

# **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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2005



## **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).

## **ACKNOWLEDGEMENTS**

The support, assistance and encouragement of many people the world over made completion of this thesis possible.

I especially thank David Hall, Executive Director of The Leprosy Mission New Zealand, who not only enabled me to undertake this thesis by approving funding from the Murray Feist Memorial Scholarship Fund, but believed absolutely in my ability to achieve this goal and provided constant encouragement and direction along the way.

I thank my colleagues at the Auckland office of The Leprosy Mission New Zealand, all of whom carried extra workloads, enabling me to have the time and space needed to complete this thesis.

People within The Leprosy Mission internationally supported my research and in particular I thank Mr Trevor Durston, General Director of The Leprosy Mission International; also Dr Piet Both, Africa Director and Dr Ditch Townsend, South East Asia Director, for their blessing as I worked in their respective field areas of Ethiopia and China.

My supervisors at Massey University, Dr Barbara Nowak and Dr Manuhua Barcham, gave much careful guidance and wisdom as I brought together a wealth of research information and turned it into this thesis document, and I am grateful.

Most importantly, I am deeply grateful to the wonderful people of ENAELP and HANDA, who so graciously opened their hearts to me and shared their stories. Some stories enabled us to share laughter together; whereas others caused us to weep. All are experiences I profoundly treasure; they have truly enriched me. This thesis is a product of the generosity of ENAELP and HANDA members and staff with their time and the information they provided to me. Having heard firsthand so many times of struggles to survive what can only be called severe human rights violations, I sincerely respect their steely determination to utilize this opportunity to increase their visibility in today's world. As they told me with pride many times, this is their thesis.

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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 Gerhard 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>injera</i> is made
wereda	Administrative unit equivalent to a District (Ethiopia)
Woizero (W/ro)	Mrs
yuán	Basic unit of RMB (Chinese currency)



## CHAPTER 1: INTRODUCTION

**de-ve´lop:** *v.t. to unfold more completely; to evolve the possibilities of; to make active (something latent); to advance; to further; to promote the growth of; to make more available or useable. v.i. to grow, evolve, expand, mature, ripen, to unfold gradually (as a flower from a bud).*

*Webster's Collegiate Dictionary (1947)*

This thesis explores reasons for the recent emergence of grassroots leprosy organisations and asks whether leprosy-affected people can achieve social inclusion and empowerment through membership of such organisations. While general grassroots membership organisations have been developing for the past twenty or thirty years (Clark, 1991: 102), this is a much more recent happening for leprosy-affected groups of people. There does not appear to be much, if any, academic literature or documented studies on grassroots leprosy organisations, and literature looking at the social effects of leprosy is minimal with medical studies and medical literature predominating. Even literature on general grassroots membership organisations that promote broadly-based social development remains sparsely documented and poorly understood (Howes, 1999: 7).

Through case studies of two grassroots leprosy organisations in different developing countries this thesis will show 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 leprosy has been a scourge and a disease of fear for thousands of years with social exclusion and disempowerment resulting for millions of people, this new phenomenon of grassroots leprosy organisations has the potential to transform historical perceptions of leprosy and how people affected by the disease wish others to regard and consider them.

## **RESEARCH CONTEXT**

The research ideas for this thesis gestated over time and were born out of contact with two grassroots leprosy organisations, ENAELP (Ethiopian National Association of Ex-Leprosy Patients) in Ethiopia and HANDA in China. Firstly, my introduction to both groups, and subsequent time spent with them, came about through my position on the staff of The Leprosy Mission New Zealand as International Programmes Manager. My role meant I was a major player in developing formal partnerships with both organisations and during this period my interest in their goals and aspirations increased. Regular field experience gave me firsthand insights into the social dilemmas faced by these people because of leprosy and enabled me to become more familiar with their position as a minority group facing huge challenges. I selected them for research case studies on this basis.

Secondly, my involvement as a student in post-graduate Development Studies was particularly helpful in leading me to a greater appreciation of the problems of minority groups and reaffirmed, even intensified, my personal belief that identity, dignity and inclusion should be a basic right for all people. One of the most useful discussions was in relation to policy approaches for women's development in Third World countries, and the use of a framework to analyse five major approaches (Moser, 1989). These include welfare, equity, anti-poverty, efficiency and empowerment approaches, with welfare and empowerment at opposite ends of a linear scale. This framework works just as well for other minority groups, leprosy-affected groups of people included, and identifies whether development initiatives will meet only short-term or immediate needs or if they will contribute to long-term strategies to transform the structures which oppress the minority group in question. With this in mind it was interesting to recognise that some development work done today, even with the best of intentions, can closely resemble neo-colonialism in guise.



*My first encounter with members of a grassroots leprosy organisation was in March 2002, in Ethiopia. Birke Ngatu, Chair of ENAELP, fascinated me: she was an energetic, dynamic woman who had experienced leprosy and had visible disability which would forever proclaim this fact. We spent time together: she talked about her life experience. Leprosy had certainly made its mark physically, but it had made a deep mark psychologically and socially too. Her occasional tears vouched for that. Only a fighter could climb above such abuse, and she had done so. Where did she find the strength? Well, she married a man who loved her, believed in her and respected her dignity. He had leprosy too, but together their shared strength combined into a force to be reckoned with. She fought to attend adult education classes, and then learned English. She also became the mother of four daughters. Her words to me, which I will always remember, were: "I am married: I am a wife and I have a husband. I have had children: I am a mother. My daughters are complete, whole people, which my husband and I produced. Why should they and we be anything less just because of leprosy?" This tiny woman believed passionately that people with leprosy were as valuable as anyone else and had the same right to dignity as every other human being on earth, and she was going to spend her life fighting for it.*

*We traveled together to visit isolated groups, all made up of people with leprosy, and all who were members of this grassroots leprosy organisation: hours and hours in the sweltering heat in an old four-wheel drive vehicle over dusty, corrugated tracks in the desert. Early on in the trip we were regularly overtaken by late model four-wheel drive vehicles with the names of large NGOs on the side panels, all with windows wound up to benefit from the air conditioning. Not so for our battered well-used vehicle which the driver had to continually coax to keep going. Later, as we got closer to our destination, we saw no vehicles, just a few horses with carts, and people walking along the side of the road, such as it was.*

*Seven hours later we found ourselves in a small straw hut, guests of honour, with a group of people who never received visitors. All had been isolated by force years earlier by the government in its attempt to stop the spread of leprosy. Now, with at least two additional generations, these people were still isolated and living in absolute poverty. Extreme disability was evident, as were the symptoms of other diseases of poverty. So what was lighting up their*

*eyes in this darkened space after years of neglect? It was their membership of this grassroots organisation. They belonged to something larger than themselves, and the solidarity it offered was the pinnacle of their new hope.*

*But how, I asked myself, can such a minority group so neglected and abused for countless generations, even begin to realise the dreams they have of equality with the general population, social inclusion and respect of their human rights? I returned to New Zealand haunted by the squalor, degradation and indignity of human life I had experienced and asked myself, “What is my contribution going to be? Will it be one that will meet only immediate or short term needs or will I commit to join in a fight for long-term strategies to transform the structures which oppress these people? How can I best do this?” After much thought and a subsequent visit to China in November 2003 where I shared similar experiences with a new grassroots leprosy organisation there, I discovered some answers to my questions. To begin, I would write this thesis.*

## **RESEARCH APPROACH AND QUESTIONS**

This study acknowledges as its starting point the fact that grassroots leprosy organisations have begun to emerge in various developing countries in the last decade or so, and examines why and how this is occurring, as well as exploring the viability and effectiveness of these groups.

To structure my research, I asked the following questions:

- What factors influenced groups of leprosy-affected people to form grassroots organisations?
- How can leprosy-affected people achieve social inclusion and empowerment through membership in their own grassroots leprosy organisation?
- To what extent are grassroots leprosy organisations accepted by international anti-leprosy organisations and is it possible to have meaningful alliances and partnerships between them?

I addressed these questions by undertaking field work in Ethiopia over a period of two weeks in October 2004, and in China over a period of one week in December 2004. This augmented

previous knowledge and experiences from earlier visits made in my professional capacity since 1997 (ENAELP) and 2003 (HANDA). I also visited an international organisation (IDEA: International Association for Integration, Dignity, and Economic Advancement) based in the USA made up of individuals and organisations that have faced leprosy.

It was my goal to listen to the people within these organisations, to hear their experiences, and learn from them. I set out to try to understand and comprehend their realities although recognizing my reality as a 'healthy' Pakeha New Zealander would never allow me to entirely achieve that. My questions asked as a researcher embedded deep within my own cultural context and also in the wider international development culture, were made up of complex assumptions from which I could only attempt to separate myself. For the most part such separation was impossible and I needed to accept my limited position within these differing cultures rather than attempting to be someone I was not. However, I was constantly able to learn and to use Chambers' (1983: 217) words; it was very much a situation where "putting the last first not once but again and again and again" enabled me, an outsider, to conclude this research a much richer individual for the experience.

## **RESEARCH METHODOLOGY**

I approached the Managing Director of ENAELP and the General Secretary of HANDA to gain permission to research their respective organisations. Both gave permission wholeheartedly and promised they would do all they could to help the research process especially at the time of my field visits and in regard to choosing case study locations.

I used a combination of methods of inquiry including semi-structured interviews and focus groups, along with participant-observation. These had varying levels of success; the interviews generally produced extensive and detailed information with participants fully engaging in the activity. Some of the focus groups tended to progress in a somewhat haphazard fashion and grew in size as the discussion proceeded because of the public arenas where they took place and the inquisitiveness of other local people. While this meant that not all of the focus groups worked entirely as anticipated they did provide useful opportunities to collect worthwhile research information. I cross-checked information by using the same questions with different

people and groups in different places especially making use of both village-based and office-based environments.

Whether involved in interviews or focus groups I informed everyone their participation was entirely voluntary and they were not obliged to take part, and if they did, were not obliged to answer all the questions put to them. No one declined involvement or declined to answer a particular question.

### **Interviews**

With the help of a translator I undertook 27 semi-structured interviews with people in ENAELP and 15 with people in HANDA. I selected participants on the basis of their role in the organisation, gender, and location. Interviews focused on personal experiences of leprosy and how and why they became involved in either ENAELP or HANDA, then going on to explore current involvement and what it means to them. I tailored some interviews to ensure I captured an individual's expertise and experience especially in relation to the founding of the organisations and their involvement in that process. Information collected in initial interviews was cross-checked (without identifying anyone) in later interviews to verify accuracy and detail. The majority of interviews took place in an office environment which provided privacy to the participants, including myself and the translator.

### **Focus Groups**

Conducting focus groups had several objectives. The first was to enable groups of ENAELP and HANDA members, who made up Local Associations, to discuss the reasons for their membership and subsequent achievements of their respective groups. Secondly, homogeneous groups of various types, such as women's groups, micro-finance groups and vocational training groups, were set up to talk about their particular experiences with ENAELP or HANDA. The aim was to discover if there had been any significant changes as a result of belonging to these groups, and if so, how and why this had occurred.

