

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



LSHTM Research Online

Porter, JD; Ogden, JA; Rao, PV; Rao, VP; Rajesh, D; Buskade, RA; Soutar, D; (2002) Lessons in integration–operations research in an Indian leprosy NGO. *Leprosy review*, 73 (2). pp. 147-59. ISSN 0305-7518 <http://researchonline.lshtm.ac.uk/id/eprint/16872>

Downloaded from: <http://researchonline.lshtm.ac.uk/16872/>

DOI:

Usage Guidelines:

Please refer to usage guidelines at <http://researchonline.lshtm.ac.uk/policies.html> or alternatively contact researchonline@lshtm.ac.uk.

Available under license: Copyright the publishers

<https://researchonline.lshtm.ac.uk>

Lessons in integration—operations research in an Indian leprosy NGO

J. D. H. PORTER*, J. A. OGDEN*,
P. V. RANGANADHA RAO**,
V. PRABHAKAR RAO**, D. RAJESH**,
R. A. BUSKADE*** & D. SOUTAR****

**Departments of Public Health and Policy and Infectious and Tropical Diseases, London School of Hygiene and Tropical Medicine, Keppel Street, London, UK*

***LEPRA India, Krishnapuri Colony, West Maredpally, Secunderabad*

****Koralep, LEPRA India, Jeypore, Koraput, District, Orissa*

*****LEPRA, Fairfax House, Causton Road, Colchester, Essex*

Accepted for publication 11 February 2002

'To integrate'—to combine into one whole, to unify diverse elements of community (Collins Dictionary)

Summary Since the Alma Ata Declaration in 1978, health systems supporting the treatment and control of infectious diseases like leprosy and tuberculosis have been encouraged to 'integrate' into the primary health care structure within countries. Now, more than 20 years later, countries are still grappling with the concept of integration and looking for ways to achieve it. This study reports findings from a leprosy/Tuberculosis/AIDS awareness pilot project conducted by LEPRA India, a leprosy non-governmental organization (NGO), between 1996 and 2000 in Koraput district, Orissa. The project addressed the issue of integration on two levels. On the one hand LEPRA used the context of the project to explore ways in which to integrate TB services into their existing leprosy control structure. On the other hand, lessons from the pilot study were intended to help the organization find ways of linking with the government health care structure. Following a 'qualitative approach', this operations research project assessed the perceptions of communities and providers about leprosy and tuberculosis services. Providers across the spectrum of this plural healthcare system were asked to provide comment on developing stronger networks with each other, with NGOs and with government, while patients and communities were asked to describe the resources available to them and the constraints they face in accessing health care in general, and for leprosy and TB in particular. LEPRA staff from top management to the outreach workers were also approached for their views. Patients

Correspondence to: J. D. H. Porter (e-mail: j.porter@lshtm.ac.uk)

and communities noted that physical access to treatment was a major constraint, while the existence of local providers and family support structures facilitated health and health care. Providers expressed a willingness to collaborate (with LEPRO and the government), but lacked training, adequate staff support and the appropriate equipment/technical resources. Also lacking were adequate information campaigns to inform the public about these diseases and their treatment. This information has provided LEPRO with an understanding of how they might best fill gaps in the existing system and therefore assist in the process of integrating services in their own organization and through the primary health care structure. To achieve this aim, LEPRO will increasingly become involved in developing relationships and partnerships with government in the delivery of training and services and in infrastructure development.

Introduction

The Alma Ata Declaration in 1978 affirmed the responsibility of governments to provide adequate health and social measures, and pointed to primary health care as an essential component.¹ This required a fundamental shift in the prevailing infectious disease control paradigm at the time, which focused on vertical programmes controlled from the centre, to a more integrated and decentralized approach. Thus in order for vertical disease control programmes to link with Primary Health Care, they had to undergo a change in orientation and identity as well as a process of integration.² Neither clarity about what this process of integration would entail, nor specific guidance on how was it to be achieved, however, were provided. In the new century, the international health world is still trying to work these issues through, and a number of important problems continue to plague integration efforts. For example, while Alma Ata indicated the need to change from vertical to horizontal delivery of health care services, competing management targets between disease programmes left managers on the one hand encouraged to integrate, but on the other, being forced to ensure that particular disease targets were met.

