

Towards a Strategy for Leprosy Elimination in Tribal Areas



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Danida has been supporting the National Leprosy Eradication Programme (NLEP) since 1986 in the states of Orissa, Madhya Pradesh (now bifurcated into Madhya Pradesh and Chhattisgarh) and Tamil Nadu. During the first two phases of the project, innovative approaches to community participation, health education and human resources development were successfully tried out. During the third phase (1998-2003), the project has focused on promoting the integration of the NLEP into the primary health care system. However, it has also been a priority to identify new strategies for reaching the un-reached, including the tribal communities of the program states.

According to the 1991 census, the tribal population constitutes about eight per cent (67.7 million) of the total population of India. Orissa and undivided Madhya Pradesh were the states with the numerically largest tribal populations in India. Focusing on the three states of Orissa, Madhya Pradesh and Chhattisgarh, it is the thrust of this document to discuss specific problems related to leprosy elimination in tribal areas, and to present the DANLEP experiences in this connection. An outline of a general tribal strategy for leprosy elimination on the basis of the lessons learnt is presented in this chapter.

The concept of 'tribal'

Before independence, tribal communities were variously named and were included under the category of 'depressed classes'. After independence, the concept of 'Scheduled Tribes' (ST) was coined and given legal status, as it was included in the Constitution vide Article 342 (i) empowering the

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President of India to specify the tribes or tribal communities by public notification. Consequently, the identification of tribal groups has been established as part of an administrative process, whereby the peoples thus identified became eligible for certain development schemes and other state-sponsored benefits.

From a social and cultural perspective, however, the word 'tribal' is more than a simple administrative category naming a social group. Often, the term is associated with negative connotations of primitivity, superstition, backwardness and similar ethnocentric notions. Such prejudice is counter-productive for promotion of a dialogue between 'tribals' and 'non-tribals' as they pose a radical distinction between 'them' and 'us'. More useful approaches recognize people in terms of certain concrete criteria, such as a distinctive culture, religion, language and self-ascribed ethnic identity, through which people distinguish themselves from others.

Language is one of a range of possible characteristics used to define an ethnic group. However, it is not always clear what is meant by language and dialect. In a linguistic sense, a dialect is a local form of a more widespread language. Therefore, it is assumed that people speaking different dialects of the same language would usually be able to understand each other. This is generally not the case for different languages, which do not share vocabulary, grammar, syntax and/or other distinctive characteristics. Hence, there is nothing distinctly tribal about tribal languages; and from a linguistic point of view, any language (be it English, Greek or Sanskrit) has once been a 'tribal language'.³ In that sense, Gadaba and Juang spoken by different ethnic groups in Orissa are different languages in the same sense as English and Hindi are different.

Another distinguishing attribute of tribal societies has been the egalitarian nature of gender relations. This is reflected in a near-equal sex ratio in many tribal groups, often with a majority of women. While women may traditionally have an equal or even higher status compared to men, it is also true that these structures of equality are undermined as the tribal groups become more socially, economically and politically integrated with

³ Mahapatra, Kh: Tribal Languages of Orissa. In Kh. Mahapatra (ed.) *Tribal Language & Culture of Orissa*. Orissa, 1997: Academy of Tribal Dialects & Culture, Government of Orissa.

mainstream society. According to the 1981 census, while the sex ratio among the Gond, Halba, Munda and Kanar tribes of Madhya Pradesh was equal between men and women, the corresponding figures for the Bhil Meena, Korku and Kolam tribes were even then closer to the present sex ratio for North Indian towns like Delhi and Chandigarh (less than 900 females per 1,000 males).

Issues of marginalisation

While stressing the need to acknowledge the differences among 'tribes', including socio-cultural differences, different levels of economic development and different forms of political organisation, being defined as 'tribal' in the first place points to certain socio-economic and cultural disadvantages.

There are many assumptions about tribal communities, some of which have a core of factuality while others are mere stereotypes based on prejudice. Tribal communities are marginalised from the mainstream society in important ways. These, more often than not, include living in a hilly or otherwise harsh geographical environment with limited control over natural resources, limited access to public services such as health care, education, water and sanitation, and infrastructure for transport and communication. This document is concerned with such marginalised tribal communities and the issue of making leprosy services both available and availed of under such circumstances.

Perhaps due to the classification of many different tribes under the unifying category of Scheduled Tribes, there has been a tendency to ignore the differences among the tribal communities by mainstream society. This has resulted in disregarding their local knowledge, reducing tribal languages to the status of dialects and ignoring locally developed technologies. Assimilation into, rather than integration with, mainstream society has been the consequence, when tribal populations have migrated to urban areas.

