On the other hand,
vertical staff were not ready to leave ownership of the programme to the GHC staff. They
were not ready and prepared to hand over their records, which they had prepared and
maintained with much effort and dedication for many years. Before integration, since the
vertical staff served only the leprosy programme, records and reports displayed every
possible detail and were well maintained. There were about 13 registers to be maintained,
including a survey register, master register, RFT register, deformity register, surveillance
register and healthy contact register. In an integrated setup, formats and records maintained
by vertical staff were considered to be too complicated and too many in number, and hence
simplification was thought to be necessary.

Before simplifying records and reports

Before the development of Simplified Information System (SIS) guidelines, an assessment of
availability of treatment and drug stock register was included in the leprosy elimination
monitoring (LEM) exercises in the year 2002. It was found that the availability of treatment
registers (old or new) with GHC staff ranged from 0% of the health facilities visited by the
monitors in the state of Madhya Pradesh to a maximum of around 64% in the states of West
Bengal and Tamil Nadu. Availability of drug registers with GHC staff ranged from 5% in the
State of Chhattisgarh to a maximum of 75% in West Bengal and Tamil Nadu. The latter was
the first state to have started integration (in the year 1997), long before the Government of
India began its initiatives for integration. In some states, ILEP agencies developed their own
simple case cards and provided them to the health centres.

Simplification of records and reporting formats

To simplify records and reporting formats and to facilitate provision of leprosy services
through GHC staff, a national level meeting was organized at Delhi in May 2002.
Representatives from the Government of India (GOI), World Health Organization (WHO),
International Federation of Anti-Leprosy Associations (ILEP) and experts from non-leprosy
fields were invited. The purpose of this meeting was to design an SIS. Comprehensive
guidelines, known as the SIS guidelines, were developed, containing the methodology to be used for managing leprosy through GHC staff. A simplified case card, treatment register, drug stock register and reporting formats were designed. These guidelines also contained explanations for filling case cards and other records, indicators to be used and instructions on how to calculate them. After its development and distribution to the states, state leprosy officers were requested to send proposals for its printing at state level so that copies could be distributed to all the health centers of all the districts. Printing of case cards, treatment registers etc., were dependent on preparation of proposal at the state level, its approval by the state leprosy society and approval from the central government before it could be printed in bulk. Depending on the efficiency of the states, these records and reporting formats were printed and distributed to health centres. In some states due to delays, availability of simple case cards and registers was patchy. In some places, old case cards, treatment registers and reporting formats continued to be used, mostly by former NLEP staff, posted in the GHC centres.

After simplifying records and reports

When the simplified case cards and registers were printed and distributed, it was presumed that the guidelines were very simple and self-explanatory, hence no formal discussions were held at state and district levels to explain the maintenance of these records and preparation of reports. GHC staff were expected to be supported by former vertical staff in filling and maintaining these records. Officers from some states did not find this simplicity acceptable, and modified the records and reporting formats. Besides other technical support, major contributions made by ILEP support teams were in the form of transferring of their skills to GHC staff, in maintaining and updating of these records and preparation of reports as per SIS guidelines.

After the development of the SIS and its implementation in September 2002, availability of the guidelines, records and reports was assessed in the LEM exercise in the year 2003. It was found that on average 32% of the health facilities visited by the monitors had new SIS guidelines, ranging from 0% in West Bengal and Karnataka to 84% in Madhya Pradesh. The SIS guidelines were found in less than 20% of the health facilities in Bihar, Delhi, Karnataka, Orissa, Tamil Nadu, Uttarakhand and West Bengal. This percentage reflects the importance given by the states to print and distribute these guidelines to each health centre. Only one state, Madhya Pradesh (MP), had the guidelines available in more than 80% of the health facilities. This high percentage could be attributed to the printing and supply of these guidelines by the Danish agency DANLEP, which was supporting leprosy in MP at the time.

With regard to other supplies, on average 66% of the health facilities had new SIS patient cards, ranging from as low as 0% in Delhi to more than 80% in Chhattisgarh, Karnataka, Andhra Pradesh, Maharashtra, West Bengal, Orissa, Uttar Pradesh and Uttarakhand. With regard to treatment registers, MDT drug registers and monthly reports, these were available in on average 68, 63 and to 79% of health facilities, respectively. The high percentage of reporting forms could be due to feasibility of using photocopies of the reporting formats. This variation in the availability of printed material was mainly due to the initiative and efficiency of the state for printing them from society funds.

The same analysis was performed in the LEM exercise in 2004. It was found that availability of SIS guidelines had increased to an average of 47% of health facilities, ranging from 6.8% in Uttarakhand to around 96% in Delhi and 100% in Andhra Pradesh. Availability
of SIS patient cards and treatment register was found to be around 94%, while MDT stock register and monthly reports rose to 84 to 98%, respectively. This rise in availability and use is due to momentum given by the Leprosy Division and to better monitoring and support given by ILEP support teams. At present in almost all the health facilities, patient cards, treatment register and MDT stock registers are available and maintained as per SIS guidelines, though the quality differs. It has to be ensured now that the quality of maintaining these records and reports does not go down and that supply is uninterrupted.

References