Most of the focus groups held in the villages proved difficult to conduct without an audience, in part because of lack of privacy, but largely owing to curiosity and the fact an outsider was

present. This proved to be disconcerting for one of the women's groups who were understandably reluctant to relax and talk about their issues when others, mainly men, were looking on and trying to listen from the periphery. The fact that the size of the group was too big for the room in the first place, and then that both the windows and the door had to be closed in the heat of the day, did not make for a conducive interviewing environment. Given that I had to conduct the majority of focus groups outside because of a lack of facilities the privacy issue could have been more of a problem than it was. Although sensitive questions generally were avoided in the focus groups, closer scrutiny of sensitive issues was possible in interview situations.

### **Participant Observation**

Participant observation was revealing in that it provided opportunity for me to validate information provided in interviews and focus group situations. Where I conducted focus groups in participants' villages there was clearly evidence of social exclusion and extreme poverty. Housing was dilapidated, in most cases water was distant, and any income was either from daily labouring or begging. These observations matched information provided to me in the interviews and focus groups.

### **RESEARCH ETHICS**

Given my professional role with The Leprosy Mission New Zealand, perceptions of conflict of interest may have emerged. However, I recognised my position as researcher openly, and sought to find a way forward which was acceptable to the participants. There was no doubt that I was undertaking the research for a reason and that it would culminate in a Masters thesis. How then could this benefit and empower the participants as well as me, the researcher? At this point I stepped back to allow them space and time to think without influencing them. I was afraid that even though I had tried to mitigate against it, with their concept of me as an 'important' person, their aim to please may mean they came up with answers they thought I would want to hear. In the end, in both Ethiopia and China, my translators proved to be a first class go-between, trusted by the local participants as well as by me. Their skills in "hearing" all the views, both stated and unstated, recognizing body language, plus their extensive knowledge of local culture as well as the difficulties borne by the long-term socially excluded members of

our group of participants, helped to identify a mutually agreed starting point and *modus operandi*. The outcome: with pride the beneficiaries think of this as their thesis.

## **THESIS OUTLINE**

This chapter introduces the subject of grassroots leprosy organisations, and then introduces two such organisations: ENAELP (Ethiopia) and HANDA (China). I introduce the research questions and my reasons for undertaking the research. I also acknowledge my professional and cultural biases as a researcher, which are inherent in such a study.

Chapter Two gives a brief history of leprosy and its medical treatment, and seeks to identify the complexities of the disease which positions this research into both its historical and current contexts. The chapter then looks at social exclusion and human rights issues surrounding leprosy, all of which dis-empower people, and seeks to show the importance of fully addressing social issues and not stopping with the traditional medical focus. The concepts of social inclusion and empowerment are presented as appropriate development principles for leprosy-affected people so they are enabled to make decisions relating to their own destiny.

Chapter Three explores grassroots organisations and reasons for their development. The chapter seeks to show that the solidarity of socially excluded people through membership in grassroots organisations does contribute to social inclusion and empowerment, and that members' decision-making and control of resources is not only desirable, but essential. The concept of putting the last first, and bottom-up versus top-down, is introduced as an appropriate development ethic: this not only allows socially excluded poor people, including people affected by leprosy, to take charge of decisions pertaining to their own development but also provides them with the strength and impetus to challenge social exclusion and be freed from it, not just to survive it.

Chapters Four and Five present the primary data collected during the case studies. They discuss factors relating to the emergence of ENAELP and HANDA as grassroots membership organisations, and briefly refer to IDEA as an international leprosy membership organisation. Exploration of the key research questions provided an opportunity for listening to people whose

voices are seldom heard, and whose identity and dignity has been shattered. It gives a place in the academic world for leprosy-affected people at the bottom (not the top) to be included, and allows the last to go first.

Chapter Six revisits the research questions, drawing on material presented in Chapters Five and Six for discussion and response. The factors specific to the two grassroots leprosy organisations and their members are discussed in order to understand how it is that members of ENAELP and HANDA have managed to achieve varying levels of social inclusion and empowerment whereas medical treatment alone had previously left them in serious socially compromised situations. The chapter also analyses the reasons why grassroots leprosy organisations are emerging and their subsequent relationships with international anti-leprosy organisations.

Chapter Seven brings together the case studies, the research aims and the ideological contexts and discusses what emerges as the main conclusions of this research: firstly, the failure of welfare programmes plus the common experience of leprosy and subsequent human rights abuses have driven leprosy-affected people to join together in collective action; secondly, working with a participatory approach that attributes as much importance to process, i.e. a bottom-up model of working, as to results contributes significantly to the sense of belonging that membership of the grassroots organisations has brought about; thirdly, meaningful alliances and partnerships are possible with some international anti-leprosy organisations but much depends on the organisational culture of each organisation; and fourthly, membership in grassroots leprosy organisations is achieving a measure of social inclusion and empowerment for the members. The chapter concludes with a summary of the main contributions this thesis has made.

## CHAPTER 2: LEPROSY

*“Those who deny others their freedom are not themselves free. They are locked behind the bars of prejudice and ignorance.”*

*Nelson Mandela*<sup>1</sup>

Leprosy, also known as Hansen’s Disease, as a purely medical phenomenon is often subject to conjecture, with many arguing it should also be seen in a full sociological context. This chapter attempts to give a sense of breadth to the implications of leprosy in order to show the complexity of issues. While it is scientifically proven that medical treatment cures leprosy, is a medical cure enough for people with the disease or do they desire a holistic cure which may only be possible when sociological issues are also recognised and addressed? It is well known and understood that leprosy-related disability is difficult to hide and therefore compounds the stigma associated with the disease, reinforcing social exclusion and disempowerment. Added to this predicament, there remains legislation relating to leprosy in some countries which directly contravenes the Universal Declaration of Human Rights (United Nations: 1948). This chapter seeks to determine whether a completely holistic cure for leprosy is possible when people are medically cured from the disease, or if to truly experience social inclusion and empowerment, plus the fundamental human rights to which they are entitled, a parallel sociological cure needs to occur.

### A BRIEF HISTORY OF LEPROSY

For thousands of years leprosy has struck fear into people the world over. It was well recognised in the oldest civilizations of China, Egypt and India and it is generally claimed the first clear and accurate description of leprosy was in India about 600 BC (Davey, 1987: 15; WHO, 2003). The Leprosy Archives in Bergen, Norway, however, say that leprosy is mentioned in sources from Egypt from as early as 1350 BC (Nedrebó, 2001). There are several references to leprosy and the word ‘lepers’ in the Bible with Leviticus, the third book of Moses, referring to the disease as a plague and giving rules on how to behave towards ‘lepers’. The New Testament showed Jesus demonstrating considerable mercy and special concern towards people with leprosy, whom other people despised. Although the Bible refers to leprosy, far earlier than the first Indian

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<sup>1</sup> Nelson Mandela: South Africa Civil Rights Leader, won the Nobel Peace Prize in 1993. Born 1918.



description, there remains conjecture as to whether it was in fact leprosy as it is known today or a word used to describe any number of unpleasant skin diseases (Davey, 1987: 15).

Leprosy was rampant during the 13<sup>th</sup> century in Europe (WHO: 2005a). Evidence of this is built into gothic churches in Europe and Britain; the so-called 'leprosy squint holes' through which the person with leprosy would peer and watch the priest at the altar celebrating mass. Prior to this, a service of expulsion would have taken place, with the leprosy-affected person shrouded under a black cloth and the mass of death read followed by a list of prohibitions: never again to enter a church, a house, a tavern or a market-place; or to walk through narrow lanes or speak 'down wind' to anyone; never to speak with children; always to wear a 'leper's' uniform, which included gauntlet gloves, and a 'leper' warning given either with a 'leper's bell' or 'leper's rattle'<sup>2</sup> when approaching other people. For all practical purposes the person with leprosy was 'dead' to society (Davey, 1987: 16). By the 17<sup>th</sup> century, Norway and Iceland were the only countries in Western Europe that had large numbers of people with leprosy.

### **Three Key Men: Hansen, Bailey and de Veuster**

During the 1830s there was a considerable increase in numbers in Norway with the situation becoming a political issue. An important breakthrough in leprosy research took place in Bergen in 1873 when Norwegian, Gerhard Henrik Armauer Hansen, discovered the leprosy bacillus or *mycobacterium leprae* (*M.leprae*). This discovery was the first time a bacillus and a disease were clearly linked making Hansen world renowned (Davey, 1987: 30). The evidence was clear: a bacterium causes leprosy, it was not hereditary, a curse, or from sin. Since then the disease has also been known as Hansen's Disease with many people preferring this term because of the negative connotations associated with 'leprosy'. Historically people with the disease were referred to as 'lepers', but this term is now widely rejected and classed as insulting and offensive because of the pejorative meanings associated with it.

At the same time Hansen discovered *M.leprae* in Norway, Wellesley Bailey, an Irishman, was encountering people with leprosy in India. So affected was he, by what he saw, Bailey returned to Ireland determined to make a difference – somehow. In 1874, in Dublin, what is known

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<sup>2</sup> Use of a 'leper bell' or 'leper rattle' was mandatory by people with leprosy in order to warn they were coming within proximity of well people (Richards, 1977: 50).

today as The Leprosy Mission was born. Wellesley Bailey returned to India to begin work but it was an uphill battle. The government of India's 1898 Leper Act decreed that beggars with leprosy be treated as criminals requiring compulsory segregation from society, and district magistrates were given powers to commit them to authorised establishments (Davey, 1987: 50).

Also in 1873 a Belgian priest, Joseph de Veuster, who was a missionary in Hawaii, sailed from Honolulu to Molokai, the island of death where the United States Government enforced people with leprosy into isolation. No one who went there ever left. Sixteen years later, de Veuster himself died, having become one with those he went to serve. His famous words "we lepers..." (Eynikel, 1999: 91) were prophetic as eleven years into his self-imposed exile he himself discovered he had leprosy. He is now remembered as Father Damien.

These three men, unknown to each other, were key figures in the struggle against leprosy in the latter part of the 19<sup>th</sup> century. Their pioneering spirits combined with a strong quest for justice formed a solid foundation from which leprosy work today continues to benefit. This is clearly an early challenge to leprosy-related social exclusion and human rights abuses.

## **COMPLEXITIES OF LEPROSY**

Even although leprosy has been known about for centuries, the mode of transmission remains uncertain. The fact that it is caused by a bacterium, *M.Leprae*, which multiplies very slowly, means there is a long incubation period of five to fifteen years making research into transmission difficult (Lockwood, 2004: 269). Many researchers are of the opinion it is spread from person to person in respiratory droplets by coughing and sneezing, but this is not scientifically proven. Humans seem to be the only natural host of *M.Leprae* with the exception of the 9-banded armadillo found in parts of Central America (WHO, 2004).