When local knowledge is acknowledged, for example in a study of ethnobotany among the Sahariyas in Madhya Pradesh, this is more likely to benefit the outside world rather than the tribal community.⁴

⁴ R.M. Painuli and J.K. Maheshwari: Some interesting ethnomedicinal plants used by Sahariya tribe of Madhya Pradesh. In J.K. Maheshwari (ed.): *Ethnobotany in South Asia*. Jodhpur, 1996: Scientific Publishers.

Observers have adopted different perspectives on the issue of tribal development. Some have seen it as a central purpose to preserve tribal cultures. The supporters of this position highlight the detrimental effects of contact between tribal and non-tribal groups. For instance, increased migratory labour and alcoholism may lead to cultural extinction of the tribal communities. This position entails a risk of establishing living museums where people do not have access to the benefits of the outside world. Others wish to promote assimilation under or integration with the society at large, arguing that there is no legitimate rationale for denying the tribal communities access to the services, opportunities and risks that exist for mainstream society.

Tribal areas and the health system

In addition to the general problems of physical isolation, social marginalisation poverty and illiteracy, there are other factors, which adversely affect the delivery of health services in these areas.

Due to the physical remoteness and general underdevelopment of the tribal areas, many health workers do not want to be posted there. In existing health posts in the tribal belts, there is a paucity of manpower due to the frequent transfer of officials. Furthermore, each NLEP worker may be assigned 150-200 villages. The scattered location of the villages, many comprising several hamlets of four to six houses, makes traditional case-detection with an active search approach a momentous task. The absence of roads, the large distances combined with the vagaries of the weather and geographical terrain, are obstacles to health workers in performance of their routine work. In addition, tribal people regularly migrate to the towns in search of work outside the agricultural season, making coverage by NLEP workers even more difficult.

Apart from the natural and material constraints on account of poor accessibility, harsh terrain and inadequate manpower, the quality of health care delivery in tribal areas may also be adversely affected by the general perceptions and attitudes of non-tribal health workers, who some times function within a framework of social stereotypes about tribal mentality and way of life. These stereotypes are derived from the same ethnocentric notions of primitivity and backwardness discussed earlier and may largely be linked to the general ignorance about the distinctive cultures and

languages of the tribal groups. Alcoholism, non-vegetarianism, absence of physical hygiene, violence, promiscuity and gambling form the cluster of attributes often used to describe 'the tribal way of life'. This configuration may not facilitate health workers' communication with tribal communities. For instance, a joke doing the rounds among health workers in the tribal areas in Madhya Pradesh mocked that "after 7 pm these tribals take MDT", where M stands for mutton, D stands for *daru* (alcohol) and T stands for toddy. While seemingly innocent, such jokes point to a disturbing implicit racist perception of tribal groups.

The social distance between tribal communities and the health system is not a one-way street. Due to the historical inequity between tribal and non-tribal societies, non-tribal health workers are often met with mistrust, suspicion and non-cooperation from tribal people. Special communication strategies are required to enter into dialogue with them. Language is the most potent medium of communication not only for sharing knowledge but also for negotiating behavioural change. While many tribals may be fluent in the dominant language in the area, this should not lead to the assumption among health workers and managers that, consequently, there is no need to use the tribal language for health communication. When the aim is not only to share knowledge about the basics of leprosy as a curable disease and the availability of free and effective treatment, but to transform deep-seated perceptions and stimulate behavioural change, particularly in areas where leprosy is highly stigmatised, then the use of the local vernacular is likely to be more effective. Making the effort to do this would increase the credibility of the health system and would likely translate into higher rates of voluntary reporting, treatment seeking and treatment completion. Enrolling a larger number of tribal health workers fluent in the local language is one operational strategy in this regard.

A long distance between community and health facility is not only a deterrent to service delivery, but will also adversely affect service utilisation. However, the nearest health sub-centre may often be miles away from the village.

***Panchayati raj* institutions in tribal areas**

The *panchayati raj* institutions (PRIs) are self-government units at the local level, designed to plan and implement developmental programmes, either

formulated by themselves or being the result of higher-level planning. The *panchayats* are engaged in a range of activities in the areas of water and sanitation, agriculture, power, health and environment. The aim of the system is to accelerate socio-economic development through decentralised planning and implementation. It is a three-tier system with the *zila parishad* at district-level, *jan parishad* at block-level and *gram panchayat* at village-level.