Integration was needed on other levels as well. In the realm of infectious disease control, an important focus in the 1990s was on elimination, particularly in relation to leprosy and TB control. Towards this end, an international strategy for TB control was developed by WHO and the International Union Against Tuberculosis and Lung Disease, known as 'DOTS'. By the end of 1998, the DOTS strategy had been taken up by 119 countries world-wide,³ although 'elimination' remains a distant possibility.

The situation for leprosy is significantly different. In May 1991, the 44th World Health Assembly set out a strategy for leprosy elimination that was widely adopted. In this strategy elimination was defined as 'attaining a prevalence below one case per 10,000 population'.⁴ The goal of elimination was thereafter taken up by leprosy oriented non-governmental organizations (NGOs) such as LEPRO India, and 'elimination' has been the focus of their activities since the early 1990s. By the end of the decade, as numbers of cases were falling, there were concerns within these organisations as to what their focus should be after leprosy had been 'eliminated' in 2000. Taking up the delivery of tuberculosis services was deemed by many to be a logical way forward. A TB focus provided the organization with a means to ensure the optimal utilization of staff as leprosy work fell with elimination, a way of dealing with the perceived broad health needs of the communities that LEPRO served, as well as a way of paying attention to the increasing opportunities being provided nationally and internationally for NGOs to work in tuberculosis control. Since then NGOs involved in

leprosy control have been considering their future role in providing care for leprosy *and* TB patients in the new century. For many organizations, this has meant integrating their services with those of government health care structures, and in the process negotiating new partnerships and collaborative arrangements. In India, local state government has devised a methodology to integrate leprosy vertical programmes into primary health care in stages, initially integrating the functional component of services and later merging the infrastructure of the National Leprosy Eradication Programme (NLEP).

This paper reports on an operations research study conducted by LEPRO-India between 1996 and 2000. The research was carried out in the context of a pilot leprosy/TB/AIDS awareness project in Koraput District, Orissa. The paper describes the development of the operations research and the findings of the work that point to ways that the NGO can assist, and integrate with, the government services to provide appropriate and accessible care for people living with leprosy and TB.

Background

In India, as on the international stage, governmental discussions about the integration of infectious disease programmes increased in the late 1990s. By 2001, in certain states, like Orissa, NGOs were asked to rapidly integrate their programmes into the primary health care structure.⁵ The objective of the primary health care structure is to provide curative and preventive services for a population of approximately 50,000 people. PHCs are managed by medical officers with the support of multi-purpose workers. At that time, LEPRO India had been monitoring the international climate regarding leprosy control and infectious disease programme integration with government structures, and was attempting to prepare itself for the changes that were anticipated.⁶ LEPRO recognized the need to find a way of continuing to address the control of leprosy and rehabilitation of patients, while heeding increasing pressure from the Indian Government to ‘integrate’ leprosy into the Primary Health Care infrastructure. During this process the organization addressed itself to a number of key questions:

1. How do we integrate our vertical leprosy programme into the government primary health care structure?
2. What will we do and how will we identify ourselves as an organization when leprosy has been eliminated?
3. How can we plan and make the necessary changes at all levels of the organization—from the rural outreach workers (paramedical health workers or PHWs) to those in the top levels of management?

Meanwhile important changes were happening in the TB world as well. The long-standing National Tuberculosis Programme of India was evaluated in 1993, and the decision taken to revise the Programme, bringing it in line with the new international strategy. Thus in 1997, India introduced the Revised Tuberculosis Control Programme (RNTCP).⁷ The strategy included the internationally approved DOTS strategy with its five central components: government commitment, case detection by smear microscopy, standardized treatment regimen of 6–8 months with direct observation for at least the initial 2 months, a regular supply of drugs and a standardized recording and reporting system.⁸ The strategy encouraged the development of collaborative partnerships between NGOs, private health care providers and the government for implementation.⁸

LEPRA Pilot Leprosy/TB/AIDS awareness project

The Koraput Leprosy Eradication Project, KORALEP, was established by LEPRA India in 1991 as vertical project exclusively designed for the eradication of leprosy.⁹ The project covers a population of 1.5 million who live in 6000 villages and hamlets in hilly, difficult to access terrain connected by fair weather roads. The area is under-developed, and the population is largely composed of people belonging to a number of India's ethnically 'tribal' communities. A tribal community is often referred to as 'an aggregate of families of indigenous people from a common descent forming a community'. In Orissa, the tribal population constitutes nearly 22% of the total population of the State. Between 1991 and 1995, LEPRA detected 7700 leprosy cases and cured 5363. By 1995, the annual case detection had fallen from 19/100,000 to 7.6/100,000.

