

Towards Leprosy Elimination in Tribal Communities

Experiences from
Madhya Pradesh, Orissa and Chhattisgarh

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DANLEP

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Abbreviations

ADMO	Additional District Medical Officer
ALM	American Leprosy Mission
ANM	Auxiliary Nurse Midwife
AWW	<i>Anganwadi</i> Worker
BEE	Block Extension Educator
BDO	Block Development Officer
BMO	Block Medical Officer
CBO	Community Based Organisation
CEO	Chief Executive Officer
CHC	Community Health Centre
CHV	Community Health Volunteer
CDMO	Chief District Medical Officer
CDPO	Child Development Project Officer
CMO	Chief Medical Officer
CV	Community Volunteers
DA	Daily Allowance
Danida	Danish International Development Assistance
DANLEP	Danish Assistance to the National Leprosy Eradication Programme
DDP	Drug Delivery Point
DLO	District Leprosy Officer
GHS	General Health System/Services
GoC	Government of Chhattisgarh
GoI	Government of India

GoMP	Government of Madhya Pradesh
GoO	Government of Orissa
HI	Health Inspector
HSC	Health Sub-Centre
HW	Health Worker
ICDS	Integrated Child Development Scheme
IEC	Information, Education and Communication
IPC	Interpersonal Communication
ISM	Indian Systems of Medicine
ITDA	Integrated Tribal Development Agency
JSR	<i>Jana Swasthya Rakshak</i>
LAP	Leprosy-affected Person
LEC	Leprosy Elimination Campaign
LHV	Lady Health Volunteer
LEU	Leprosy Elimination Unit
MB	Multibacillary
MDT	Multi-drug Therapy
MLEC	Modified Leprosy Elimination Campaign
MO	Medical Officer
MPW	Multi-purpose Worker
NCDR	New Case detection Rate
NGO	Nongovernmental Organisation
NLEP	National Leprosy Eradication Programme
NMA	Non-Medical Assistant
NMS	Non-Medical Supervisor
PA	Project Administrator
PB	Paucibacillary
PHC	Primary Health Care/Centre
PoA	Plan of Action
PP	Private Practitioner

PMW	Paramedical Worker
POD	Prevention of Disability
PR	Prevalence Rate
PRA	Participatory Rapid Appraisal
PRI	<i>Panchayati Raj</i> Institution
RFT	Released from Treatment
SAPEL	Special Action Project for the Elimination of Leprosy
SC	Scheduled Caste
SDMO	Sub-Divisional Medical Officer
SHG	Self-Help Group
ST	Scheduled Tribe
TA	Travelling Allowance
TLM	The Leprosy Mission
VARRASA	Voluntary Association for Rural Reconstruction and Social Awareness
VHN	Village Health Nurse
VRC	Voluntary Reporting Centre
VVW	Village Voluntary Worker
WHO	World Health Organization

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The Editors



Preface

Danida has been assisting the National Leprosy Eradication Programme since 1986 in the states of Tamil Nadu, Orissa and Madhya Pradesh (bifurcated into Madhya Pradesh and Chhattisgarh in November 2000). One of the main aims of the third and final phase of DANLEP has been to develop strategies for reaching the un-reached groups, including the tribal communities, in the programme states.

The main problems in tribal areas, which diminish the capacity of both the health care system to deliver quality services and of the people to avail of them, are physical isolation, social marginalisation, under-development, poverty and illiteracy. It is in this context that the World Health Organization has put forward the concept of Special Action Projects for the Elimination of Leprosy (SAPELs) for the coverage of difficult, inaccessible areas and neglected population groups. SAPEL is an intensive time-bound project, concentrating resources within a limited area.

Due to the high investment of human resources in the planning and implementation of SAPELs and the time-bound nature of the campaign, DANLEP sought to develop a more sustainable strategy based on social mobilisation and community participation leading to local ownership of the leprosy elimination programme.

Based on the principles of intersectoral collaboration and community participation, the outline of a tribal strategy presented in this document seeks to build partnerships for leprosy elimination activities between different stakeholders at the local level.