The establishment of the PRI system in tribal areas has not been without criticism. One central issue of this debate has been the expansion of the *panchayati raj* institutions to include all communities in the country. For example, Patnaik asks:

“Where the tribal *panchayats* are still effective as indigenous political institutions and run along democratic principles and serve well the cause of peace and good government for the tribals, what is the point in superimposing an alien political structure like statutory *gram panchayat* which the tribals do not understand and do not feel as theirs?” (P. 97).⁵

However, a detailed and thorough study of the Dongaria Kondh of Orissa suggests that “the interference of the *panchayati raj* system into the traditional, political organization after Independence has brought some changes in the regional political culture. Though the Dongaria Kondh have become subservient to the present *panchayat* system, their traditional political organisation is still functioning and in most of the cases the traditional leaders have modernised and partly become *panchayat* leaders”.⁶

Acknowledging the importance of the *panchayati raj*, it is also necessary to be aware that the relationship between the local *panchayat* and the marginalised parts of the population in its constituency varies, as does the effectiveness with which the *panchayat* addresses local needs, as is occasionally brought to public notice by the press.⁷

⁵ Patnaik, Nityananda: *Anthropological Studies on Indian Societies*. Modern Book Depot, 2001: Bhubaneswar.

⁶ Jena et al.: *Forest Tribes of Orissa, Vol. 1: The Dongaria Kondh*. In K. Seeland and F. Schmithüsen (eds.): *Man and Forest Series*. New Delhi, 2002: D.K.Printworld.

⁷ An example of this was published in *The Indian Express* on 14 November 2002, pointing to a direct link between cases of starvation and hunger among tribal populations and the lack of direct interaction with the *panchayat* institutions.

Realising such problems, it is found essential to continue working towards strengthening the *panchayat* institutions as key players for health in general, and for leprosy elimination, being the concern of DANLEP, in particular. As will be described below, it has been a central feature of the DANLEP activities in the tribal areas in Orissa, Chhattisgarh and Madhya Pradesh to work through the PRIs to establish networks for leprosy elimination.

Outline of a strategy for leprosy elimination in tribal areas

The outline presented below of a generic model for leprosy elimination activities in tribal areas is based on the lessons learnt from pilot projects involving the *panchayati raj* institutions in Orissa, Chhattisgarh and Madhya Pradesh.

The geography of many tribal areas – remoteness from centres of trade, administration and public resources, difficult terrain and scattered habitations – is a major barrier for delivery of and access to health services. The main economic activity in tribal area continues to be seasonal agriculture, with little or no industrialisation. Periodic migration to the cities for manual labour is often the only alternative source of livelihood.

On this background, the objective of the tribal strategy is suggested below.

Key elements of a strategy

The outline of a strategy for leprosy elimination in tribal areas is based on the following key elements:

Objective of the tribal strategy

To provide decision-makers and service providers with a model for development of community-based leprosy elimination activities and networks in tribal areas based on the involvement of local stakeholders, panchayat institutions, NGOs and other potential partners, and taking into account the specific context of limited or no access to health care services, language barriers, widespread illiteracy, poverty and marginalisation of tribal communities.

- Networks for leprosy elements involving PRI and tribal *panchayats*, NGOs, local stakeholders and the government health system to function as an extension of the GHS in areas with inadequate primary health care services.
- Involvement of bilingual persons in the network who can bridge the communication gap between tribal language minorities and majority population with a different language.
- Involvement of traditional healers and practitioners of other systems of medicine in the network.
- Sensitisation and training of stakeholders to be able to undertake the required activities for leprosy elimination.
- Sensitisation and training of non-tribal health staff to enhance understanding of the tribal communities with which they work, and to address prejudice and discrimination against tribal populations, if required. Existing experiences with gender training may serve as a model.
- Development of IEC materials involving local tribal artists, using local motives and stories.
- Combination of voluntary reporting with special action projects for case detection and destigmatisation.
- Exploration of the applicability of accompanied MDT services in tribal populations.

An outline of a leprosy elimination strategy for tribal areas is described below, keeping the above contextual features in mind.

Why an outline?

As will be evident from the following chapters, the DANLEP experiences with leprosy elimination in tribal areas that have been documented in this book are based on pilot projects. That is reflected in the nature of the steps that have been identified in this chapter by the fact, that focus is exclusively on the block- and village-levels. While the Orissa chapter stands out for having involved six blocks with different tribal communities, the strategic expansion of the initiative at district and state levels does not follow from these pilots. Hence, further work in tribal areas remains to be done, before

a proper strategy can be carved out. The work presented in this volume should, therefore, be seen as a first step towards developing such a strategy. Subsequent steps of the development of the strategy should be taken with the active involvement of representatives for the tribal populations in question.