In 1996, LEPRA India, together with KORALEP, undertook a pilot project to explore the possibility of linking their leprosy control activities with TB control and HIV awareness raising. The pilot project was funded by the UK Department for International Development and the European Union. The pilot provided LEPRA with the first stage of a process to assist them in the longer term aim of 'integrating leprosy control with primary health care'. The pilot project covered a population of 261,000 in both urban and rural areas of Koraput District. The main objective of the project was to continue their usual leprosy control activities, while introducing key TB control measures such as case finding, sputum microscopy for diagnosis, and the involvement of Angawadi workers (Community based volunteers working for community development projects) as providers of 'directly observed treatment' (DOT) for TB patients.

A team made up of internal and external experts evaluated the project in 1998. Part of the evaluation pointed to the need for 'operations research' to be conducted to determine the feasibility of integrating the programme into the government primary health care system.⁹ Expansion into primary health care required an assessment of the potential 'gaps in implementation' and an analysis of whether NGOs like LEPRA India could be involved in filling these gaps.

One major recommendation from the assessors was that '*a system of integration of the LEPRA strategy with the government system needs to be considered. This would ensure that LEPRA is aware of how their services fit into the government structure and help to ensure that certain patients are not left out of the strategy*'.¹⁰ A further statement noted that '*a good relationship has been developed with the government and this needs to be strengthened. If these services are to be maintained, developed and sustained, this has to come through the government health structures*'.¹⁰ The evaluation team suggested that operations research be conducted in the pilot area to assist with a decision on further expansion and to assess gaps in the process of implementation of both leprosy and TB control strategies.

Background to the research

After the evaluation of the pilot project it was decided that LEPRA should conduct an operations research project in order to address the following issues:

- To understand the perspectives of TB and leprosy patients and their communities in order to learn how best to orient service provision to meet needs;

- To assess the capacity of the existing health institutions to play a complementary or supplementary role in the delivery of these services;
- To understand the level of expertise and perceptions of those who are already working in the field of TB and leprosy; and
- To assess its own capacity to integrate leprosy and TB services (implementation of the RNTCP) into the Government Health System.

The overall intention of the work required a shift in philosophy within the organization. A focus on exploring the mechanisms to integrate its leprosy and TB work into the Government Health Care System ran counter to the previous orientation of the organization which was the provision of a separate, vertical leprosy control programme.¹¹

The research focused on mapping the communities and exploring the experiences and perceptions of the community, of patients and of providers. To determine how LEPRA could work more closely with the government, part of the research looked at how leprosy and TB programmes were fitting into the government system. LEPRA was seeking to clarify its role in the delivery of an integrated leprosy and TB service; how it could shift from 'a vertical control role' to a more complementary or supplementary role vis á vis the public system. The purpose of the research, therefore, was to identify ways to support the process of integrating leprosy and TB services into the government primary care structures. The research was also used as 'a catalyst for change' in perspectives within the NGO from a culture of verticality outside government health systems, to an organization that is integrated with the government system in the delivery of health care services.

Research methods and methodology

The research employed a 'qualitative approach'.¹² This research strategy provides the basis for including the full range of social, economic and environmental factors in the development of infectious disease control programmes. In order to achieve this aim, research is conducted in each domain of interest, which in this case included the patient, community, provider and programme/policy domains. The underlying principle of this research methodology is that an in-depth understanding of the interests, perspectives, resources and constraints of each group of actors is necessary in the creation of effective, appropriate and sustainable health care interventions. The methodology was particularly useful for this study in that it enabled LEPRA to explore not only the needs and perspectives of patients regarding TB and leprosy, but also to learn from the relevant groups of providers whether and to what extent they would be able/willing to collaborate in the delivery of services. The process of carrying out the research itself also enabled the members of LEPRA to gain first-hand knowledge about the ways in which they function as an organization and how they might change to facilitate the integration process. Figure 1 outlines the overlapping domains and the data collection techniques employed in each aspect of the study.