## **Leprosy and its Treatment**

The outworking of *M.Leprae* is known as tuberculoid leprosy and first seen as pigmented patches on the skin usually accompanied by loss of feeling. Further symptoms become evident as *M.leprae* attacks surface nerves in cool parts of the body, and areas such as hands and feet gradually experience loss of feeling also. Subsequent injuries occur because of lack of pain and

often go unnoticed for some time with permanent deformity and disability resulting. Left untreated, leprosy will continue to destroy nerves causing anesthesia, and once lost, feeling will never return, meaning prevention of disability becomes a lifelong battle. A worse form of the disease is lepromatous leprosy which is very infectious. Here *M.leprae* multiplies at a steady rate and infiltrates the skin producing unsightly nodules on the face and body.

From the early 1900s to the late 1940s, leprosy was treated by giving injections of oil from the chaulmoogra nut. While this appeared to work for some people, long-term benefits were questionable. Dapsone pills were used during the 1950s but disappointment followed when *M.leprae* began developing Dapsone resistance (Davey, 1987: 61). Drug trials on the island of Malta in the 1970s led to an effective combination of drugs and in 1981 the World Health Organisation recommended Multi-Drug Therapy (MDT). The combination of Rifampicin and Dapsone (known as paucibacillary multi-drug therapy or PB-MDT) over six months or the triple drug combination of Rifampicin, Dapsone and Clofazimine (known as multibacillary multi-drug therapy or MB-MDT) over twelve months were highly effective in curing leprosy (Lockwood, 2005: 230). This cure was a major breakthrough.

### **A Social Disease**

Today leprosy is generally recognised as a disease exacerbated by poverty, poor nutrition, hygiene and sanitation (Buckingham, 2002:17). Wilkinson (1996: 1-9) argues strongly that inequalities produce poverty and unmet social needs thus impairing health; therefore, perhaps leprosy should be seen as an affliction of an unhealthy society. Leprosy is also a highly stigmatised disease and the word 'leper' has a near mythical status as a synonym for extreme social exclusion (Silla cited in Kabeer, 2000: 5). The reasons for exclusion from society hark back to the history of leprosy and an inherent fear of the disease. Misconceptions including beliefs that it is incurable, hereditary or a divine punishment contribute to stigma (Rao et.al. 1996: 191) which in turn intensifies the social exclusion that inevitably follows.

### **SOCIAL EXCLUSION AND LEPROSY**

Social exclusion discourse gives the term social exclusion a variety of meanings, although Silver (1994: 535) claims that "defining exclusion is not an easy task". Firstly, the French Republican

tradition, drawing on Rousseau<sup>3</sup> and his emphasis on solidarity [defined by Silver (1994: 539) as the *solidarity paradigm*], and an idea of the state as the embodiment of the general will of the nation, defines social exclusion as the rupture of a social bond, which is cultural and moral, between an individual and society. It is the opposite of social inclusion, mirroring the perceived importance of being part of society, of being included. The poor, unemployed, and ethnic minorities are often excluded from and by society, defined as outsiders (de Haan, 2001:27); there is no doubt this is applicable to leprosy-affected people too, all vulnerable in terms of insecurity, defenselessness, and exposure to risk and shocks (de Haan, 2001:30).

Secondly, in Anglo Saxon tradition, poverty is seen as a separate issue, rather than an element within social exclusion, defined by Silver (1994: 539) as the *specialisation paradigm*. John Locke's<sup>4</sup> liberal thinking contributed to this notion which sees actors primarily as individuals who are able to move across boundaries of social differentiation and economic divisions of labour. Unenforced rights and market failures are seen as common causes of social exclusion. In this paradigm exclusion reflects discrimination, the drawing of group distinctions that denies individuals full participation in exchange or interaction (de Haan, 2001:27-28). While in the normal course of events an individual may not be excluded in every sphere (Silver, 1994:543) the fact here is that leprosy-affected people would have no freedom of movement across spheres; their discrimination would be total and their choices would be nil. With Sen's work on capabilities and entitlements (1981 in de Haan, 2001:31) stressing "that what counts is not what (poor) people possess, but what it enables them to do", leprosy-affected people would be confined to a position where they could do nothing.

Thirdly, the *monopoly paradigm* (Silver, 1994: 539) draws on the work of Weber<sup>5</sup> and is influential in northern European countries, including Britain. Emphasis is on the existence of hierarchical power relations in the constitution of social order. Group monopolies are seen as responsible for exclusion with powerful groups restricting the access of outsiders through social closure. Inequality overlaps with such distinctions but is mitigated by social democratic citizenship and participation in the community (de Haan, 2001: 28). Given that people affected

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<sup>3</sup> Jean Jacques Rousseau (1712-1778)

<sup>4</sup> John Locke (1632-1704)

<sup>5</sup> Max Weber (1864-1920)

by leprosy are generally the lowest of the low in terms of social order, their exclusion according to this paradigm would be total.

The claim that some people may be excluded in some areas, and included in others, and some may choose not to be included while others are included against their will, (de Haan, 2001:29) suggests the extent of social exclusion varies according to context and is a relative deprivation (de Haan, 2001:30). However, history shows that social exclusion in relation to leprosy-affected people is generally absolute. What is more, “the action of exclusion becomes structural when it is repeatedly confirmed through social relations and practices” (Silver, 1994: 545).

Farmer (2003, 29-50) talks about structural violence. He says this term is apt because much suffering is structured by historically given and economically driven processes and forces of which gender inequality, racism, poverty and a stratified society are at the heart. Often there may be no physical violence, but people may be radically violated: this, says Farmer, is structural violence. It is where inequalities of power prevent the sharing of opportunities; where lives are dominated by decisions taken by others; where the asymmetry of power generates a quiet brutality. Nowhere is this more distinct than it was in previous years, in many countries, when governments forced people with leprosy into remote, isolated areas for the remainder of their lives. Families were split, children taken from their mothers, and those with the disease left alone with others in similar predicaments to gradually perish, forgotten by society. A participant in this research stated: “It is not the leprosy or the poverty that kills our spirits; it is the loneliness and loss of hope” (Field Notes. 2004).

Social exclusion is of additional significance for women who often have a low status and subordinate places in many communities. Women with leprosy face additional social and psychological problems and greater suffering irrespective of their socioeconomic status (Rao et al, 1996:191). While gender in itself may translate into areas of social exclusion, it can also differentiate and exacerbate other forms of disadvantage, and thus feed into Kabeer’s so-called ‘destructive synergies’ which underlie social exclusion. For example, the stigma of leprosy operates regardless of gender; but being a woman exacerbates the stigma of leprosy. Rao et al, (1996, 197) confirmed this when he found various restrictions operated against both women and

men with leprosy, but that these restrictions were much greater for women. Children always bear the brunt of a leprosy-affected parent being socially excluded, and when children themselves have leprosy their future prospects are even more severely limited. Psychological challenges such as feelings of uselessness, hopelessness, and exclusion, are dangerous dynamics for children to face as they may lead to drugs, alcohol or hostilities to the system and with an accumulation of such a potent mix, plus a lack of positive relationships, they will most probably lack the resources to ever find their way back into society (Silver, 1994:559).

Freire (1989) insisted that oppressed people must struggle for their own interests and not leave their fate to others. He claimed that even when privileged groups think they have others' best interests in mind, they rarely do. While Freire conceded an occasional need for consciousness-raising amongst the oppressed so they are aware of their rights and can decide what is in their best interests, he maintained the finest struggles with the best results are those fought by oppressed people themselves. If we accept Freire's claim it means leprosy-affected people should be deciding what is in their best interests and how best to gain social inclusion, for which they must fight to achieve themselves.

## **HUMAN RIGHTS AND LEPROSY**

The inhumane way some governments and societies have treated leprosy-affected people, and their families, amounts to serious human rights violations. Enforced lifelong social exclusion in isolated areas with poor facilities, abandoned by those closest to them, poor or no health care and employment opportunities are just some of the violations experienced by people with leprosy. In some instances leprosy-affected people have been targets of abuse and physical attack. Often marriage and giving birth to children has also been denied them (Yokota, 2005:5). Although Article 1 of the Universal Declaration of Human Rights states that: "All human beings are born free and equal in dignity and rights", leprosy-affected people and their families generally do not enjoy this fundamental provision. In fact, all thirty articles in the Universal Declaration of Human Rights (United Nations: 1948) have been breached by many countries, both in the developed and Third World, in relation to leprosy-affected people.

Kazumi Sogano from Japan said,

“The Leprosy Prevention Law neglected the human rights of those affected by leprosy. The law allowed society to treat us inhumanely. Once a person had leprosy, he or she became a non-human being. We have fought to change the law so that we would be treated as human beings, just as anyone else, for 45 years from 1951 to 1996. The law was finally abolished in 1996. Today is a result of our struggle and efforts” (IDEA, Sep-Dec 2004).

This quotation refers to the 1907 “Act on Leprosy Prevention” passed in Japan, “for the sake of vagrant lepers”. This stringent exclusion policy lasted until 1<sup>st</sup> April 1996, when after a long struggle by leprosy-affected people it was repealed (Ohtani, 1998: v). History shows that the world over, leprosy-affected people have suffered horrific human rights violations. Many countries had, and some still have, discriminatory laws, and even if the law does not sanction discrimination, it usually does not prohibit it either.

Farmer cuts no slack when he says,

Human rights violations are not accidents; they are not random in distribution or effect. Rights violations are, rather, symptoms of deeper pathologies of power and are linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm (2003: 7).

If governments and other large institutions with authority and influence placed greater importance on human rights issues, which they hold the power to do rather than placing emphasis on economics or budgets, then the weak would have a greater opportunity to be socially included. Condoning quiet cruelty by violating various treaties and charters is just as bad as overt physical violence to which the guilty parties, nation states, by and large, are so often signatories (Farmer, 2003: 8). The powerful generally have uncontested free reign to reinforce structures which will only exacerbate the weaknesses of those who are already weak. There is no doubt leprosy-affected people are amongst the weak who suffer at the hands of perpetrators of open violence. But they must live with cloaked violence too:

We live in a time in which violence is right before our very eyes. The word is applied to extremely varied contexts, but each is marked by open violence – by violent acts, fury, hatred, massacres, cruelty, collective atrocities – but also by the cloaked violences of economic domination, of capital-labour relations, of the great North-South divide, to say nothing of all of the ‘every day’ violences perpetrated against the weak: women, children, all those excluded by the social system (Françoise Héritier in Farmer, 2003: 7-8).

The fact Farmer believes ‘the stage is set for more of the same, even though we are reassured by the powerful that the age of barbarism is behind us’ (2003: 7) means there is a fight ahead if human rights as stated in the Universal Declaration of Human Rights are to be enjoyed by the majority of the world’s people. Because in many cases international financial institutions and transnational corporations now dwarf the dimensions of most states, and the small number of powerful states that control them are holding unfettered sway over the lives of millions,’ (Farmer, 2003: 18) the fight for human rights is difficult and complex. Is, therefore, Freire’s (1989:101) theory of consciousness-raising and his insistence that the oppressed struggle for their own interests actually reasonable? Should this include leprosy-affected people, and if so, how will they make out?