Strategic steps for tribal leprosy elimination

It is a strategic assumption, that marginalised tribal communities as initially described in this chapter would by and large have little or no access to general health services. Hence, integration of NLEP with the GHS would make little difference in such areas, and the need for special efforts to achieve leprosy elimination in many tribal areas would remain, even after integration of leprosy services has taken place. Based on experiences with such special initiatives, a number of steps have been identified for leprosy elimination in tribal areas:

1. Selection of intervention area.
2. Baseline data on population and health.
3. Participatory local study on leprosy and health.
4. Identification and assessment of stakeholders.
5. Sensitisation of PRI members at block-level.
6. Sensitisation at village-level and development of PoA.
7. Budget.
8. Training.
9. Ensuring service delivery.
10. IEC Activities.
11. Case detection: Skin and POD camps.
12. Case detection: IPC.
13. Documentation.
14. Monitoring and follow-up.

The model provides some guidelines for planning leprosy elimination work in tribal areas. The suggested procedure is indicative and not absolute. The sequencing of events, the composition of stakeholders and the timing of activities should be worked out in response to the local context in which the model is being operationalised. Often a time lag is observed between the planning, implementation and monitoring phases of a project. Experience has shown the time frame for the completion of the various tasks has been

quite lengthy, ranging from a period of nine months to two years. A realistic, but preferably short (six to nine months) time frame is likely to produce the most optimal results.

STEP 1: Selection of intervention area

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| <i>Activity</i> | Selection of one or more tribal blocks. Areas with a PR above five and areas where there is reason to question a reported low PR should be prioritised. |
| <i>Responsible person/institution</i> | NLEP/GHS officials, especially the CDMO and the BMO, and local NGOs. |
| <i>Process</i> | Preliminary discussions among government officials, NGO representatives and tribal <i>panchayat</i> members at block-level on the feasibility of the project. Establishing preliminary consensus on the project. |
| <i>Outcome</i> | Tribal areas selected according to criterion, based on consensus among stakeholders. |
| <i>Resources</i> | Time and commitment of involved parties. |
| <i>Risks</i> | Lack of interest and enthusiasm to focus on leprosy as a priority. |
| <i>Assessment indicators</i> | <ol style="list-style-type: none"> 1. Level of interest shown by different stakeholders. 2. Level of cooperation. 3. Level of commitment expressed. |

Once a consensus has been reached, further baseline data should be obtained to get an overview of the area. In practice, steps one and two may merge, as the process of establishing the necessary background information may closely interwoven with a series of meetings to select the intervention area(s).

STEP 2: Baseline data on population and health

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| <i>Activity</i> | Situational analysis to get an overview of the demographic composition, including the possible co-existence of several tribes and languages spoken, a general health profile as well as the prevailing leprosy situation, and available health resources and other infrastructure in the selected area. |
| <i>Responsible person/institution</i> | NLEP/GHS officials (especially BMO), NGO functionaries, who have agreed to participate, and, if possible, partnering research communities. |
| <i>Process</i> | Collecting and analysing statistical information on demographic and health profile, the leprosy scenario and information on the health and other infrastructure in the selected area. |
| <i>Outcome</i> | An area-specific database on leprosy prevalence and health infrastructure in the target area. |
| <i>Resources</i> | <ol style="list-style-type: none">1. Block-level statistical data on leprosy (SAPEL, LEC reports).2. Directory of government and NGO sponsored health facilities in the area, as available with local health department.3. Mapping of private clinics and traditional healers in the area. |
| <i>Risks</i> | <ol style="list-style-type: none">1. Unavailability of reliable and up-to-date data.2. Unavailability of a competent data analyst. |
| <i>Assessment indicators</i> | A situational analysis available, covering the following aspects: a) demographic and socio-economic description of the population; b) data on the health profile and leprosy situation in the area; c) the number of health facilities available categorised by location, sector (public, private, NGO), and system (biomedical, ISM, other), and availability of treatment. |

Apart from the general health profile and leprosy related data, it is necessary to assess the local knowledge on skin diseases, on leprosy in particular, and on health seeking behaviour and related issues in general. This research may call for establishing partnerships with existing research communities that have experience with doing research in the area and/or with the use of participatory rural appraisal (PRA) techniques.⁸ Such skills may also be available with NGOs working in tribal areas.

In addition to the gained knowledge, the use of participatory research methods in this context also serve to set leprosy on the agenda during research-related group discussions and exercises in the tribal community, thereby increasing the dialogue and mutual understanding between the stakeholders and the community at large.

A limited local study further serves as a correction to the general statistical data obtained for the baseline analysis, which may cover larger population groups and hence not be specific to the local area selected.