SITE OF STUDY

The operations research was conducted within the pilot (population coverage 261,000) and expanded area (population coverage 1.5 million) of the Koraput TB/leprosy/AIDS awareness study. A total of six areas were chosen: two urban, two rural and two tribal. A tribal area

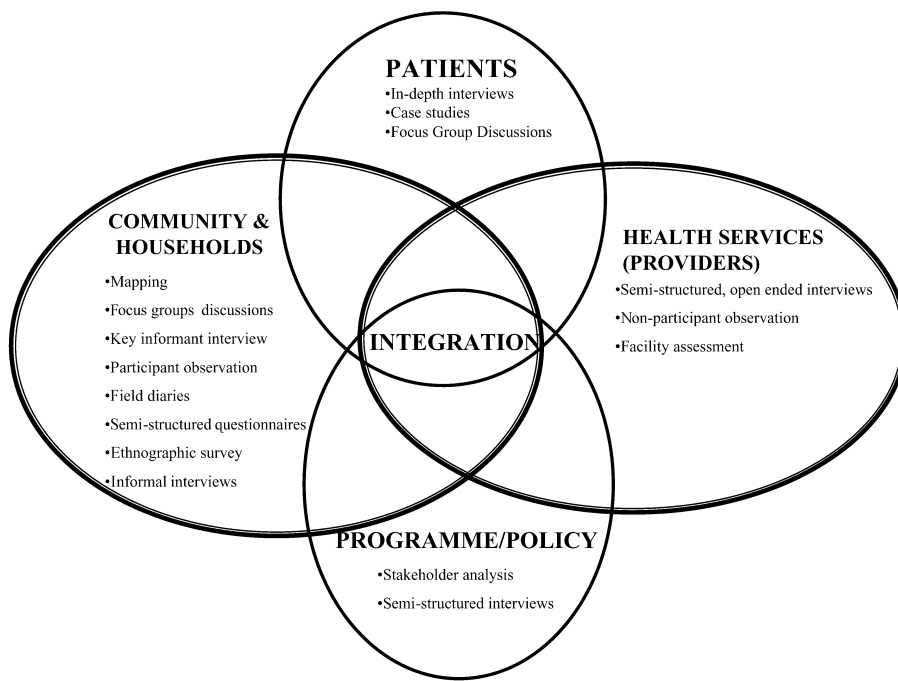


Figure 1. Methods and methodology of the research.

was defined as an area outside the Municipality limits with a predominantly tribal population. The rural area was defined as one, which lies outside the Municipality limits and has a predominantly non-tribal population. The urban area was one within the limits of a municipality.

METHODS OF DATA COLLECTION

As can be seen from Figure 1, the research was wide-ranging and applied a variety of techniques. In this paper we will focus on data collected that is particularly relevant to the question at hand, which is the integration of TB and leprosy services into the government primary health care structure. Thus the data we draw on here comes largely from the following aspects of the study only:

- Focus group discussions with the following groups: lay members of the community(ies); multi-purpose health workers (MPHW); Angawadhi Workers (AWW); paramedical workers (PMW) of Koralep; municipal health workers.
- Semi-structured interviews with the following stakeholders:
 - Community members (60 interviews)
 - Local providers (2 doctors in rural, 2 in urban and 2 in tribal)
 - Laboratory technicians (7 interviews in PHCs and 2 in LEPRAs)
 - Laboratory attendants (7 in PHCs and 3 in LEPRAs)
 - Pharmacists (8 interviews)
 - TB supervisors (9 interviews)

Medical officers of Primary Health Care centers (10 interviews)

Patients (12 active cases of TB and 12 active cases of leprosy)

- Case studies conducted with six TB patients.
- Participatory and non-participatory observations conducted in a variety of settings including primary health care centres.