## **FRAMEWORK FOR RESEARCH**

This chapter opened by questioning whether a medical cure for leprosy is sufficient on its own or if a holistic cure obtained by recognising and addressing sociological issues relating to the disease is also necessary. It has shown that the history of leprosy goes back thousands of years during which time leprosy-related stigma has compounded causing social exclusion and human rights abuses for generations of people in many countries. Through two case studies, this thesis will show that concepts of social inclusion and empowerment are important to the development of leprosy-affected communities because the people want it and need it, and they want to make decisions relating to their own destiny. This thesis explores social inclusion and empowerment, plus human rights issues, from within the context of two grassroots leprosy organisations.



## **CHAPTER 3:**

### **GRASSROOTS MEMBERSHIP ORGANISATIONS**

*“Equality is not created by hand-outs”.*

*Yusuf Hiliqawi (Coleridge, 1993:168)*

The previous chapter showed social exclusion and human rights abuses are major problems for leprosy-affected people, and argued that these issues are not addressed by the medical ‘cure’ for leprosy. While some international anti-leprosy organisations remain staunchly committed to the medical cure alone, others are venturing into the wider sphere of participatory community development in areas where leprosy is a problem. Within this environment, it is interesting to see recent moves in some countries by leprosy-affected people to organise themselves into groups: as a result they feel collectively stronger and believe they will achieve greater long-term impact when speaking with one voice. Thus, solidarity in the form of grassroots leprosy organisations appears to be a significant factor contributing towards leprosy-affected people reclaiming social inclusion and empowerment.

In the 1980s and 1990s grassroots membership organisations began emerging in the developing world (Clark, 1991: 102; Garilao, 1987: 114) and the recent advance of leprosy-affected groups into grassroots membership organisations appears to be following this trend. This chapter explores why grassroots membership organisations have emerged and investigates their viability and success in achieving members’ goals and aspirations. It examines formation and leadership issues, membership, governance, external relationships, and other characteristics which make up these organisations. After a brief exploration of the concept of empowerment, the chapter introduces a Grassroots Development Framework which helps to define and measure social change and organisational impact. The chapter concludes by asking: ‘can the members of grassroots leprosy organisations expect similar results and measures of success to those achieved by general grassroots membership organisations?’

## **ORGANISATIONAL START-UP**

The origin and formation of grassroots organisations are critical factors which define their growth path (Nogueira, 1987: 173) and eventual ability to transform into strategic organisations in their own right (Garilao: 1987: 114). Their emergence appears to follow a continuum with some grassroots organisations beginning as self-help groups or projects which sought sustainability by investing control in the people (Clark, 1991: 102) but are often established with external financial, conceptual or technical support (Avina, 2002: 126). Others are more organic, self-generating in origin, indigenous, emerging as local people responded to local problems (Clark, 1991: 102) and are internally financed in the initial start-up phase, before looking to external options for additional funding (Avina: 2002:126) and other forms of support.

Motivation to form an organisation may come from many sources, including the desire to fill a gap in public services or some catalytic event may inspire local action (Avina, 2002: 126 & 128). Or it may be a response to societal conflict and tensions (Garilao, 1987: 114); the need to respond more effectively to crisis situations in the face of the breakdown of traditional structures (Garilao, 1987: 114); or the ideological and value differences with powers-that-be in planning and implementation of development work (Garilao, 1987: 114). There may also be a desire to improve local income-generating capacity (Avina, 2002: 126). Schemes devised and run collectively by the poor are demonstrating the poor can indeed organise themselves to take action which radically alters their situation. They are recognising that “organisation is the weapon of the weak in their struggle with the strong” (Michels in Esman & Uphoff: 1984: 53). Individuals can do little as they have few assets, no access to parliamentary or legislative processes, no skills they can threaten to withdraw. They have no bargaining power. Initially, they may believe any changes to their situation must come from foreign donors, but many are finding their collective action is more powerful than they thought. They are coming to realise answers lie within themselves, in their solidarity and working collectively and together (Clark, 1991: 103).

The legitimacy of grassroots organisations varies from country to country with much depending on political factors - especially a society’s political past (Nogueira, 1987: 171). However, while a society strongly influences an organisation’s existence and behaviour (Heyer et al, 2002:21), it is

also important to realise that over time the organisation, and associated group behaviour, will contribute to the formation of different societal norms. In the case of grassroots leprosy organisations, this may be a critical factor in the process of eradicating stigma and changing behaviour so that leprosy-affected people are included and empowered in their own societies.

The next section seeks to identify early characteristics of grassroots organisations, in particular, self-generating groups and externally initiated groups, and how these differing modes of start-up influence ongoing growth and development.

### **Characteristics of Self-generating and Externally-initiated Groups**

#### *Formation and Leadership*

Self-generating groups are usually small in nature with localised impact, born from the initiative of a catalytic agent, either a motivated leader or a small group of local people (Avina, 2002: 126). Typically, charismatic people of deep commitment and vision who lead by inspiration and personal qualities are founders of self-generating groups (Clark, 1991: 65) and not only do they tend to set the mission and vision, but they also choose the staff when the time comes (Hailey et al, 2002: 404). Organisations, particularly in their founder phase (though not exclusively) tend to be very much moulded in the image of their leader (Hailey et al, 2002: 404) so ongoing leadership issues are especially critical.

Conversely, externally initiated groups, while generally beginning on a small to medium scale, vary in character depending on the type of external catalyst; donor, parent organisation, international NGO or other. The first programmes may be based on models pre-tested elsewhere or pilot tested *in situ* (Avina, 2002: 128). When foreign funding directs modes of action, or inhibits certain actions (Nogueira, 1987: 170) there may be occasions when it could be asked if a true grassroots organisation is emerging or if it is a donor-driven exercise with the new organisation merely a conduit for funds (Garilao, 1987: 113; Avina, 2002: 129). This is not easily answered when an organisation is in start-up phase as there will be a scant accumulation of experience (Nogueiro, 1987: 170) and it will be aiming to please both the membership and potential funders.

Leadership of an externally initiated organisation varies, depending on the level of influence and input. It is likely, however, to be more professional than the leadership of self-generating organisations. A paid senior position is likely, plus additional paid staff positions, even some international staff or technical assistance from a professional consulting agency. In some cases an institutional model complete with prefabricated administrative and managerial procedures may have been imported to reflect a funder's requirements, with a strong push early on to establish a formal executive structure with clear oversight powers and legal incorporation (Avina, 2002: 128-129).

### *Membership*

The viability and sustainability of any initiative, whether self-generating or externally initiated, is highly dependant on local ownership (Avina, 2002: 130) and understanding the local area (Howes, 1997: 599). While this may be relatively straightforward for self-generating groups, it is less so for externally initiated groups which, through lack of local knowledge, may experience misunderstandings and poor ownership by members, ultimately leading to failure. Local ownership may be achieved in several ways: by meeting with locals, or staff who have resided in the area and can provide wide-ranging knowledge; give time (several months if necessary) for preliminary dialogue with a cross-section of local people, or a more short-term and intensive participatory group approach may be used (Howes, 1997: 599). .

### *Governance*

Limited exposure to modern management structures and practices can mean self-generating groups may follow traditional or semi-formal institutionalised patterns characterised by a low level of administrative sophistication and formal accountability, with for example, accounting and monitoring being rudimentary (Avina, 2002: 127). This will inevitably provide a challenge if the organisation wishes to grow as it will have to work out how to address this gap to secure external funding. Devising an adequate structure not only to fulfill its goals and mandate, but to also satisfy donors, may become a tension. Incumbent in this is the balancing of the role and obligations of members with their expectations of the organisation; and the decision if and when to formally incorporate if the organisation is required to obtain juridical status before qualifying for state funding or assistance from foreign aid agencies (Avina, 2002: 129). In addition, the

philosophical issue of ‘will our organisation be participatory or top-down in style?’ (Avina, 2002: 130) is a critical factor, but one which is often unrecognized by self-generating groups. It would seem to place new organisations into greater positions of strength if they can make such decisions proactively.

Externally initiated organisations generally experience an early and strong push to establish a formal governance structure with clear oversight powers. They are likely to gain legal status earlier than self-generating groups, and thus have a clear charter with rules governing the terms and mandates of officers and employees from a very early stage (Avina, 2002:129). Priorities in governance change over time, which means the composition and functioning of the Board must change also to accommodate the organisation’s life-cycle (Tandon, 2002:219). An externally initiated organisation may reach this point earlier than a self-generated group, but it is a dynamic that will eventually affect both.

The fact that some donors wish to see members playing an active role on the Board, showing ‘beneficiary participation’, often brings about tokenism. Even if there is no tokenism, there will inevitably come a time when the Board needs to acquire greater formality and professionalism with structure and processes. Structural amateurism of a Board made up of voluntary members, even if they are highly committed people, can stifle creativity and slow or halt strategic decision-making if they are not well equipped to do their job. While good at one level, in that it reflects the membership and a voluntary ethos, it does, however, distance the highest level decision-making from the direct professional experience in the organisation (Clark, 1991: 66-67). Tandon states, “this temporal dimension of governance requires understanding and attention if effectiveness and accountability are to be maintained” (2002: 219). However, he gives no hints as to how to achieve this, while maintaining grassroots ownership at governance level.

### *External Relationships*

Links between self-generating organisations and the external environment are minimal in formative stages since by definition self-generating groups are largely unassisted. Levels of contact with private or government agencies vary and depend on a number of factors: leadership, location (urban or rural), organisational mandate, and governmental disposition and

priority (or otherwise) depending on the focus of the new organisation. While new organisations may actively seek external assistance, many are unaware of how to initiate or formalise this process (Avina, 2002: 127). Thus, a small resource base is one of the more indicative aspects of a self-generating organisation during a start-up phase. For example, a service-oriented organisation may be financed by members' contributions, or an income-generation organisation by a portion of members' savings. Following demonstration of an organisation's value, it may receive outside support from private distributors or intermediaries who purchase and market their goods, but conversely, if the new organisation is viewed as a threat, these same intermediaries may seek to undermine it (Avina, 2002: 127).

An externally initiated organisation is likely to be more resilient than a self-generating organisation because of its stronger resource base and external leverage to withstand outside pressures. There is no certainty externally initiated organisations will not make fundamental mistakes at start-up but if they do, they are better positioned to weather crises. However, should they attract broad local interest because of their resource profile, they must realise such attributes cannot preserve an organisation which ultimately fails to meet local needs and interests. It may continue to function for a time without strong local enthusiasm, and this may provide a buffer period to re-engage with local people, but ultimately the organisation will not survive much beyond the duration of its external funding (Avina, 2002: 130).

Higher levels of institutional accountability are generally expected from externally initiated organisations usually due to donor requirements. Heightened accountability will often include a systematic accounting procedure (if not an actual project accountant) and annual external audit of all project expenses. In addition, there are likely to be pre-established systems for project monitoring although the nature and caliber of project monitoring can vary widely, depending on the interest of staff and the rigorousness of the donor (Avina, 2002: 128).