⁸ See S.K. Singh: *A Research-cum-Intervention Initiative among Sahariya of Madhya Pradesh*, this volume. PP.61-77

STEP 3: Participatory local study on leprosy and health

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| <i>Activity</i> | To establish an emic understanding of leprosy and its treatment among the tribal group(s) in the selected area through dialogue and participatory research methodology. ⁹ |
| <i>Responsible person/institution</i> | NLEP/GHS officials, NGOs and, if possible, partnering research communities. |
| <i>Process</i> | Collating a descriptive account of local understanding of leprosy and its treatment based on documentary and field work, using a range of participatory research methods, as required. |
| <i>Outcome</i> | The stakeholders obtain a better understanding of local knowledge about leprosy, its symptoms and treatment. The community become involved in leprosy- and health-related discussions. |
| <i>Resources</i> | <ol style="list-style-type: none">1. Existing anthropological and other relevant studies.2. Oral accounts of health workers.3. Fieldwork in selected villages (individual interviews, focus group discussions, key informant interviews with leprosy patients, their families, traditional healers and PRI methods).4. Sufficient time to carry out the study. |
| <i>Risks</i> | <ol style="list-style-type: none">1. Competent researcher(s) not available.2. Reliable data not available.3. Funding for study not available. |
| <i>Assessment indicators</i> | Availability of descriptive account(s) of illness perceptions and health-seeking behaviour of the relevant tribal group(s). |

⁹ 'Emic' refers to a socio-cultural analysis based on local knowledge and terminology.

Many predominantly tribal habitations are located in small hamlets and are generally situated at the outskirts of a largely non-tribal village. For instance, among the Sahariyas, there is very little social and cultural exchange between the main village and the surrounding hamlets. When identifying stakeholders, care should be taken to ensure that populations are not left out due to this residential pattern. Residents from the main village may not automatically include peripheral hamlets in the activities.

Traditional healers have been identified as important stakeholders, but they are not the only non-government service providers, even in remote tribal areas. While private biomedical practitioners may still be few and far between, quacks and ISM practitioners have made in-roads in these areas. What status they should be accorded in the tribal leprosy elimination strategy should be decided on the basis of an assessment of the individuals involved, as part of Step Four.

While the identification of stakeholders is described as a separate step, it would be an advantage to carry this out as part of a PRA study, in connection with individual and group interviews and other exercises.

Where a language barrier exists between the initiators of the leprosy elimination in the specific area and the selected population, it is very important to ensure the presence of bilingual resource persons in the stakeholder group, who would be able to bridge the communication gap.

STEP 4: Identification and assessment of stakeholders

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| <i>Activity</i> | Identification of stakeholders at policy, provider and community-levels. |
| <i>Responsible person/institution</i> | NLEP/GHS officials (especially BMO), NGOs. |
| <i>Process</i> | Systematic listing of potential partners for participating in leprosy elimination campaigns, and relative assessment of each stakeholder's contribution, availability of time, interest, willingness and potential drawbacks, preferably as part of a PRA. |
| <i>Outcome</i> | <ol style="list-style-type: none">1. The participation of selected stakeholders has been assessed in terms of the above criteria.2. A final list of stakeholders has been prepared. |
| <i>Resources</i> | <ol style="list-style-type: none">1. Reliable information on <i>panchayat</i> bodies, ethnic and language groups, health providers, NGOs, and local human resource potential.2. Information on local pathways of influence and power.3. The above may be generated through PRA methods (Step Three). |
| <i>Risks</i> | <ol style="list-style-type: none">1. The list of stakeholders may not be representative of the community and/or may not include all categories of players of interest (for example women, LAPS, traditional healers).2. The list of stakeholders may not adequately capture and represent the interests of people or groups who are marginalised within the tribal community. |
| <i>Assessment indicators</i> | <ol style="list-style-type: none">1. An overview is established of local decision-makers, health service providers (including traditional healers), former and current patients, influential families and other groups and individuals of the community.2. A comprehensive list is available of important stakeholders including <i>panchayat</i> members at block- and village-levels, teachers, shop owners, health workers and others who could function as volunteers. |

STEP 5: Sensitisation of PRI members at block-level

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| <i>Activity</i> | Sensitisation about leprosy issues of <i>panchayat</i> members at block-level. |
| <i>Responsible person/institution</i> | NLEP/GHS officials (especially the BMO), the <i>sarpanch</i> and NGOs. |
| <i>Process</i> | Sensitisation workshop at block-level attended by <i>panchayat</i> members, functionaries from different government departments like education, tribal welfare, revenue and local NGOs. |
| <i>Outcome</i> | <i>Panchayat</i> members are sensitised about leprosy and agree to participate actively in the elimination initiative. |
| <i>Resources</i> | <ol style="list-style-type: none">1. Time of participants;2. Space to hold meeting;3. Resource persons;4. TA/DA;5. Refreshments. |
| <i>Risks</i> | Participants do not attend or do not agree to prioritise leprosy elimination. |
| <i>Assessment indicators</i> | <ol style="list-style-type: none">1. Participants are familiar with leprosy as a disease, its treatment and the elimination strategy.2. They are committed to taking active part in the campaign.3. The PRI members agree to schedule similar sensitisation workshops at <i>gram sabha</i>-level. |