TIMETABLE

The operations research was undertaken between April 1999 and February 2000 by a research team that comprised two research officers, and eight research assistants, who were supported by technical staff within LEPRO India, and by researchers from the London School of Hygiene and Tropical Medicine, UK. The fieldwork was conducted between July and to October 1999.

Results

THE HEALTH SYSTEM

The health system in these areas includes publicly funded facilities and personnel, qualified and non-qualified private providers of allopathic medicine, qualified and non-qualified providers of Indian Traditional Systems of Medicine (i.e. Ayurvedic and Unani traditions), and a range of spiritual and herbalist healers. In addition, there are a number of NGOs operating, which support the communities in a variety of ways. Some NGOs have taken on the total management of particular conditions, as LEPRO India has done for leprosy. The Government system consists of a subdivisional headquarter hospital at Jeypore (the main urban area in this part of the District), Community Health Centres (CHCs), Primary Health Centres (PHCs), dispensaries and Auxiliary Nurse-Midwife (ANM) centres. Despite this vast range of treatment options most patients interviewed in the tribal and rural areas went first to the traditional healer, or *disari* (the traditional functionary in most tribal villages, combining religious and medical functions), when they were sick—of which more below.

KORALEP activities extend over an area of nearly 15,000 km². Within that area, there are over 6500 villages, many of which are small, with a population of less than 200, scattered over a vast area. The project is pyramidal in structure with an extensive network of rural outreach workers who deliver support and treatment to leprosy patients, and treatment points where drugs are delivered on specified days. There are 124 treatment points in all, and 40 paramedical workers servicing the all areas of the district. The project has a well-equipped and well-established laboratory in Jeypore town. This laboratory is appropriately equipped to investigate and handle both leprosy and tuberculosis specimens accurately and safely. KORALEP also has a physiotherapy unit, established in Koraput, to provide physiotherapy care to patients in need. A trained and experienced physiotherapist heads the unit. KORALEP carries out a range of activities including active case finding for leprosy symptoms, contact surveys, case holding and treatment, and health education outreach activities in all areas of operation.

In the following section results from the study relevant to the question of integration are presented. We focus here on the assets and the problems faced by the community and relevant providers in obtaining and delivering health care services. This discussion highlights the needs of the community and the gaps in services rendered by the public health system that LEPRO might usefully fill.

As previously noted, a large proportion of the population in the project areas live in extremely remote and difficult-to-reach areas. Although for most areas there was a primary health centre within 1–10 km, our team found that very few were staffed by doctors, and most were run by the ‘compounder’. Community Health Centres (CHCs) were located at a distance of 20–40 km from most of the villages. The lack of access to the government system is coupled with the lack of trust that has developed over the years due to failures to fill the vacant doctor’s posts and lack of adequate drug supplies. Indeed a theme of the focus group discussions and patient and community member interviews was *‘the community and patients do not have much faith in the public health system’*. Some informants were even unaware of the existence of a publicly funded health service. For these reasons, as well as the general under-development of the area and poverty of the inhabitants, most people experiencing illness consult local providers. The first port of call for most patients is the local traditional healer, or *disari*. The *disari* is nearer to the patient and has faith in the traditional system of medicine including herbal medicine. They charge less for their services and have good communication with the people.

Patients also find ‘other providers’ to help them understand their illness and to find ways of dealing with it. For example, in addition to the *disari*, patients will visit religious leaders, traditional birth attendants, local unqualified allopathic practitioners, opinion leaders and NGOs operating in their areas. Less remote populations also have access to and seek help from qualified private practitioners, pharmacies and private laboratories. While accessing these services is sometimes convenient, however, it is also costly. It was not uncommon to find a TB or leprosy patient who had to discontinue treatment when they ran out of money to pay their private doctor.

Issues of access to care and the problems encountered when trying to enter the government health system are highlighted by the following stories collected in the field.