Existing organisations may pose problems. If so identification of conflicting interests is essential and also that the new organisation has the means to manage tensions that may arise. Howes (1999: 28) contends that this may be very demanding for a new organisation as initially it will not have established networks of support. Frequently, funding pressures and tight time

schedules mean few resources are available for understanding existing institutions and nurturing appropriate networks but not doing this can, at worst, spell disaster or, at best, leave the new organisation functioning as a shell. Both self-generating and externally initiated organisations need to know and understand the prevailing external environment and be robust enough to compete in it.

## **GROWING STRONG MEMBERSHIP ORGANISATIONS**

Esman and Uphoff's (1984:35) experience suggests that maintaining effective membership organisations may be more difficult than calling them into existence in the first place. Their seminal study found that the performance of membership organisations depends significantly on supportive interaction with others, especially government agencies who in some places regard any organised activity as potentially subversive. Some governments accept membership organisations but only if they can be effectively controlled by the state: in fact, some governments have suffocated organisations with surveillance and attention so paternalistic they have undermined all local initiative. Local elites often represent another problem given their traditional status and greater education, the contacts they enjoy with officialdom, and control over land and other resources. They tend to perceive organisations of the poor and marginalised as threats to their domination and in some countries are willing to employ organised violence to intimidate or destroy such efforts (Esman and Uphoff, 1984:36).

While some adversity may strengthen a new organisation, too much may prevent its formation, dominate and control those that exist, or allow elites to gain resources intended for poor and marginalised people (Esman and Uphoff, 1984: 36). The development of strong grassroots membership organisations is complicated and uncertain, and a relatively long-term exercise, even when external actors and events appear broadly favourable. The remainder of this section looks at grassroots membership organisations moving from start-up into the next stages of growth and consolidation.

### **Guidelines for Growth**

Identifying guidelines for organisational growth is important according to Esman and Uphoff (1984: 72ff) who give a number of guidelines after researching more than 150 organisations.

### *Effective Planning and Goal Setting*

Esman and Uphoff (1984: 72ff) give effective planning and goal setting first place. Clark (1991: 105) endorses this saying young organisations should be encouraged to chart their own course because success is empowerment, but success in pursuit of the organisation's own plans is doubly so. It is sometimes tempting for external agencies to do the planning, intending to leave ongoing decision-making to the organisation after initial decisions about priorities and programme support have been made. Esman and Uphoff (1984:74-75) explored this in detail concluding that planning and goal-setting should be undertaken by the organisation itself from its inception. They also concluded there may well be extra benefits from involving the wider community if the organisation conducts these tasks in a participatory way, (Esman & Uphoff, 1984: 73) which demonstrates the importance of *process* in planning and goal setting. This links with Carroll's view (1992:78) that participation is both a *process* and a *result*. He clarifies by stating beneficiary involvement in initial decisions, implementation, accountability and resource mobilisation is a *process* of capacity building, and that:

...participation as a *result* is an increase in the beneficiary group's ability to influence decision-making and the extent to which the process has become more regular and institutionalised in terms of norms, procedures and organisational structures (Carroll, 1992: 78).

Carroll further claims:

...[a] participatory style is essential to the strengthening of base capacity... many forms of participation, such as open communication or broad consensus, do not of themselves build capacity. Group capacity, as the term implies, is the ability to act together, not once but consistently, to 'get ahead collectively' (Hirschman 1984 in Carroll, 1992:95).

And, Carroll believes, when participatory ethics and techniques have permeated an organisation they are observable in most day-to-day activities (1992: 85).



Esman and Uphoff's (1984:74-75) opinion is that planning and goal setting require a certain level of sophistication on the part of organisation leaders and members. This seems to indicate that those involved in such positions and processes cannot be from the poorest of the poor, who are often illiterate and without even basic education. Therefore, Carroll's argument becomes valid, that if "...the challenge is to seek out the poorest, the most isolated, the least informed and organised, then the [funder] has to intervene and take a more active role" (1992: 87). While Esman and Uphoff are saying local level planning need not require many technical skills or resources and local knowledge is needed more than scientific training, Carroll is cautioning by stating this may only be possible when working with what he refers to as "not the poorest of the poor" (1992:67), or outside assistance may be necessary. People with leprosy are generally the poorest of the poor.

### *Conflict Management*

According to Esman and Uphoff (1984: 75) managing internal conflict is best performed where least visible, and imperative for retaining group solidarity and achieving common purposes. They contend that when explicit efforts at conflict management come into play it may mean more informal measures have failed. In such situations, sympathetic outsiders may unwittingly become 'hatchet men', doing unpleasant things for leaders who feel constrained by internal kinship and political ties, wanting to remain in the membership's good graces and blame outsiders if necessary (Tendler 1982a in Carroll, 1992:89). Of significance is how the conflict is handled; whether energies are channeled into reconciliation or dissipated in mutual sabotage.

Some conflict within organisations should be regarded as normal, and within limits, as useful if successfully resolved because it can mobilise resources and build larger, broader, and deeper commitment to common purposes (Esman and Uphoff, 1984: 75). Two factors that appear to be associated with successful conflict management are good leadership and the existence of informal modes of organisation. Building good communications skills is also important as the leader may not only need to mobilise and motivate members, but pre-empt misunderstandings by poor or lack of communication (Clark, 1991: 106). Esman and Uphoff (1984:76) warn that inability to manage internal conflict is a key cause of organisational ineffectiveness, therefore learning to deal with it in a timely and appropriate manner should be a priority.

“Expect threats and be prepared to respond” is what Clark (1991: 108) says regarding external conflict. He claims that whenever the poor win a victory it is likely someone more powerful has lost and reprisals can be certain: his experience is in Bangladesh where “these can be particularly vicious” (Clark, 1991: 108). Leaders and members should be prepared for such situations and give whatever defence is necessary. One approach is to develop a political strategy (Clark, 1991: 107) to influence local structures and secure alliances which will stand by the organisation and advocate for justice if tensions break out. Influential allies can be very helpful as well as recognising not all elites are anti poor, which may be a hugely affirming strength to many group members. Forging alliances with other local groups is also beneficial, especially when a bigger battle can only be fought by large numbers of similar groups coming together in coalitions and networks to support each others’ struggle (Clark, 1991:106).

### *Resource Mobilisation*

The third imperative for successful organisational operation is resource management (Esman and Uphoff’s (1984:77). This includes the acquisition of outside resources as well as raising local resources, and realising many organisations may be competing for the same resources (Garilao, 1987:117). Human resources are a case in point. According to Clark (1991:95) one of the main blocks to successful organisational growth is finding the right people and giving them the right training, but when sufficient attention is given to this and organisations have developed an active recruitment and training strategy it has more than paid off.

Resource mobilisation is a relative matter, according to Esman and Uphoff (1984:77), since its value depends on how much or how well it meets the needs of members and their community. Small amounts of resources put to use in alleviating urgent problems can represent great success from the perspective of members so assessments of value best reflect such judgments rather than an absolute amount. Esman and Uphoff (1984:78) also found self-help activities, even if small, are an extremely important part of organisational function because if outside resources only are involved then lack of ownership and poor performance results. Carroll (1992:81) endorses this by stating it is important “to deal with the ‘free rider’ syndrome, members who do not contribute their share [but] expect to benefit anyway from the effort of others”. He reinforces his point by discussing cost recovery and asking why it is so seldom on

the agenda of organisations to charge for services. He provides evidence from his experience showing if a service is reliable, recipients are usually prepared to pay for it (1992:81).

In regard to external resources, Clark (1991: 108) states that “external funders should see their role as pump-primers” because they cannot provide funds indefinitely, and experience shows that groups become stronger when they develop self-reliance because it leads to empowerment. However, where organisations face patriarchal, patronising relationships or class structures, resource management is inevitably more demanding (Howes, 1999: 28). Recognition of paternalism which is likely to inhibit self-help and therefore self reliance, and even undermine patterns of community initiative, is essential.

### *Resource Management*

Fourthly, Esman and Uphoff’s study found resource management had the highest correlation with overall organisational performance and was the most influential (1984:78). They describe resource management as keeping track of funds, collecting loans, maintaining buildings and equipment and so on, and in turn increasing the volume of resources made available to members. Conversely, poor resource management may be poor maintenance or corruption by officers or staff. This means the tasks of resource management and conflict management are related in that organisational conflicts are more likely to arise if there is poor management of local and human resources. Since many reported experiences of poor resource management involve ineffective or dishonest handling of financial resources, this is one area toward which outside training and support efforts could be usefully directed (1984:79). While training is more likely to be effective with regard to skills like bookkeeping or equipment maintenance, than to attitudes, for example, honesty, reinforcing constructive skills and attitudes can be a positive experience.

Resource management is especially important to organisational development if an inspired and strong founder leader steps aside. This is a crucial stage in organisational dynamics where growth, influence and prestige may be forfeited if the organisation is unable to change leaders successfully and rethink its comparative advantage, consolidate its scope and streamline its strategies (Carroll, 1992: 41).

### *Provision and Integration of Services*

According to Esman and Uphoff (1984:79) the provision and integration of services is generally easy to conceive and describe because local organisations are seldom solely responsible for services such as social services. However, they may contribute significantly in conjunction with a government or private agency, even supplementing a service which is limited or incomplete thereby improving benefits. Such integration means organisations are able to increase relevance, timeliness, and efficiency of services even when only involved in their co-ordination. Exceptions are organisations concerned with lobbying or legal redress, or even gaining access to the legal system itself, which is thought to reflect the resistance of bureaucratic agencies to any horizontal input at local level. Carroll (1992: 42-43) adds caution because while NGOs are generally thought to have a superior ability to serve populations that are not reached by public agencies they can often face so many problems and complications in providing services they neglect their broader goals. Thus, services intended as a means, may become the end.

### *Control of Bureaucracy and Claim-Making*

Involvement in the control of bureaucracy and claim-making (Esman and Uphoff, 1984: 80 & 81) is arguably the most difficult. Local members and leaders often know more than central government officials as to what lapses or misdeeds are occurring in programme operations and local organisations are in a much better position to insist on improved performance. With functioning organisations at local level there is room for greater co-ordination, even control, from below which should be able to supplement if not replace the oversight of political and administrative superiors. This depends very much on the goals and values of top political leadership who have it in their power to frustrate, if not always to promote, effective local organisational activity. A government must expect certain costs from claim-making, and even if demands from an organisation are regarded as reasonable by its members, a regime having limited resources or different priorities may consider them excessive and unreasonable. If understanding on both sides is possible, that a government cannot always respond favourably, this will allow continuing dialogue instead of an impasse. Carroll (1992: 122) agrees stating high performing grassroots organisations are adept at identifying, cultivating, maintaining and institutionalising relationships with the public sector, although often these tend to be of an ad hoc nature. He then goes further saying:

...support from people in power is especially important when the organisation moves into areas of conflict, when it touches upon entrenched interests... or when it expands beyond a few isolated communities and begins to look less innocuous (Carroll, 1992: 123).

Allies are particularly important in more repressive or unfriendly regimes so “being able to identify common or mutually compatible objectives and complementary resources is an indispensable skill” (Carroll, 1992: 123).