STEP 6: Sensitisation at *gram sabha*-level¹⁰

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| <i>Activity</i> | Sensitisation workshops at <i>gram sabha</i> -level and/or of tribal <i>panchayats</i> , listing of volunteers and development of a local plan of action (PoA). |
| <i>Responsible person/institution</i> | PRI members, especially <i>sarpanchs</i> and heads of health committees in coordination with local NLEP/GHS functionaries and NGOs. |
| <i>Process</i> | Sensitisation workshops about leprosy are conducted within a realistic time frame in all <i>gram sabhas</i> of the selected block(s). |
| <i>Outcome</i> | Sensitisation workshops have been conducted in all villages and a list of volunteers to function as link workers made available. |
| <i>Resources</i> | <ol style="list-style-type: none">1. Time, and space for meetings.2. Resource persons.3. TA/DA.4. Refreshments. |
| <i>Risks</i> | <ol style="list-style-type: none">1. <i>Sarpanchs</i> and <i>panchs</i> are not adequately motivated.2. An adequate number of volunteers not available. |
| <i>Assessment indicators</i> | <ol style="list-style-type: none">1. <i>Gram panchayat</i>/tribal <i>panchayat</i>-level commitment for leprosy work.2. A village-level plan of action (PoA) for IEC, leprosy search and case detection is prepared on the basis of consensus-building meetings.3. List of volunteers at village-level. |

¹⁰ Wherever there are traditional panchayats in operation in tribal villages, every attempt should be made to involve them in leprosy elimination strategy.

STEP 7: Budget

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| <i>Activity</i> | Budget for the activities stated in the PoA. |
| <i>Responsible person/institution</i> | PRI members, especially <i>sarpanchs</i> and members of health and finance committees, in coordination with local NLEP/GHS functionaries and NGOs. |
| <i>Process</i> | Working out a budget for planned activities, including compensation for volunteers, materials needed and other costs relating to the PoA. Identifying adequate resources for the financial requirements. |
| <i>Outcome</i> | Planned activities are matched with available resources for successful implementation of the action plan. |
| <i>Resources</i> | <ol style="list-style-type: none">1. Resources from involved agencies.2. Voluntary contributions in cash and kind from the community. |
| <i>Risks</i> | <ol style="list-style-type: none">1. The PoA is not sufficiently detailed, or does not include all activities.2. Involved costs are not realistically assessed.3. Inadequate finances to implement the PoA. |
| <i>Assessment indicators</i> | <ol style="list-style-type: none">1. A realistic budget produced that matches the activities of the PoA.2. Resources available for implementing the action plan. |

STEP 8: Training

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| <i>Activity</i> | Training of master trainers and local volunteers for IEC and search. |
| <i>Responsible person/institution</i> | PRI members in coordination with local NLEP/GHS functionaries and NGOs. |
| <i>Process</i> | Local sensitisation-cum-training meetings organised to orient master trainers (mainly local health care workers) and volunteers on: i) leprosy as a disease and its treatment; ii) IEC methods and skills; iii) suspecting and referring cases. Training should be conducted in local language(s). |
| <i>Outcome</i> | An adequate number of master trainers and volunteers trained to carry out IEC and search activities in the area. |
| <i>Resources</i> | <ol style="list-style-type: none">1. Resource persons.2. Space for holding training workshops.3. Time of participants.4. Refreshments.5. Training materials - booklets, charts, notebooks, audio-visual presentations. |
| <i>Risks</i> | <ol style="list-style-type: none">1. Inadequate number of master trainers and volunteers to cover target area.2. Deficiencies in training (non-uniform training, contents of training do not meet local needs).3. Inadequate representation of important groups among volunteers, such as women, teachers and panchs. |
| <i>Assessment indicators</i> | <ol style="list-style-type: none">1. The group of volunteers is representative of the community2. All volunteers are trained and able to communicate key messages about leprosy in the local language(s). |

STEP 9: Ensuring service delivery

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| <i>Activity</i> | Strengthening infrastructure for treatment delivery. |
| <i>Responsible person/institution</i> | PRI members in coordination with local NLEP/GHS functionaries, NGOs and other local stakeholders, including local service providers and healers. |
| <i>Process</i> | Drug delivery points (DDPs) are created in health facilities in the government, private and NGO sectors. Drugs may also be kept at the <i>panchayat</i> office for patients under treatment. Introduction of accompanied MDT. |
| <i>Outcome</i> | All patients have access to MDT and other treatment delivery services. |
| <i>Resources</i> | 1. Medicines. 2. Reporting and registration formats. |
| <i>Risks</i> | 1. Health functionaries are not familiar with the reporting procedures. 2. Lack of cooperation from private service providers and traditional healers. |
| <i>Assessment indicators</i> | Adequate supplies of MDT drugs, registers and reporting formats are available and accessible for all leprosy patients to be fully registered and treated. |

