

UPDATE

CONTINUING MEDICAL EDUCATION

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The process of integration of leprosy in Bihar - a recountable and rewarding experience

Bihar, one of the economically backward and leprosy-endemic states in India, has succeeded to a large extent in making leprosy an integral part of general health service. The evolution of the integration process in the state is a seamless portrayal of an upward arc of success, of diligent leadership, of synergies of partnership, of adroit employment of scarce resources and of surprising self-indulgence in commitment. Those who have been fortunate to be in the thick of things will, no doubt, vouch for the supreme verve and flexibility with which the state inexorably marched towards integration. The experience is worth sharing.

1996- the beginning: the worst-case scenario:

The story like any other story starts at the beginning. It was 1996. Leprosy control was run with unipurpose, leprosy-exclusive staff through leprosy control units or Mobile leprosy treatment units. The 55 districts (each district with a population of 1.5 to 2.5 million) in the

state (Jharkhand was part of Bihar) were divided into high, moderate and low endemic based on prevalence. High endemic districts had Leprosy control units, one for every 400000 to 500000 population with a Medical Officer, 4-5 Supervisors and 20 to 25 paramedical workers (one for every 25000 to 30000 population). Moderate and low endemic districts had a Mobile leprosy treatment unit, one for every million population with a Medical Officer and a Supervisor and 20 paramedical workers. In actual fact the number of vertical staff in the state was less than 50% of



the expected. Their competence was questionable because they had been trained long time back or scarcely trained. There was only one training center run by an NGO and the training was as per the Government prescription agonizingly stretched out. Coverage was therefore inadequate. Cases were detected through occasional surveys and were treated at ill-organised roadside clinics. Treatment completion was never more than 40%. General health service facilities and staff were not involved in the programme. The supervisory staff lacked mobility support

and supervision and monitoring was nonexistent. Information dissemination to the community was not worth mentioning, drug supply management was woefully inadequate and information system was rudimentary. Prevalence was highly inflated (patients in the register were rarely removed). Leprosy control in Bihar was thus known for all the wrong reasons.

1996-1997 - one step ahead:

The programme needed an urgent infusion of momentum. A shortened task-oriented training programme was initiated for the vertical staff to improve their technical and operational competence. This resulted in increased coverage of vertical personnel for training. Expert resident technical support teams were introduced by Damien Foundation India Trust (DFIT) and World Health Organisation (WHO) to provide on-the-job guidance to the vertical staff and build their competence levels. There was no systematic case detection

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Editor :

Dr. P. KRISHNAMURTHY

Secretary,
Damien Foundation India Trust.

Associate Editor :

Mr. D.V. PREMKUMAR VELU

Advisers :

Dr. CLAIRE VELLUT

Dr. P. VIJAYA KUMARAN

Dr. JACOB MATHEW

Dr. T. PRABHAKAR RAO

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The process of integration of leprosy in Bihar - a recountable and rewarding experience - Contd. from page 1

activity. Leprosy elimination Campaigns (LEC) were carried out in three districts- Patna, Bhojpur and Singhbhum to flush out backlog cases. The number of cases detected was almost three times that reported in the previous years. IEC campaigns were carried out in hard to reach areas. The Government appointed contractual staff in high endemic districts. The DTSTs assisted the districts in practically all activities including drug supply distribution. Very few districts had full-fledged District Leprosy Officer. Mobility remained a problem and therefore supervision and monitoring by the Government staff continued to suffer. The programme was still in the hands of the vertical staff.

1998-watershed year:

The year witnessed the determined convergence of efforts and brought into focus the immediate need to seek the involvement of all the stakeholders in leprosy control activities. A state level coordinator was identified for coordination of efforts from all the major partners and activities. All the staff, vertical and those from general health, were given three-day, task-oriented training. Publicity was intensified. The staff used flash cards for dissemination messages regarding leprosy. Active search for cases was carried out for a week by all the staff and community volunteers, specially identified and trained for the purpose, in a well-organised systematic campaign called Modified Leprosy Elimination campaign (MLEC). The state reported an astronomical 200000 new cases. Case cards were provided by DF. Validation of the cases detected revealed that wrong diagnosis was about 17%. The campaign was the starting point for integration. One person from each health facility was identified and trained for managing information system and for distributing drugs. Tuesday clinic for leprosy was started at all health facilities for managing leprosy cases. Vertical staff were redistributed at the Primary health centers. Even though leprosy services were available at most of the primary health centers they were managed mainly by the vertical staff.