The guidelines outlined combine and inter-relate in various ways for different organisations as members aim to achieve their own goals of growth and viability and face their own specific dilemmas. However, there appear to be important principles which, if applied, will determine characteristics of grassroots organisations. They include ensuring decision-making is undertaken by grassroots members and that their full participation is recognised as both a process and a result; recognition that some internal conflict can be regarded as normal but must be well managed; valuing both local and external resources and managing them well, especially human resources; and cultivating an adeptness to relate to other organisations, both local and external, plus government, which can provide allies. These principles need to be reinforced by a sound organisational structure.

### **A Structure to Support Growth**

Organisational structure, according to Howes, (1999:8) should fit a large and heterogeneous membership into small base groups with strong horizontal and vertical linkages. He bases this on the probability that a structure should at least cater for some of the members’ needs and improve chances that the multiple sources of their deprivation will be addressed. Where growth continues and horizontal linkages come together, care is needed regarding the transition from informal to formal types of decision-making. Similarly, care is necessary with vertical linkages which need to ensure mechanisms of accountability to both the base and the top are strong and remain intact. Howes (1999:8) goes on to advocate for a participatory assembly for decision making, ideally combined with elements of delegation to committees. Esman and Uphoff (1984: 145) agree, saying one can argue in favour of executive decision-making in the name of

efficiency; however, the more oriented an organisation is to changing the status quo and the more resistance it is likely to face, the more it must speak with one voice and pursue a co-ordinated course of action. This means there must be broad participation in decision-making and implies a great reliability on assemblies.

Esman and Uphoff (1984: 137ff) contend organisational success is closely related to a structure which supports a relatively large number of functions. Their study found organisations that are multifunctional from the beginning are more likely to build up both resources and the commitment from members to operate effectively over time, arguing also that because the needs of the poor are multiple, improvements on only one front are likely to have little effect. This opinion is contrary to that of Tendler (in Esman and Uphoff, 1984:139) who strongly favoured single function organisations with one goal which is achievable in a limited time period. Her argument is that the organisation can continue with other activities once the first goal is achieved. Howes (1999, 29) also believes identifying one initial core activity is the best structure for a new organisation and later moving on from the core activity in a way that enhances organisational development. He believes organisational development is weakest in instances where a range of initiatives have been supported without considering their potential to either exercise a mutually reinforcing effect, or to provide a focus around which the organisation can cohere. Clark (1991:104) talked of starting with 'an activity' people readily relate to, and 'an activity' undoubtedly means one.

Membership, according to Howes (1999:8), is best where entry is by individual choice and involves the acceptance of some obligations to attend, pay dues, make savings or take on other duties. While external resources will generally be required before starting to accept members, these should be limited to the level required to catalyse local action, and should not be so great as to induce a sense of dependence. Esman and Uphoff (1984:159) found highly participatory and egalitarian organisations can register an impressive degree of membership success, even in indifferent or adverse conditions. While an analysis of becoming and remaining a member showed that on the one hand attitudes of members were positive with voluntarism as the basis for membership, with free entry and exit; on the other hand, an organisation's resource base and strength may indeed be greater if members decide to enforce discipline and accountability so

they cannot simply contribute or not as they please. This highlights again the need to deal with the 'free rider' syndrome (Carroll, 1992:81) referred to earlier in this chapter.

## **Leadership**

Good leadership is critical to the success and growth of an organisation. If a leader maintains an ill-defined structure during the growth stage, or decision-making is dictatorial (Clark, 1991:65), then the organisation may stagnate due to the leader's inability to take it further (Garilao, 1987: 115). If a charismatic leader gains a guru-like status, while there may be periods of rapid organisational growth there will be inevitable stagnation when the leader is away, even for short periods, because of dependency on one person. Under charismatic leadership staff often have weak positions and there is a tendency to recruit staff who will follow orders and be in awe of the leader. When new ideas are from one source, a leader, the organisation will not get value from staff and it is unlikely to present career opportunities (Clark, 1991: 68). Even as organisations mature and develop, the importance of leadership in determining how an organisation functions remains paramount: the leader influences organisational culture (Hailey et al, 2002: 404).

A leader committed to participation who shares influence and functions with staff and members, and whose decision-making is a collegial process under-girded with a firm management structure, provides a good leadership model (Clark, 1991: 66). However, there may still be disadvantages. For example, participatory decision-making is slower; and power struggles between competing factions are possible if the organisational vision is not clear and owned by all members. Additionally, achieving a balance which ensures staff feel valued is a major management challenge for [organisations], particularly as they grow in size (Clark: 1991:67).

Developing a mechanism for accountability of a leader to a constituency is vital as there is no guarantee that someone from a humble background (or any background) will continue working for, or persist in advancing the interests of, the disadvantaged. Provision should be made to replace a leader who no longer has the confidence of the majority of members. The more explicit these procedures, the more of a deterrent they are to misconduct and the more easily they can be utilised when needed. While it is often desirable to have informal rather than formal procedures and practices, this is one domain where strong arguments can be made for formal or

at the least very explicit provisions (Uphoff, 1986: 201). Another important factor to understand is that in developing leaders from among the poor, they may be exposed to considerable personal risk. Even an activity which on the surface appears neutral may be viewed negatively by local elites who may retaliate. Leadership training should include dealing with the possibility of threats and how to respond to them (Clark, 1991: 96).

Leadership is a critical factor which affects every aspect of an organisation with the major challenge being to ensure the leader maintains the confidence of the majority of members. In order to deal with succession for whatever reason, having a suitable structure in place for electing a new leader is paramount.

### **Becoming a Learning Organisation**

Learning is an essential component of organisational effectiveness in all sectors – private, public and non-governmental (Edwards, 2002: 331). It is 'reflection-in-action' or 'learning-by-doing' (Schon, 1987 in Edwards, 2002: 333) whereby coaching is more important than training, dialogue replaces teaching and technical problem-solving is placed in a wider context of reflective enquiry (Edwards, 2002: 333). This requires organisations to support staff and members in a process of learning from experience so that skills and abilities are developed continuously and lessons are genuinely learned and used. Clark advocates building awareness raising and empowerment into every process (1991: 104). Strength and momentum are key characteristics of a learning organisation because it is always developing, even if it remains within the limits of local competence and capabilities.

Real learning is seldom easy or comfortable because it implies change and challenge. Superficial learning is common, selective learning is convenient. While no one likes to admit failure, organisational learning is inherently about failure as well as success. However, Carroll (1992: 115) believes it is easy to be trapped in one or the other of two common fallacies: either that the privileged outsiders possess all the scientific knowledge needed for development or that the poor are the repositories of all the wisdom they need, which means many benefits are lost. He says the answer is always a combination of permanent consultation and two-way information flows. If such opportunities are used as carefully constituted processes for learning then there will be



personal and organisational growth and discovery (Edwards, 2002:339) which will contribute to a stronger organisation and a more socially cohesive community.

Organisational performance is best monitored and evaluated in ways whereby all stakeholders can learn from the process, with strong accountability systems both downwards, to the grassroots, and upwards to trustees and donors (Edwards, 2002: 340). However, many donors work within bureaucratic systems that penalise failure more often than they recognise success, so many organisations work against a learning process (Uphoff, 1986: 192) and this gives little incentive for innovation. When evaluations are undertaken in a punitive and judgmental way, looking mainly at compliance issues for donors, learning environments are especially compromised. Carroll claims grassroots organisations “are almost never evaluated on their capacity building performance, and for that reason there is no opportunity to learn what actions under what conditions contribute to the capability of ...groups” (1992: 114). He also argues that:

...the interaction between ‘outsiders’ and ‘insiders’ is a protracted and subtle process that is exceedingly difficult to grasp and to document. Evaluators would have to observe the interactions between support organisations and their beneficiaries for several years following the termination of a project to find out whether project activities had been maintained and expanded or new activities undertaken (Carroll, 1992: 114-115).

Whether or not a grassroots organisation can develop a culture of learning which includes a safe environment to learn from mistakes depends not only on the leadership as learning organisations must have learning leaders (Hailey et al, 2002: 404) but also the requirements of donors. This means donors have a large amount of influence which, if used to reinforce a safe culture for learning rather than a compliance culture, may contribute significantly towards growth and viability.

### **Expanding Training Opportunities**

Uphoff (1986: 197) believes one of the best ways of developing local capabilities is to involve local people in planning and designing their own training. Edwards (2002: 339) who advocates

participatory, experiential learning at grassroots level, endorses this saying, “If learning is not taking place at grassroots level, then other layers...will be defective”. Therefore, if members where possible work out their own training programme, this in itself is valuable training. If needed, ideas about format and content may be drawn from examples developed elsewhere, and outside agencies may be willing to make materials available as a service in support of local organisational development. Taking this route will undoubtedly mean that a ‘trainer’ from outside will be more effective in a ‘facilitator’ or ‘resource person’ role. Undertaking training in rural areas sometimes means logistics and resources are problems, so simplifying programmes and making them less expensive in order to more directly reach greater numbers is a good way forward.

In the past unrealistic expectations have sometimes been directed toward training as if the imparting of knowledge and skills through structured programmes will improve people’s motivation and ability to carry out organisational tasks. Therefore, how can training be made more fruitful? Uphoff (1986: 196-200) makes some useful comments. Training should be more dispersed than concentrated: programmes often recruit one person from a community to attend a conventional training course, expecting him or her to return and relay to others the knowledge gained. However, a concentrated approach such as this is more likely to create monopolies and vulnerabilities within organisations because when only one person has information this can be manipulated to acquire power and advantage. When others share it from the outset incentives as well as opportunities for diffusion are greater. Also, if only one person receives training, then leaves, the organisation receives a setback. Where training is provided to a wider group, including members and leaders, it has more and longer-lasting effects.

As stated previously in this chapter, monitoring and evaluation can be very worthwhile training opportunities. When professionals visit a local organisation, they often provide some of the most valuable instruction these people receive (Uphoff, 1986: 199). Taylor concurs saying “there are many organisational processes and procedures through which the work of individuals is monitored, reviewed or evaluated. Enormous creative energy is released when these occasions can be experienced as opportunities for learning as opposed to opportunities for policing or

‘snoopection’ (Taylor, 2002:351). When real progress and real problems form the basis of totally relevant learning with training to follow, everyone benefits (Uphoff, 1986: 199).

### **External Relationships**

Grassroots organisations are heavily dependent on the nature of external relationships, especially those with funders. According to Howes (1997: 603) relationships appear to work best where a grassroots organisation shapes the initial concept for an intervention and retains effective control over its subsequent development. This, in turn, presupposes an external (international) partner providing necessary financial support in a reasonably flexible and open ended fashion, and supplementing this where required with appropriate technical inputs. While Clark (1991: 103) cautions funders saying that their support “can easily become a barrier obstructing a natural evolution of these groups towards a more permanent self-reliant role” Carroll (1992:87), as mentioned earlier in this chapter, argues that if the poorest, most isolated, least informed and least organised groups of people are being sought, then there needs to be additional intervention on the part of the funder or sponsor who must take a more active role. The dichotomy, however, is that even with the best of intentions, when funders offer guidance and capacity building support, paternalism becomes a possibility (Carroll, 1992:87). Uphoff rightly says “...support given in ways that create dependency or that alienate people is likely to be worse than giving none at all” (1986: 188).