Even with an increase in drug delivery points, the fact that habitations are scattered and inaccessible means that this is not likely to be a sufficient solution. Accompanied MDT, where drugs are provided to patients for a longer period of time supported by counselling and with the patient being accompanied by a trusted person, should also be organised. Unfortunately, this approach has not been field-tested in the DANLEP tribal initiatives, but further explorations should be undertaken in this area, possibly piggybacking on the TB DOTS programme or other relevant health programmes.

It is important that treatment is available before IEC activities are undertaken. Messages that promise treatment, which is not available, are counterproductive. Once the continuous access to services, including MDT, is set up, IEC activities should be undertaken to ensure that leprosy patients avail of the services. While certain generic IEC materials would be available, including pictorial materials specifically designed for illiterate populations, the importance of the use of locally developed drawings and pictures and terminology should not be underestimated. The prior involvement of local artists in tailoring IEC materials to the specific audience may enhance the value of the materials considerably, as the audience would readily identify with materials depicting people with their own hairstyle, ornaments, dresses, tattoos and similar markers of identity.

While seemingly evident, the use of the local language(s) for general communication to a population is not always adopted. It goes without saying, that IEC should be conducted in the vernacular of the target audience. Maximal involvement of local stakeholders is the best way to cross language barriers. Often, it may be necessary to establish mechanisms for translation through local bilingual stakeholders.

STEP 10: IEC Activities

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| <i>Activity</i> | Implementation of IEC activities as stated in the local PoA. |
| <i>Responsible person/institution</i> | PRI members in coordination with local NLEP functionaries, health department and NGOs. |
| <i>Process</i> | Context-specific IEC activities in the local vernacular, involving, for example, <i>kotwar munadi</i> , street plays (<i>nukkad natak</i> or <i>kala jatha</i>) in villages, posters and exhibitions at local <i>haats</i> , rallies, interpersonal communication (IPC), awareness camps in tribal hostels and similar activities. |
| <i>Outcome</i> | IEC activities undertaken in target area to enhance awareness about leprosy and its treatment. |
| <i>Resources</i> | <ol style="list-style-type: none">1. IEC materials, including locally developed materials.2. Volunteers to undertake IEC activities. |
| <i>Risks</i> | <ol style="list-style-type: none">1. PRI members may not be not proactive.2. Lack of coordination between different stakeholders in organisation of the scheduled activities.3. IEC messages are not locally developed, not suited to the local context and therefore ineffective. |
| <i>Assessment indicators</i> | <ol style="list-style-type: none">1. Completion of a successful IEC campaign in the selected community.2. People know about the signs and symptoms of leprosy, its curability, and the local health facilities where MDT is available.3. Stigmatisation of leprosy has been addressed appropriately.4. Increase in voluntary reporting. |

Skin and Prevention of Disability (POD) camps aim at identifying and treating people with skin diseases and leprosy patients in risk of developing disability, respectively. However, they also serve as important sites for IEC activities, involving the community at large in group discussions, counselling and care. To achieve this, the aspects of IEC described under Step ten also apply in relation to the conduct of skin and POD camps outlined in Step 11.

STEP 11: Case-detection: Skin and POD Camps

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| <i>Activity</i> | Skin and POD caps held in the target area. |
| <i>Responsible person/institution</i> | PRI members in coordination with local NLEP functionaries, health department and NGOs. |
| <i>Process</i> | Skin and POD camps are widely advertised and conducted in central locations. |
| <i>Outcome</i> | <ol style="list-style-type: none"> 1. New cases are detected through skin camps 2. Disabled leprosy patients are taught self-care procedures. 3. Stigmatisation is discussed and effectively addressed, as and when encountered. |
| <i>Resources</i> | Medical personnel, medicines, other equipment for POD camp such as tubs, hot water, oil etc. space for conducting the camp. Volunteers. Food and lodging, if a residential POD camp is planned. |
| <i>Risks</i> | <ol style="list-style-type: none"> 1. Inadequate resources and trained (including medical) personnel for conducting the camp. 2. Unfeasible timing and/or location of the camp. |
| <i>Assessment indicators</i> | <ol style="list-style-type: none"> 1. Increase in voluntary reporting. 2. Condition of leprosy patients with disabilities is ameliorated through POD camps. 3. Destigmatisation and increased social acceptance of leprosy patients. |

While it has been observed that stigmatisation of leprosy patients is non-existent or rare in many tribal groups, assimilation within mainstream Hindu society may lead to an increase of discriminating practices against leprosy-affected persons and their families. For instance according to the sambhav study of the Sahariya presented in this volume, the Sahariyas are increasingly following Hindu systems of prayer, marriage and death rituals. However, so far stigmatisation of leprosy patients has not been observed. There is also a danger that the adoption of these practices may erode the traditional non-discriminatory attitude towards leprosy-affected persons.