Mr A aged 40 of Bagaguda village demonstrates how a patient with TB moves between different systems in search of a cure. This gentleman felt pain in his chest followed by a fever. He went to the local PHC where his case was diagnosed as TB but the PHC did not have medicine. Next he went to a village near Jeypore where he met a person who treated TB; he was given 4 days of treatment without any improvement. He then went to another person at Kotpad and took treatment for 15 days. He then heard that a government doctor was at Mathali who specialized in TB. He went to Mathali, which is 70 km away, to find that the doctor had been transferred to Jeypore. He went back to his village where the *disari* agreed to give him treatment if he gave him 500 rupees to prepare the medicine. But before he could get the medicine, the *disari* died. He then went to a snake charmer.

Ms B is a 45-year-old woman from Keratal, an interior village who discovered skin patches on her body more than 18 years ago. She went to the *disari*, who told her that she had Bada Rog (the local term for leprosy) and that there was no cure. He did, however, give her some herbal medicine, which she took for 3 years without any improvement. She was eventually detected in a survey by LEPR. By then she had multiple deformities of her legs and hands. She was registered as a multibacillary case and treated for 3 years. She is now cured but has deformities.

The communities interviewed requested the following: that treatment should be freely available at every PHC; that the centre of treatment should be more easily accessible and closer to home; and that the health centre should be staffed by qualified and experienced

personnel. As far as possible the health worker should provide home treatment particularly for patients suffering from TB and leprosy. It is notable that all the people with TB in the pilot areas who were on treatment were receiving their treatment from KORALEP.

PERSPECTIVES OF THE PROVIDERS

Staff in PHC attend to malaria and diarrhoea but treatment is rarely available for other conditions. There is a poor infrastructure, in particular for laboratories in rural areas, and rural providers have little formal education. Even in urban areas working facilities and infrastructure are 'not satisfactory' and urban providers largely attend to TB cases only. There had been no training for the RNTCP, there was a poor working knowledge of infectious diseases and very few of the providers interviewed had heard of the RNTCP or DOTS. Treatment costs were high and doctors felt that the information, education and communication to both patients and providers was weak. For those doctors who had been trained in DOTS, some thought it made their job easier, but some reported that it added to their burden of work and made their jobs more difficult. Some, but not all, of the PHCs are staffed by qualified and professionally experienced staff.

The Community Health Centres (CHCs) and hospitals lack proper facilities for patients. These government hospitals do not have an adequate supply of drugs, the pathology unit and laboratories are not properly equipped and there are no storage facilities for drugs. An additional problem for implementing the RNTCP stems from the lack of a systematic sputum collection process. Inappropriate or absent sputum collection containers force staff to use crude methods like match boxes, leaves, or polythene bags. Lack of sufficient staff and a lack of commitment of staff to tackle TB are also prevalent problems. Staff have multiple responsibilities and priorities, and are not specifically trained in TB. Due to fear of infection and their belief that the government should offer them risk allowance for handling TB patients and specimens, they lack interest in working in the field of TB.

The views about the need for creating effective networks between local providers, NGOs and government were mixed. Local providers (unqualified and qualified practitioners of allopathic and Traditional Indian Systems of Medicine) were, on the whole, in favour of the idea. One local provider, a homeopath, noted '*the idea is very good, provided I will be allowed to carry on treating the patient with homeopathy*', and this opinion was echoed in the responses of many local providers. The view of the PHC medical officers were more mixed. While one doctor who has worked with TB for over 18 years, and has been trained in the RNTCP considers '*proper networking shall be able to prevent a lot of duplication*', another doctor told us that in his area '*collaboration with NGOs did not work*'.

Within LEPRAs, the views were also mixed. The doctors were in favour and were able to articulate with some clarity their views. One doctor noted: '*an organization has to play the spider role, if a network is established. This spider role should consist of ensuring infrastructure at every point of the network. Such infrastructure should consist of medicines, equipment, expertise, as well as knowledge dissemination to the community that such a network exists*'. LEPRAs TB supervisors, however, were less unanimous in their views. Three TB supervisors interviewed all expressed scepticism about the notion of a network, and felt unsure about how it would impact them directly in their work. To them, '*network means that everyone in the net are expected to be responsible. We are not sure of it*'.

Approaching ‘integration’

On the basis of the research, LEpra were able to develop an understanding of the needs and resources of the local system and specific gaps, which they as an organization might be able to fill. We set out a number of these areas below.