Kajese (1987:81) looks at this from the perspective of an indigenous grassroots organisation and argues that financial aid and technical support should not be the controlling criterion of a partnership. He calls for western organisations to think about whether the word ‘partnership’ is an acceptable term to describe the link between international NGOs and their indigenous counterparts in the Third World. Carroll (1992:88) claims the secret of non-paternalism is “mutuality - in obligations, contributions, and benefits – and the right to question or protest” with mutual legitimacy recognised as part of the exchange. But is such a relationship possible? Kajese cuts to the quick saying that because international NGOs have wealth and status as funders, and indigenous organisations suffer financial poverty and have the status of ‘recipient’, the nature of the partnership is at best benevolent, and at worst malevolent. He claims,

The language of concern for 'effectiveness', 'accountability', 'efficiency', 'professionalism', etc, masks the real language that in fact says 'we have the money and know-how therefore the power'. The [indigenous] NGOs are quite aware that money and know-how spell 'power' in the hands of [western] NGOs. This is a fact, not an accusation (Kajese, 1987:80).

Kajese believes members of indigenous grassroots organisations are trapped by their needs and therefore forced to remain in silent "secure servitude" (1987:81) when they actually want to talk revolution. He talks of participating in "numerous so-called workshops in the South where a significant amount of time is spent on the popular past-time of 'donor-bashing'." (1987: 79). According to Kajese this is symptomatic of relationships where basic principles are either wrong outright; not clearly understood; or widely perceived as unjust, dominating, and exploitative. According to Kajese people at grassroots view participation and self-reliance as involving at least three facets, firstly,

In order to achieve and sustain self-reliant development, peoples' authentic and original ideas, relevant to their situation, must be used as bases for their development. Secondly, local organisational structures through which these ideas are put into effect must be utilised. Thirdly, people should have the right to choose and be able to acquire any outside assistance for their self-determined development (1987:81).

Garilao advocates capacity building (1987:119) and challenges international NGOs not to provide funds to grassroots organisations without an accompanying package to help build their capacity and mobilise local resources (1987:118). In addition, he strongly urges grassroots organisations to develop their own local constituencies and resources to ensure the supply of foreign funding does not become a disincentive for seeking and mobilising local resources. This, he claims, can be a double edged sword: not only is there the trap of dependency, but an organisation may also be distracted from building its own local resource base. He argues strongly that:

If First World resource agencies are interested in contributing to democratic stabilisation in developing countries, they must look beyond the traditional role of resource transfer. They must be prepared to play a role or invest in the capacity building of their local indigenous partners (Garilao, 1987: 119).

Garilao affirms the legitimacy of this stance from his own experience saying it is possible to help a grassroots organisation define what it wants to do without imposing an agenda. This results in members thinking through situations and dilemmas for themselves, articulating what they want, and identifying the strategic role they want to play in the larger picture. According to Korten the grassroots organisation then has 'the ability to position its resources to achieve leverage on larger systems...at all levels' (Korten in Garilao, 1987:119). However, for the poorest of the poor, including resource-poor grassroots leprosy organisations who have little if any leverage, is this realistic? Although Garilao believes so, saying it is a skill of great value to members of an indigenous organisation, it appears possible to contest his point of view.

Fowler argues strongly that use of the word 'partnership' needs reconsidering because it is a subtle form of external power imposition even though it appears benign, inclusive, open, all-embracing and harmonious. He argues it intrinsically precludes other interpretations of reality, options and choices without overtly doing so (2002: 249). A redefinition of partnership, according to Fowler (2002: 251), would need to include at least the following seven factors for it to become anything akin to authentic. Firstly, only start a relationship when there is clarity about why it is wanted and what realistically can and cannot be put into it. Secondly, apply the principle of interdependence, recognising that authentic partnership cannot be an add-on and that must be equally important, although in differing ways, to both partners. Thirdly, assume a contextual, systems approach and perspective, because organisational relationships cannot function in isolation, they exist in a complex dynamic world. Fourthly, adopt an organisational rather than a project focus in order to develop a deep organisational relationship. This means looking at a project as a vehicle to explore relationships, not as the basis of them. Fifth, create processes for local validation and shared control; work against the power asymmetry inherent in many aid relationships by establishing joint processes and structures that produce opportunities for mutuality. Sixth, encourage each partner to invest in their own reform. Authentic

partnership must be a two-way process, therefore donors need to set up internal conditions required to share rather than take and retain control of the weaker partner. The ultimate goal of a partnership is to enable the weaker partner to become strong enough to move from (inevitable) initial dependency through independence to self-chosen interdependence (Kaplan, 1996: 20). Finally, a donor must demonstrate ways in which it may be held accountable otherwise authentic partnership is unlikely to exist.

Although the issues surrounding external relationships are complex and diverse, there is essentially one outcome that would reasonably be the desire of everyone, and that is empowered grassroots membership organisations. But what actually is empowerment and is this possible for grassroots organisations and their members?

## **EMPOWERMENT**

Empowerment entered development dialogue in the mid 1980s when the global economic crisis stirred interest in alternative approaches to development which were focused at grassroots level. It emerged mainly from the writing of Third World feminists and from the grassroots organisational experience of Third World women (Sen and Grown, 1987: 78) and has since been supported by Western academics and development practitioners who have contributed towards its growth. By the mid 1990s a variety of agencies with diverse and contradictory philosophies, such as the World Bank and radical NGOS, had begun to adopt the term and use the language of empowerment (Parpart, 2002: 338) but there were, and still are, many differences in interpretation and practice.

### **What is Empowerment?**

According to Parpart (2002:338-339) mainstream development institutions and their practitioners for the most part envision empowerment as a means for enhancing efficiency and productivity within the status quo rather than as a mechanism for social transformation. Conversely, Rathgeber (1990:493-495) sees beneficiaries of the development process as agents of change rather than passive recipients, therefore, empowerment from below is crucial. Kabeer's contribution to this discussion, while coming from a gender perspective, argues that

the participation of beneficiaries is not enough if the power to define priorities remains at the top (1994: 262).

Rowlands (1997:14) states that “empowerment is more than participation in decision-making; *it must also include the processes that lead people to perceive themselves as able and entitled to make decisions*”. She explores four different types of power: power over; power to; power with; power from within (Rowlands, 1997:20) and then defines empowerment as bringing people who are outside decision-making processes into them so they can maximize the opportunities available without constraints. Rowlands highlights an important concept saying, “From a feminist perspective, interpreting ‘power over’ entails understanding the dynamics of oppression and internalised oppression” (1997: 14). However, internalised oppression is far from limited only to the experiences of women; it also relates directly to the experiences of leprosy-affected people. ‘Power with’ provides a sense of whole-being where a group can tackle problems more effectively than as individuals. ‘Power to’ and ‘power within’ provide transformative understandings of power and “the processes by which people become aware of their own interests and how those relate to the interests of others, in order both to participate from a position of greater strength in decision-making and actually to influence such decisions” (Rowlands, 1997: 14). Furthermore, Rowlands argues that empowerment can be experienced and operate within three dimensions: personal, relational and collective (Rowlands: 1997:15)<sup>6</sup> which relates particularly well to Schuler’s model of levels of empowerment (1986:33)<sup>7</sup> that suggests individual consciousness leads to collective consciousness and to the inclination for people to work for change as they begin to gain skills and organise better. This can develop into political power.

The fact that the word ‘empowerment’ has become development jargon means “an essential objective of participation and its radical, challenging and transformatory edge has been lost” (Cleaver, 2002: 227). In addition, empowerment is often referred to implicitly, rather than explicitly saying who is to be empowered and how this is to occur. Radical empowerment discourse, with its roots in Freirean philosophy, is associated with both individual and class action, with the transformation of structures of subordination through radical changes in law,

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<sup>6</sup> See Appendix 2: “The three dimensions of empowerment” (Rowlands, 1997: 14).

<sup>7</sup> See Appendix 3: “Model of levels of empowerment” (Schuler, 1986: 33).

property rights and institutions of society (Cleaver, 2002:227). However, at a practical level, there may be difficulties in maintaining the interests of very poor people in conscientisation and empowerment when they have pressing short-term needs (Edwards & Hulme, 2002: 65). Despite these problems, achieving empowerment remains a major factor in whether or not poor, socially excluded people, can eventually take responsibility for their own development and self-determination.

Efficiency or empowerment can dichotomise participatory approaches in means and ends classifications (Oakley et al, in Cleaver, 2002: 226). The efficiency approach uses participation as a tool for a better outcome while the empowerment approach believes participation is a process which enhances the capacity of individuals to improve their own lives and facilitate social change to the advantage of disadvantaged or marginalised groups. While participation in itself may be considered empowering by some regardless of the means and ends, many development agencies (funders) are more concerned with efficiency, the achievement of activities in a set time, and quantifiable costs and budgets, with “manageable manifestations of collective action ...commonly cloaked in the rhetoric of empowerment” (Cleaver, 2002: 226).

### **Moser and Empowerment**

Moser (1989) presents a framework, ‘Policy Approaches to Low-Income Third World Women and Gender Planning’<sup>8</sup> for assessing the extent of empowerment gained by women as a result of their involvement in development processes. She discusses differences between practical and strategic needs<sup>9</sup> in policy and practice before reflecting on policy approaches which sit on a linear scale from welfare, equity, anti-poverty, efficiency, to empowerment, and how these shifts in development thinking occurred. While this is a gender framework, the concept seems to fit other minority groups also, especially leprosy-affected people facing social exclusion.

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<sup>8</sup> See Appendix 4: “Policy Approaches to Low-Income Third World Women and Gender Planning” (Moser, 1989).

<sup>9</sup> The basis for frameworks which analyse Practical and Strategic Gender *Interests* was set by Maxine Molyneux (1985) who defined practical interests as dealing with conditions (1985:233), while strategic interests deal with positions (1985:232). Caroline Moser (1989) adapted Molyneux’s ideas so they would be more readily applicable to development planning processes, thereby establishing the concept of Practical and Strategic Gender *Needs*. Practical Needs are addressed by responding to an immediate perceived need which is identified by women in a specific context. Conversely, Strategic Needs challenge unequal, unsatisfactory organisation of society, especially in terms of both the structure and nature of relationships between men and women. This will vary depending on cultural and socio political contexts (1989:1803). Kabeer (1994:90) explains further saying that practical needs are met within existing conditions and structure, while strategic needs challenge structural inequalities and seek to transform women’s positions. She also claims “The distinction between practical and strategic helps to unpack the very real tension between policies which seek to distribute resources in ways that preserve and reinforce these inequalities and those which use women’s everyday practical needs as a starting point to challenging those inequalities”.