Lady in the role of traditional healer: street theatre on leprosy in a tribal village.

STEP 12: Case-detection: IPC

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| <i>Activity</i> | Plan of Interpersonal Communication (IPC) activities in the selected areas. |
| <i>Responsible person/institution</i> | PRI members in coordination with local NLEP/GHS functionaries, NGOs and local volunteers. |
| <i>Process</i> | Volunteers trained in IPC interact with as many people as possible, for example at <i>haats</i> , and through individual contacts. |
| <i>Outcome</i> | <ol style="list-style-type: none">1. People are advised to get skin patches examined and are informed about health facilities where treatment is available.2. A number of hitherto hidden cases are detected and put on treatment. |
| <i>Resources</i> | <ol style="list-style-type: none">1. An adequate number of trained volunteers.2. Every volunteer to be provided with educational IEC material such as pictorial folders, leaflets, pamphlets, brochures, body charts and the like. |
| <i>Risks</i> | <ol style="list-style-type: none">1. An inadequate number of trained volunteers are available.2. The timing of the activity coincides with rains, a festival, marriages, seasonal work or other priority event or activity. |
| <i>Assessment indicators</i> | <ol style="list-style-type: none">1. Increase in voluntary reporting.2. Improved understanding of the basics of leprosy in the community and potential stigmatisation addressed. |

The current outline of a strategy for leprosy elimination in tribal areas has been developed on the basis of DANLEP experiences and pilot projects among a few tribes in a few states. In order to further develop this outline, it will be important to continue to document experiences with and lessons learnt from the implementation of these activities as well as other means to the same end.

STEP 13: Documentation

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| <i>Activity</i> | Document the tribal initiative for dissemination. |
| <i>Responsible person/institution</i> | NLEP/GHS officials, NGOs. |
| <i>Process</i> | A detailed account of the planning and implementation of the tribal initiative, including a discussion of the expected outcome and actual achievements. |
| <i>Outcome</i> | The document is widely circulated to relevant players at the state and national level for further development of the strategy. |
| <i>Resources</i> | <ol style="list-style-type: none"> 1. Availability of reliable information on the process and outcome of the initiative. 2. A competent documenter for data compilation and report writing. |
| <i>Risks</i> | <ol style="list-style-type: none"> 1. Incomplete records. 2. Lack of initiative of responsible person/institution. 3. A suitable documenter cannot be made available. |
| <i>Assessment indicators</i> | Clear chronological account of the initiative, the planning, process, successes, failures and lessons learnt. |

While the documentation may be a useful tool in the longer term, it is also necessary to establish an ongoing, sustainable mechanism for monitoring of the local leprosy situation, based on which local stakeholders can decide on renewed leprosy elimination activities.

STEP 14: Monitoring and follow-up

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| <i>Activity</i> | Monitoring the impact of the initiative and follow-up as required. |
| <i>Responsible person/institution</i> | PRI members in coordination with local NLEP/GHS, NGOs and local stakeholders. |
| <i>Process</i> | <ol style="list-style-type: none">1. Regular review meetings of stakeholders to assess the leprosy situation, follow-up on ongoing activities and planning for future interventions.2. Leprosy to be a subject on the agenda of the village <i>panchayat</i> and <i>gram sabha</i> meetings, and required data to be made available by the NLEP/GHS officials to support discussions. |
| <i>Outcome</i> | A mechanism for ongoing monitoring and follow-up is established. |
| <i>Resources</i> | Time and commitment of NLEP/GHS officials/the main coordinating agency and <i>sarpanchs</i> . |
| <i>Risks</i> | Initial enthusiasm may fade and other health issues may take priority over leprosy. |
| <i>Assessment indicators</i> | <ol style="list-style-type: none">1. Increase in voluntary reporting.2. A short term increase in PR.3. Wider availability of MDT. |

The above steps may serve as a guideline for developing networks for tribal leprosy elimination involving local stakeholders, NLEP and GHS officials, *panchayati raj* institutions and tribal councils, NGOs and research communities. Networks and partnerships are necessary to reach the un-reached, not only for leprosy elimination but for a range of other health and other services as well. The remainder of this book describes the various activities that have fed into the development of the above outline of a strategy for leprosy elimination in tribal areas. Further work needs to be done by other players after the phasing-out of DANLEP in this area to develop this outline into a strategy proper.