TRAINING

LEpra is in a position to provide specific training for capacity building in both the RNTCP and leprosy treatment for various levels of health staff. In addition to assessing the training needs and providing materials, the organization could build-up a trainer team locally to follow up. Training could be provided to the full range of governmental and non-governmental providers, including laboratory staff.

DIAGNOSIS AND TREATMENT

The research found that labs do exist in many (though not all) government facilities. We also found, however, that access to appropriate diagnostic services was difficult for most patients, and that staff are not trained or equipped to handle sputum samples. LEpra could assist by supplying laboratory reagents, training staff and establishing a system of quality control. They could also help to develop the diagnostic infrastructure by mobilizing support for primary health care centre and laboratory construction through their contacts with bilateral agencies. LEpra’s existing infrastructure also places them in a strong position to improve the reach of sputum microscopy services by using their outreach workers to refer patients into the centre and/or by establishing additional sputum collection centres in remote areas.

CASE HOLDING

The research found that there is a system for case holding within the government system, and that in most places there are staff to undertake this activity. LEpra could further strengthen the existing system by providing counselling to family members about treatment, giving information to the community about diagnosis and treatment, and strengthening the defaulter retrieval system. Extra support from LEpra could also help to support treatment among migrants by ensuring transfer systems are in place.

DOTS TREATMENT

The research identified a number of possible stumbling blocks to the implementation of the RNTCP. At the time of the research, no government system was in place to deliver TB or leprosy treatment through direct observation. We found there was inadequate staff in place, particularly in the remote areas, and no proper storage facilities for the drugs. LEpra could fill this gap by involving (and training) other local NGOs and Anganwadi workers to implement DOT. Building on their leprosy networks, in particular with the private sector (private providers and private laboratories), LEpra could also be involved in establishing DOT centres and drug distribution centres in less accessible locations.

There is currently a significant dearth of IEC from the government system. LEPRA have many years of experience in developing effective and appropriate IEC materials and delivering them to health providers and communities in innovative ways. LEPRA see an important role for themselves in providing training to government staff in IEC, organizing the activities, and supporting the development of IEC materials for different target groups.

Discussion

Non-governmental organizations involved in leprosy control have been struggling to find their way forward in the era of 'elimination' and 'integration'. This study reports on the process undertaken by LEPRA India to address the process of integration and what it means to the organization in terms of future plans, service to the community and support of the struggling government health services. By linking the process of organizational change with operations research LEPRA was able to find a way of supporting the change happening within its midst, while at the same time ensuring that the 'voices of the communities' of leprosy and TB patients are heard.

Linking leprosy and TB control gave LEPRA an opportunity to understand more about the government health services. Whereas the vertical programme of leprosy elimination had encouraged a management structure which worked separately from government services, the revised TB control programme (RNTCP), took a step towards integration and therefore gave the organization an opportunity of developing a relationship with government health services.

The operations research provided an opportunity for LEPRA to investigate the perceptions of the communities they serve as well as the perceptions of the health providers in the community, including the difficult work of the government services. Through the study, the researchers and eventually the technical and other staff at LEPRA were able to understand the realities of working in and with the fragmented government services. By finding ways of supporting the development of the PHC infrastructure, the organization has found a way to be involved in the process of 'integration'.

Currently, disease control strategies are dominated by international targets that allow little flexibility in which organizations like NGOs can operate,^{13,14} forcing the creation of linkages and partnerships between organizations. Within the straightjacket of elimination, leprosy NGOs were also being asked to increasingly 'integrate' their programmes into government health structures. The process of 'integration' is difficult, requires the development of partnerships and relationships and organizational change. Research can assist this process in helping to provide a background of information in which to find gaps in services that can be filled by appropriate organizations. Linking with government services that are failing requires a change in perspective from the 'negative' to the 'positive'. Rather than concentrating on 'why government services don't work', NGOs are forced to find the positive ways of working alongside government health providers to find solutions to their problems. For example, if the drug supply is failing and there are no storage facilities for drugs, what can an NGO do to help to resolve this problem? In this way, the perceived negative findings of research studies can become the positive processes of integration, bearing in mind that the process required is one of slow evolution.