1999-2001-consolidation of gains:

Importance was given to fortify the inroads made into the general health system. Job responsibilities for all the categories of the general health staff was formulated and learning materials for all the categories of staff in 14 regional languages were prepared and used to train the general health staff. Case cards and registers were printed by DFIT and distributed to all the Primary Health Centres. The person identified from each PHC for drug distribution and record maintenance was trained again. Surveys were the main focus of case detection. MLECs were continued on an annual basis. The WHO DTSTs were replaced by DTSTs from ILEP (Federation of International antileprosy associations) agencies (LEPRA, TLM and NLR). Each DTST had an experienced Medical officer and a supervisor with a vehicle. The mandate of the team was to assist and guide the staff in the district in planning, organizing, supervising, monitoring and evaluating the programme. One team covered one to three districts depending on the need. Three drug depots were created to help improve the drug distribution within the state. ILEP often helped the state in procuring the drugs from GOI Medical Store depots and transporting them to the state depots and from there to the districts. ILEP also provided prednisolone (supplied by Sasakawa Memorial Health Foundation) in blister packs for managing patients in reaction. The state of Jharkhand was formed with 18 districts. Bihar had 37 districts.

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2002-2003-moving forward:

Even though there were many gains, challenges were equally large. Surveys were still the main focus of case detection. The Government had to resort to MLEC even though its relevance at the time was questionable. Several important decisions were taken which had a considerable bearing on the strengthening of GH involvement. Leprosy services which used to be offered only on Tuesdays became every-day affair. Information system was simplified to facilitate the management by the general health staff. There was a shift in focus for the teams from vertical staff to all the staff. GOI with assistance from WHO posted coordinators at the state and zonal level to coordinate the activities of all the stakeholders. For the management of DTSTs a state level coordinator was identified. Phased retrenchment of contractual vertical staff began. MLECs continued. Validation of leprosy cases showed that wrong diagnosis was 8% and reregistration was 10%. However, the extent of incorrect diagnosis was found to be low among routinely detected cases. Involvement of the general health staff in the programme showed much improvement. In an evaluation carried out by independent teams MDT services were found to be available on all days in at least 80% of health facilities.

2004-2006-the road to sunshine:

Intensified monitoring and coordinated efforts of all the major partners led to considerable improvement in integration status. With the removal of the contractual vertical staff, one of the main stumbling blocks for integration disappeared. Active case detection was replaced by encouraging people affected with leprosy to report voluntarily at the primary health centers. To encourage voluntary reporting intense community education campaigns using different methods was introduced. The Government took a wise decision to discontinue MLEC. Regular vertical staff were redeployed so that at least one was available at each PHC. On the job training was given by the DTSTs. Validation of newly detected cases was introduced as a means of improving the competence of the GH staff. One day a month was recognized as counseling day when problem cases were discussed by the DTSTs with the Medical Officers and other staff at the PHC. In each of the thirty out of 37 districts a district nucleus consisting of DLO, a Medical Officer and two paramedical workers or supervisors, has been formed and trained. The District nucleus along with the district hospital would be the resource center for managing complications and also for monitoring and supervising the programme. The district leprosy society has been merged into the District health society. Similarly, at the state level the state leprosy society has been merged into the state health society. The state leprosy officer who also looks after other programmes is part of the state health society and is responsible for managing the programme in the state.

The leprosy situation in the state is admirable. Leprosy services are available in all the health facilities on all days. Leprosy suspects are identified by the GH staff and referred to PHCs or they report voluntarily at PHCs. The diagnosis and initiation of treatment is done at PHCs and follow-up treatment is done either at PHCs or at Subcentres depending on the patients' convenience. Simple records are maintained at the PHCs which generate report every month to be sent to District nucleus for action and consolidation. DTSTs help the PHC staff in managing difficult cases and providing on the job training. NLEP coordinators assist the programme officers in implementing predetermined set of activities. Monitoring of the programme is done by the SLO through field visits and through quarterly meeting of District leprosy officers and DTSTs. Prevention of disability programme has been initiated in at least two blocks in all districts. This will be extended to all the remaining blocks by the end of 2007. Reconstructive surgery services have been started in two medical college hospitals with help from DFIT.

