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**EXPLORING GRASSROOTS LEPROSY  
ORGANISATIONS:**

**Is social inclusion and empowerment  
possible for members?**

**Case Studies in Ethiopia and China**

A thesis presented in partial fulfillment of the requirements for the degree of  
**Master of Philosophy in Development Studies**  
at Massey University, New Zealand

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## **ABSTRACT**

This thesis explores reasons for the recent emergence of grassroots leprosy organisations and through case studies of two such organisations, ENAELP in Ethiopia and HANDA in China, shows that varying measures of social inclusion and empowerment are achievable by members working collectively and in solidarity. Two major factors contributing to the emergence of these organisations are the common experience of leprosy plus the failure of welfare programmes, both of which provide significant impetus to members for collective action.

The key to success for a grassroots leprosy organisation is recognising the importance of operating with a participatory development approach which attributes equal importance to processes and results, cultivating a strong sense of ownership by members and opening the way to the empowering journey of self-determination. While some international anti-leprosy organisations cling to assumptions that decision-making and self-determination by leprosy-affected people for themselves is not possible, others strongly support these grassroots endeavours.

Although leprosy has been a scourge and a source of fear for thousands of years with social exclusion and disempowerment resulting for millions of people, this thesis concludes that grassroots leprosy organisations have the potential to transform historical perceptions of the disease. In addition, these organisations provide opportunities for leprosy-affected people to demonstrate how they wish society to regard and consider them. This thesis did not take a static view of social inclusion and empowerment, but rather analysed changes in terms of how they are moving towards these two inter-related goals. There is no doubt that movement towards both social inclusion and empowerment is occurring, showing that the finest struggles with the best results are those fought by oppressed people themselves (Freire, 1989).

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## LIST OF ABBREVIATIONS

ALERT	All Africa Leprosy Education and Rehabilitation Training Centre
DAWN	Development Alternatives with Women for a New Era
ENAB	Ethiopian National Association of the Blind
ENAD	Ethiopian National Association of the Deaf
ENAELP	Ethiopian National Association of Ex-leprosy Patients
ENAPH	Ethiopian National Association of the Physically Handicapped
GLRA	German Leprosy Relief Association
GONGO	Government organised NGO (according to Chinese scholars)
HANDA	Chinese National Association of Ex-leprosy Patients
IDEA	International Association for Integration, Dignity, and Economic Advancement
IAF	Inter-American Foundation
MB	Multibacillary
MDT	Multi Drug Therapy
MOH	Ministry of Health
MOLSA	Ministry of Labour and Social Affairs
NGO	Non Government Organisation
NZAID	New Zealand Agency for International Development
PB	Paucibacillary
PNA	Participatory Needs Assessment
RMB	Renminbi is the Chinese currency: basic unit of RMB is the yuán
SEWA	Self Employed Women's Association
SOOM	Support Organisation for the Mentally Retarded
TLA	Textile Labour Association
TLM	The Leprosy Mission
TLMI	The Leprosy Mission International
TLMNZ	The Leprosy Mission New Zealand
VASS	Voluntary Agency Support Scheme (positioned in NZAID)
WHO	World Health Organisation
WLD	World Leprosy Day
(W/ro)	Woizero (Mrs)

## GLOSSARY

Amharic	Main language of Ethiopia
Ato	Mr
birr	Ethiopian unit of currency
Cantonese	People and language of Southern China
Clofazimine	One of three drugs that make up Multi Drug Therapy. The other two are Dapsone and Rifampicin
Dapsone	One of three drugs that make up Multi Drug Therapy. The other two are Clofazimine and Rifampicin
DAWN	An organisation of women activists, researchers and policy-makers from the Third World
Derg	Military government in Ethiopia from 1974 to 1991
Hansen's Disease	Another name for leprosy, after Gerhauud Henrik Armauer Hansen who discovered the leprosy bacillus
kabele	Lowest administrative unit (Ethiopia)
leper	Derogatory term for a person affected by leprosy
M.leprae	mycobacterium leprae, the leprosy bacillus
multibacillary	WHO Classification: more than 5 skin patches, plus nodules, showing leprosy
Pakeha	New Zealander of European descent (Source: Te Reo Maori)
paucibacillary	WHO Classification: 1-5 skin patches showing leprosy
Multi Drug Therapy	Combination of three drugs which make up the cure for leprosy
Rifampicin	One of three drugs that make up Multi Drug Therapy. The other two are Dapsone and Clofazimine
SEWA	A union of India's poorest women, most of whom are self-employed
teff	Fine wheat from which the Ethiopian staple food <i>injura</i> is made
wereda	Administrative unit equivalent to a District (Ethiopia)
Woizero (W/ro)	Mrs
yuán	Basic unit of RMB (Chinese currency)