The work has provided LEPRA with a focus for the future. It will be able to use its

expertise in laboratory services, social rehabilitation and dealing with stigma through education and information, to work with the government services to provide a better health care service for the communities they serve. The work has identified gaps in the health system that LEPRO, and other NGOs can fill.

There were many themes that emerged during the course of the work: integration, operations research, infectious diseases, systems, organizations, management, change, and infectious disease policy. In order for any achievements in disease control there is an increasing need for the development of partnerships and relationships between organizations. The process of 'integration' provides individuals and organizations with an opportunity to develop these partnerships and to find ways of working together to provide more appropriate care for communities.¹⁵ The next challenge will be to address the quality of these partnerships and to ensure that the focus remains on the care of the person with leprosy or tuberculosis.

Linking leprosy services with TB and HIV provides a focus for change for NGOs. This change provides an opportunity for NGOs to support governments to re-establish strong health care infrastructures through which to administer infectious disease control programmes.

Acknowledgements

We would like to thank the UK Department for International Development (DFID) for providing the funds for the pilot project, and the European Commission for supporting the extended project in the whole district.

The authors would like to express thanks for the sincere work put in by colleagues in the project: B. V. Prasad, Dr M. Suna, Dr K. S. Sudhakar, K. Anuradha, R. Rajendra, Anita, Manaswini, Minaram, Sahadev, A. Shushan, B. Shushan, Balwantroy, Mohammed Khan, and Sukanta.

The authors thank LEPRO and the London School of Hygiene and Tropical Medicine for providing the opportunity to conduct the 'operations research'. This work is part of an ongoing partnership that involves the link between research and practice as well as capacity building and training. The relationship also seeks to question the role of 'outsiders' in international research collaborations.¹⁵

References

- ¹ World Health Organisation. Declaration of Alma-Ata. International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978. World Health Organisation, Geneva, 1978.
- ² LEPRO India. *Modified leprosy campaigns*. LEPRO India, Koraput, 1999.
- ³ World Health Organisation. *Global tuberculosis control*. WHO Report, WHO/CDS/TB/2000.275. WHO, Geneva, 2000.
- ⁴ Noordeen SK, Pannikar VK. Leprosy. In: Cook GC (ed) *Manson's tropical diseases*. Saunders, London, 1996.
- ⁵ Government of Orissa. *Guidelines on functional integration for leprosy*. Bhubaneswar, Orissa, 1998.
- ⁶ LEPRO India. *Operational guidelines for leprosy/TB/HIV awareness project*. Koraput, 1999.
- ⁷ Khatri GR, Frieden TR. The status and prospects of tuberculosis control in India. *Int J Tuberc Lung Dis*, 2000; **4**: 193–200.
- ⁸ World Health Organisation. *What is DOTS—a guide to understanding the WHO-recommended TB control strategy known as DOTS*. WHO/CDS/CPC/TB/99.270. WHO, Geneva, 1999.
- ⁹ LEPRO India. *Rural leprosy control project: Koralep*. LEPRO Project Profile, Colchester, UK, 1998.
- ¹⁰ Koralep Joint Leprosy/TB/HIV programme evaluation. LEPRO India, February 1998.

- ¹¹ Koralep Operational Research on Joint TB/Leprosy/HIV Awareness in Jeypore subdivision of Koraput District, Orissa, India. Koralep/LEPRA-India, 2000.
- ¹² Ogden J, Porter JDH. Leprosy: applying qualitative techniques to research and intervention. *Lepr Rev*, 1999; **70**: 129–135.
- ¹³ Porter JDH, Ogden J, Pronyk P. Infectious disease policy: towards the production of health. *Health Policy and Planning*, 1999a; **14**: 322–328.
- ¹⁴ Porter JDH, Ogden J, Pronyk P. The way forward: an integrated approach to tuberculosis control. In: Porter JDH, Grange JM (eds) *Tuberculosis—an interdisciplinary perspective*. Imperial College Press, London, 1999, pp 359–378.
- ¹⁵ Ogden JA, Porter JDH. Researching TB Control in India: the politics of partnership in tropical public health. *J Soc Pol Admin*, 2000; **34**: 377–391.