Future challenges:

Since DTSTs and Coordinators have succeeded in making the GH system dependent on them to a large extent, the sooner they are phased out the better it is for the programme. Even though district nucleus has been formed in majority of the districts the members of the nucleus are generally not together (operate from different sites). This makes coordination very difficult. Mobility for the district nucleus is also a serious problem which to a significant extent hampers their ability and willingness to undertake supervisory field visits. There is also a serious shortage of general health staff. Community involvement in the programme is minimal. Integration succeeds if the Primary health care system is strong. Because of limited supply of general drugs the health facilities do not generally attract people. With an OPD attendance of only 20 to 30 it would be difficult to expect that all the cases with leprosy disease will report to health facilities promptly. The situation has started improving now. The Government has started providing general drugs to PHCs. Communication facility has improved. The vertical staff are not completely integrated because of their noninvolvement in other programmes. Their training in other public health programmes is an essential prerequisite for their complete integration. The involvement of medical colleges, private practitioners and establishments is still negligible. A referral system is yet to be established. Even though there are many challenges, they pale into insignificance when compared to the problems overcome so far. Dispassionate observers do feel happy to see that despite all the problems, leprosy control programme in Bihar is nicely integrated and is moving in the right direction.

Operational guidelines for Leprosy control activities

(World Health Organisation)

(Contd. From July 2006 issue)

1.4 What does it mean to “reduce further the burden of leprosy”?

The “burden of leprosy” can be looked at in three ways:

Firstly, the most relevant epidemiological measure of the burden of leprosy is the incidence of disease, which is the number of people developing leprosy during a set period of time, usually one year. Because incidence is difficult to measure directly, the ‘Case Detection Rate’ is used as a proxy for incidence rate. It seems likely, however, that some new cases never come for diagnosis and treatment, so the number of cases detected is lower than the number of incident cases. The global incidence rate of leprosy seems to be declining slowly but the decline is faster in some areas than in others; in a few places the incidence rate seems to be rising. Changes in incidence take place slowly, over decades, and are related to factors such as immunization with BCG and economic development, as well as good leprosy control practices. By this measure, the “burden” of leprosy is declining slowly but new cases will continue to appear for many years. Thus, diagnostic and treatment services need to be maintained.

Secondly, the burden may be related to the registered prevalence of disease, which is the number of people on treatment at a certain point in time. The prevalence of leprosy has decreased throughout the world over the last 20 years because of multi-drug treatment (MDT) provided through the Leprosy Control Programme. By reducing the duration of treatment to just one year or less, MDT has greatly reduced the numbers on treatment at any one time and hence the “burden” on the health services. Although registered prevalence was a useful indicator to achieve the leprosy elimination milestone, it is not an adequate indicator to reflect changes in the epidemiological trend of leprosy.

The third way in which the “burden of leprosy” can be viewed is through the eyes of affected people themselves. Leprosy complications can lead to disability of the hands and feet and sometimes also to blindness. These physical problems are often overshadowed by the social rejection and mental suffering caused by the stigma that persists around this treatable disease in many communities. It is estimated that more than three million people are living with disability from leprosy. Much of this disability can be prevented and the new Global Strategy calls for increased efforts to reduce this “burden” by preventing disability in new cases, by helping to rehabilitate those with disability and by fighting stigma wherever it exists.

1.5 What are “quality leprosy services”?

The Global Strategy emphasizes quality leprosy services as an essential component of an effective programme. Quality is

based on appropriate training of staff at every level, regular technical supervision and monitoring of key indicators. The pursuit of quality assumes the willingness of staff to make changes aimed at improving their skills and the functioning of the health services in which they work.