One of the key elements of a tribal strategy is the involvement of the *panchayati raj* institutions in the planning, implementation and monitoring

of leprosy elimination activities at the village-level. A second element is the development of a local corps of link workers, who would, in partnership with the local health system, undertake leprosy work in their respective areas. The approach suggested below not only seeks to involve local self-government structures embodied in the PRI and tribal *panchayats* but also NGOs and CBOs, which have emerged as the main intermediaries between state and society.

DANLEP has implemented initiatives to reach the un-reached on a pilot basis in several tribal blocks between 2000 and 2002. In Madhya Pradesh, a pilot project was undertaken in Kirnapur block of Balaghat district. In Orissa, a pilot project covered six tribal blocks, viz. Tiring, Bahalda and Jamda blocks of Mayurbhanj district, Kuarmunda block in Sundargarh district and Kotapada and Borigumma blocks in Koraput district. In Chattisgarh, Darbha block in Bastar district was the project site. In each case, the approach has been modified in response to the local context of its operationalisation.

Making health care services available to the marginalised tribal areas continues to be an urgent issue, requiring well-planned intersectoral efforts. However, sustainability and community ownership of any initiative continue to depend on local involvement and acceptability of the intervention, based on a participatory approach rather than a health system-driven top down approach.

The present document seeks to describe the activities facilitated by DANLEP for case detection and treatment delivery in tribal areas of Madhya Pradesh, Orissa and Chhattisgarh. The first chapter lays out elements of a strategy for leprosy elimination in tribal areas based on DANLEP experiences in the four states. Chapter Two summarises a DANLEP report on “Special Action Project for the Elimination of Leprosy” (SAPEL), a campaign-based approach particularly targeting remote and inaccessible areas.¹ Some of the lacunae of special leprosy elimination campaigns, such as SAPEL and Modified Leprosy Elimination Campaigns (MLECs), concern migratory workers and other un-reached segments of the population. These lacunae were identified and an attempt was made to overcome them in a pilot project in Kirnapur Block of Balaghat District in Madhya Pradesh. This project is described by R.K. Mutatkar and Pradeep Krishnatrey in Chapter Three.

¹ Narayanan, Gita. *SAPEL – A Special Project for Special Circumstances. DANLEP, 2002: New Delhi.*

Chapter Four summarises other activities in tribal areas of Madhya Pradesh, including a unique strategy of developing a corps of tribal link workers through an alliance with the Gayatri Pariwar organisation by the Madhya Pradesh DANLEP unit.

A series of health seeking behaviour studies among the Gond,² Bhil³ and Sahariya tribes of Madhya Pradesh are then presented; the latter in Chapter Five by S.K.Singh. These studies not only focus on the social conditions of leprosy-affected persons in marginalised tribal communities with numerous health problems, but also point to important differences among tribal societies, for example in the way leprosy is stigmatised or not.

Chapter Six describes DANLEP's work in tribal areas of Orissa. The challenges in developing programmes for un-reached population groups are identified and an attempt made to overcome them is described. Furthermore, the chapter provides a detailed account of a pilot project, that focused on establishing social networks and working with *panchayat* institutions, which was implemented in six endemic tribal blocks in Mayurbhanj, Sundargarh and Koraput districts.

Finally, Chapter Seven provides an account of a successful leprosy elimination campaign involving the local health system and the *panchayats* in Darbha block of Chhattisgarh.

It is hoped that the present volume will provide an overview of challenges experiences and avenues for action, and that it may be a helpful tool for providing leprosy services to the remaining un-reached tribal populations, both within and outside the states covered in book.

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² *Leprosy: Perceptions and Practices of Gonds in Betul, Chhindwara and Hoshangabad*. Vimarsh, Bhopal. DANLEP, 2002: New Delhi.

³ *Leprosy: Perceptions and Practices of Bhils in Jhabua*. Centre for Advanced Research and Development, Bhopal. DANLEP, 2002: New Delhi.