Quality leprosy services:

- Are accessible to all who need them.
 - Coverage: MDT treatment can be provided at all health units.
 - No geographical, economic or gender barriers.
- Are patient-centred and observe patients' rights, including the rights to timely and appropriate treatment and to privacy and confidentiality.
- Address each aspect of case management, based on solid scientific evidence:
 - Diagnosis is timely and accurate, with supportive counselling
 - Treatment with MDT is timely, free-of-charge and user-friendly
 - Prevention of disability interventions are carried out appropriately
 - Referral for complications and rehabilitation is done as needed
 - Maintain simple records and encourage review and evaluation

1.6 What are “principles of equity and social justice” in this context?

Communities have wide-ranging health needs. Resources (staff, time, money) should be allocated fairly to different programmes, including the leprosy services, according to the disease burden, so that each can function as effectively as possible. ‘Equity’ means that leprosy patients have the same opportunity to attend health services that are of sufficient quality to deal with their problems. It also implies that leprosy services should be neither worse nor better than other health services available in a given community. Social justice means an absence of discrimination for any reason, including type of disease, level of disability, race, gender, social class or religion; it includes the principles of privacy and confidentiality.

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2. Integration and referral

2.1 How does referral work in an integrated health service?

Effective leprosy control requires an integrated approach, which provides wider equity and accessibility, improved cost-effectiveness and long term sustainability. This implies that leprosy control activities should be implemented by the general health services, including integrated referral facilities. Integration not only improves accessibility to treatment, but also reduces the stigma and discrimination faced by persons affected by leprosy.

Integration means that day-to-day patient management, recording and reporting become the responsibility of general health staff. However, integration does not mean that specialist expertise disappears from the health service. On the contrary, this 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. A system should be in place for the referral of difficult or complicated cases to the hospitals or specialists (e.g., general medical officers with some additional training in leprosy, dermatologists or surgeons) and referral by specialists back to the peripheral health facilities for continuation of treatment. The specialized referral services for leprosy are part of the general health services, just like a surgeon in a district hospital is part of the general health services.

Depending upon local conditions (e.g. 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 specialist expertise should be made available. Peripheral general health workers should be capable of diagnosing and treating leprosy under the technical supervision of specialized 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.

Where leprosy is less common, the ability to suspect leprosy and refer the patient to a referral unit is the most important skill required for peripheral general health workers. These referral units (including district hospitals and selected health centres) should diagnose leprosy and start treatment. Continuation of treatment could be delegated to the peripheral health facility serving the community in which the patient resides. The community should be informed about symptoms of leprosy and the availability of services. In areas with small patient loads, management of nerve damage will have to be concentrated in referral units. Centres treating the difficult complications of leprosy and providing rehabilitative surgical services will be even more centralized, but could also provide some referral services through mobile units.

An adequate referral system means that specialist services should be accessible and available to any patients who need them. The main obstacle to referral in many countries is the difficulty for the patient to reach the referral unit at the right time. In such situations, the visiting supervisor should prove useful in providing the necessary support services.

All peripheral health staff should know the clinics and health staff to whom they will refer patients, so that they can advise their patients accordingly, in order to minimize their difficulties. Good communication should be maintained, to allow discussion of patients' progress and as an opportunity for further training. The convenience of mobile phones and text messaging can make this easy and timely.

Six basic principles for successful integration are advocated by WHO:

- Every health facility in an endemic area should provide MDT services on all working days
- At least one trained staff member should be available in every health facility
- Adequate amounts of MDT drugs should be available, free of cost, for patients
- Information, Education and Communication (IEC) materials should be available for the patient and their family members
- A simple treatment register should be available
- Referral services should be available and accessible, and general health staff should know where and how to refer patients

Peripheral level

Staff at the Peripheral level should develop good links with the referral units they are most likely to use regularly:

- The visiting technical supervisor
- Nearest Health Centre (with staff with additional training in leprosy) or District Hospital
- Eye clinic for anyone with eye problems
- Leprosy or dermatology specialist: for diagnosis, skin smears, reactions
- Local rehabilitation networks for anyone with long-term disability

Referral level

Staff at the Referral level should know the specialist clinics and other professionals to whom they may refer patients, such as:

- Ophthalmology for significant eye pathology
- Dermatology for diagnosis of difficult skin conditions
- Laboratory for skin smears and histopathology
- Physiotherapy for assessment and management of reactions
- Podiatry for the feet and footwear
- Occupational therapy for rehabilitation and adaptations
- Reconstructive and plastic surgery
- Social worker for assessment and further referral
- Rehabilitation specialists and CBR programme

To be continued ...

TB CONTROL PROGRAMME

Why records are often not updated in PHC?

	Reasons	Actions required
1.	<ul style="list-style-type: none"> • Health staff are not aware • Health staff not visiting patients/ DOT providers 	<ul style="list-style-type: none"> ❖ Training ❖ Guidance from STS ❖ DTO, MOTC to verify a sample of patients periodically ❖ Feedback to concerned MO-PHC
2.	<ul style="list-style-type: none"> • DOT provider not recording DOT • Duplicate treatment card not given to DOT provider 	<ul style="list-style-type: none"> ❖ Training ❖ Provide patient record along with drug box ❖ Change DOT provider if needed
3.	<ul style="list-style-type: none"> • Treatment not given 	<ul style="list-style-type: none"> ❖ Find the reason ❖ Train DOT provider ❖ Change DOT provider if needed
4.	<ul style="list-style-type: none"> • Patient refuses treatment 	<ul style="list-style-type: none"> ❖ Counsel patient ❖ Organise treatment for side effects or other illness ❖ Counsel family members
5.	<ul style="list-style-type: none"> • MO is not aware of procedure 	<ul style="list-style-type: none"> ❖ Training of MO ❖ Review during monthly meeting. ❖ Supervision by DTO / MOTC ❖ Feedback from STS
6.	<ul style="list-style-type: none"> • Overburdened with multiple programmes 	<ul style="list-style-type: none"> ❖ Magnitude of the TB problems to be emphasized during review meetings by DTO & MOTC
7.	<ul style="list-style-type: none"> • Negligence by the field staff to bring the information from the DOT centre to the health facility 	<ul style="list-style-type: none"> ❖ On the job training to the health staff
8.	<ul style="list-style-type: none"> • No fixed staff to update the records at the health facility level 	<ul style="list-style-type: none"> ❖ One person to be identified and made responsible to update the registers and records
9.	<ul style="list-style-type: none"> • Key personnel post in RNTCP kept vacant 	<ul style="list-style-type: none"> ❖ Magnitude of the problem to be emphasized during review meetings by DTO
10.	<ul style="list-style-type: none"> • Lack of mobility for MOTC/STS/STLS 	<ul style="list-style-type: none"> ❖ Magnitude of the problem to be emphasized during review meetings by DTO

HAPPENINGS

- Dr. P. Krishnamurthy and Dr. P. Vijayakumaran participated in the workshop on TB/HIV held at Alert, Ethiopia from 14th to 18th of August 2006.
- Dr. Sr. Rita (Fathimanagar) and Mr. Kothandapani (DFIT) attended consensus development conference on POD at Cibu, Philippines from 13th to 16th September.
- Endowment prize examination on Leprosy was conducted for under graduate medical students of medical colleges from Tamil Nadu.
- Seminar on Leprosy was conducted for the Post Graduate Medical Students at Madurai Medical College on 13th September 2006.
- Dr. George Bakaswa, medical deputy, working for DFB at Cango visited DFIT projects at Salem, Fathimanagar and Nellore for observing Prevention of Disability activities from 28th August to 11th September 2006.
- Five Chantier groups participated in construction activities in India.

Self care of eyes

Fig. 1



Patient with eyes open
- lagophthalmos of the right eye not obvious

Fig. 2



Patient with eyes closed
- lagophthalmos obvious

Fig. 3



VMT of both eyes - weakness of the right eye



Fig. 4

Daily inspection of both eyes by patient for redness



Fig. 5

Passive exercise - pulling outer angle of the eye outwards



Fig. 6

Keeping the eyes moist - with sterile oil / water



Fig. 7

Protecting the eyes with goggles from dust / sunlight



Fig. 8

Protecting the eyes from dust at night during sleep

Self care of eyes

- Fig.1 Patient with eyes open - lagophthalmos of the right eye not obvious
- Fig.2 Patient with eyes closed - lagophthalmos obvious
- Fig.3 VMT of both eyes - weakness of the right eye
- Fig.4 Daily inspection of both eyes by patient for redness
- Fig.5 Passive exercise - pulling outer angle of the eye outwards
- Fig.6 Keeping the eyes moist - with sterile oil / water
- Fig.7 Protecting the eyes with goggles from dust / sunlight
- Fig.8 Protecting the eyes from dust at night during sleep