The top-down, welfare nature of many development programmes, even though they create dependency rather than promoting self-reliance and independence, remain popular because they are politically safe, and don't question traditionally accepted roles and regimes (Moser, 1989: 1807). They may contribute to meeting practical needs, but strategic needs are not acknowledged or addressed. The equity approach, again a top-down intervention, recognised the practical for a livelihood, plus the strategic need created because all people are not equal. Many development agencies were hostile to equity programmes because they addressed strategic needs and their success depended on a redistribution of power (Moser, 1989: 1810). The anti-poverty approach concentrated on reducing income inequality, hence meeting practical needs. However, the poverty of the minority group was seen as a problem of underdevelopment, not of subordination, and therefore it did not meet strategic needs (Moser, 1989:1811). The efficiency approach wanted more efficient development so more practical needs could be met and this was encouraged by agencies pressuring for an elasticity of time available. Beneficiaries were seen entirely in terms of delivery capacity and their ability to extend their working day (Moser, 1989: 1813).

The empowerment approach arose from the failure of other approaches, and emerged from Third World women's writings and their experiences of grassroots organisations (Moser: 1989, 1815). It aims to empower people through greater self-reliance: subordination is seen not only as a problem of men and women, elites and poor, but also of colonial and neo-colonial oppression. Strategic needs are met indirectly through bottom-up mobilisation around practical needs, as a means to confront oppression.

### **DAWN and SEWA**

It is interesting to see Moser's references to DAWN<sup>10</sup> and SEWA<sup>11</sup> in India, two successful Third World women's grassroots organisations. Moser contends that:

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<sup>10</sup> DAWN (Development Alternatives with Women for a New Era) is an organisation of women activists, researchers and policy-makers from the Third World. Meeting from 1984 they were concerned with shaping a vision of society "...free from all forms of oppression by gender, class, race, and nation' (Sen and Grown, 1987:9).

<sup>11</sup> SEWA (Self Employed Women's Association) is a union of India's poorest women, most of whom are self-employed. SEWA brings about change by organisation and collective action, not only agitating against conditions, but advocating for their positive vision of a society which, if it had alternative structures, could positively create this reality (Rose: 1992:23).

...the origins of the empowerment approach are derived less from the research of First World women, and more from the emergent feminist writings and grassroots organisation experience of Third World women” (1989: 1815).

DAWN was established as a bottom-up organisation for women, to raise their consciousness and challenge subordination. They distinguished between strategic needs, usually long-term, such as breaking down structures of inequality between genders, classes and ethnicity; and practical needs, mostly short-term, and responding to current crises. SEWA was established by a group of self-employed women labourers, initially struggling against low wages and exploitation by middlemen, and police harassment. Initially SEWA linked with a male dominated Textile Labour Association (TLA), began a bank and provided support for low-income women, but as they grew TLA leaders felt threatened and disassociated from them. This strengthened SEWA’s resolve to continue fighting for members’ rights: it survived considerable setbacks but has not been eliminated, growing into a powerful grassroots organisation. Members of both DAWN and SEWA acknowledge that empowering themselves through organisation has been a slow process, but they have remained committed to their goals and are now recognised worldwide as successful grassroots organisations *which have empowered members*.

From DAWN and SEWA’s experience the most effective way of beginning is to address practical needs such as health or employment, but to simultaneously and strategically challenge structures, legislation, human rights abuses, etc, which would otherwise reinforce subordination and poverty. Many projects may incorporate aspects of two or three approaches discussed; however, the important factor is the realization of implications that may arise from supporting a particular approach or combination of approaches. It should also be recognised that by addressing strategic needs, as referred to in the empowerment approach, there may be possible consequences so risk analysis and plans to deal with conflicts which may arise are essential.

### **Grassroots Development Framework**

Ritchey-Vance (2002: 308-310) looks at the results of effective grassroots organisations, highlighting social capital as an important yardstick for measuring developmental success and empowerment. During her involvement with the Inter-American Foundation (IAF) in Latin

American neighbourhood and peasant associations a basic Grassroots Development Framework<sup>12</sup> was debated and developed. The premise of the framework is that grassroots development produces results on three levels: direct beneficiaries, strengthening organisations, and broader impact. Within each level there are two categories (one tangible, the other intangible) of which each in turn is defined by a set of concepts or 'variables' (twenty-two in all) that attempt to capture each category's essence.

The important factor is that the variables track results, not activities, thus measuring the social capital<sup>13</sup> produced. The conical shape that gives the framework its nick-name 'the Cone' represents the widening impact of grassroots development from the individual through the organisation to the community and then to the society at large. All the facets of the framework are interconnected and there is a constant flow among them.

Ritchey-Vance explains further,

...the balance among the variables is key. Strategic planning capability, for example, is an important achievement at the organisational level. But if it is not accompanied by a clear vision of where the organisation is going, planning becomes a sterile exercise. Mobilisation of resources is also key, but if the organisation compromises its autonomy in the process it may become ineffective in the long run. Participation, empowerment and sustainability are the basic

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<sup>12</sup> See Appendix 5: Grassroots Development Framework, Diagrams 1 & 2: Ritchey-Vance in Edwards & Fowler (2002:308).

<sup>13</sup> The social capital referred to by Ritchey-Vance is based on work done by Robert Putnam in Italy who stated 'The historical record strongly suggests that the successful communities became rich because they were civic, not the other way around'. Putnam demonstrated that neighbourhood associations, sports clubs, etc, are not just a nice by-product of social and economic prosperity; they are essential underpinnings of it. His conclusions regarding the relationship between democracy, development and civicism resound far beyond Italy's borders to countries in both the developed and developing world with profound implications for grassroots development projects, particularly the way in which the development community gauges its impact:

Similar to the notions of physical and human capital, the term 'social capital' refers to features of social organisations – such as networks, norms and trust – that increase a society's productive potential. Though largely neglected in discussions of public policy, social capital substantially enhances returns to investments in physical and human capital...The implications for social and economic policy are far-reaching... Unlike conventional capital, social capital is a public good in that it is not the private property of those who benefit from it (Putnam in Ritchey-Vance, 2002:308 & 313).

If fostering civic and social capital is important for development, then the yardstick for measuring developmental success needs to be recalibrated to take this into account (Ritchey-Vance, 2002:308).

tenets undergirding the framework, although they do not appear explicitly (2002:310).

While the framework intentionally breaks down abstract concepts into more concrete and measurable components so that increased social capital can be more adequately measured, Ritchey-Vance (2002:315) admits there are shortcomings and more work needs to be done, especially in relation to issues of gender. And as with any attempt to systemize project monitoring and evaluation, there are caveats: care must be taken not to use the framework as a prescriptive device rather than an organising principle; check the boxes, rather than to broaden understanding; overcomplicate, by proliferating the number of variables and indicators; lose sight of the forest (understanding the process) for the trees (only reporting numbers); and let the tail wag the dog, skewing projects and programmes to accommodate 'the system'.

The measurement of social capital, which Ritchey-Vance contends is more than tangible, quantifiable results, is important because,

...poverty isn't just the lack of material goods. It is also distance from decision-making and a sense of being devalued which manifests itself as apathy, anger and a weakening of the civic culture. The kind of short-term, tangible results that satisfy planners and funders may mask the symptoms of under-development. Recognising and measuring progress towards real solutions calls for imagination, creativity and a willingness to take the long view (Ritchey-Vance, 2002:317).

Consideration of Ritchey-Vance's Grassroots Development Framework along with Moser's approach to empowerment (including awareness of both practical and strategic issues), may more fully help answer the question as to whether collective action through membership of grassroots leprosy organisations contributes to the empowerment of members. Alone each framework identifies important components, but taken together, they provide a good yardstick to establish the extent of the change.

## **EMPOWERED GRASSROOTS MEMBERSHIP ORGANISATIONS**

From this literature review of grassroots membership organisations in the developing world it would appear collective identity and solidarity through membership can contribute to the empowerment of members, provided there is effective leadership that understands and utilises a participatory, bottom-up model of development. In terms of sustainability, members (both female and male) must be encouraged to participate in decision-making processes in order to take ownership of their own development, and to feel a strong connection and sense of belonging to the organisation: their organisation. Empowerment is a process towards which members move as they deal with the destruction of oppression, especially internalised oppression. The collective action that enables 'power with' strengthens members as they reclaim personal 'power to' and 'power within', subsequently perceiving themselves as able and entitled to make decisions. Learning opportunities and new knowledge contribute to the empowerment process, providing strength and motivation to members to challenge their situation of poverty and the social exclusion which has trapped them. But for true sustainable empowerment of their members, these grassroots organisations need to develop according to locally-determined understanding rather than outside-imposed ideals or models.

Leprosy, as discussed in Chapter Two, leaves a person disempowered. Is it possible that membership in a grassroots leprosy organisation can bring about empowerment for its members? This question is best addressed in a specific context rather than theoretically, since the answers may depend on the circumstances and beliefs of those involved.

Two local grassroots leprosy organisations, ENAELP and HANDA, are set within the greater context of their own developing countries, Ethiopia and China respectively, and thus are likely to exemplify the dynamics in local-level grassroots membership organisations. Both organisations provide an opportunity to explore in detail the reasons for their emergence and processes of growth, plus the challenges they face in attempting to reconcile their own development goals of social inclusion and empowerment for members.

## **CHAPTER 4:**

### **ENAELP and Leprosy in Ethiopia**

*“Our exclusion has been taken for granted in the cultures, religions and languages  
of society for generations”.*

*Ato Arega Kassa <sup>14</sup>, Ethiopia*

This chapter begins with a brief introduction of Ethiopia and a succinct background on leprosy in that country. Then I give a comprehensive view of my case study of the Ethiopian National Association of Ex-Leprosy Patients (ENAELP). Through the exploration of ENAELP this chapter will illustrate that many features of a grassroots leprosy organisation are similar to general grassroots membership organisations, as discussed in Chapter Three. Although members of both are usually poor, disadvantaged people, the main difference is the extent to which members are disadvantaged, with leprosy-affected people generally living in far worse situations. This chapter gives voice to the life-stories of some leprosy-affected people, providing them with the opportunity to speak out about the abuse and deprivation they have faced, and their fight for survival.

Having explored social exclusion as part of Chapter Two about leprosy, and empowerment issues in Chapter Three’s discussion about grassroots membership organisations, we see in this chapter how a combination of concepts and activities brought together by disadvantaged, disabled, leprosy-affected people are helping them achieve measures of social inclusion and empowerment. From my experience it appears that international anti-leprosy organisations have traditionally believed welfare assistance is the only way to adequately help and provide for leprosy-affected people: therefore, this chapter contains revolutionary information. It describes the collective action of ENAELP members and how they are bringing about change as they make decisions regarding their own development and their involvement in it. ENAELP members are reclaiming hope for their future as they challenge deeply embedded social exclusion and uproot the internalised oppression which has held their bodies and souls captive for generations. So, is ENAELP as a grassroots leprosy organisation, making a difference for its members? This case study seems to be indicating the answer is yes.

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<sup>14</sup> Ato Arega Kassa: Former Chair of ENAELP

## INTRODUCING ETHIOPIA

Ethiopia, located on the horn of Africa, is one of the world's oldest Christian civilizations, and with the longest paleontological record of any country on earth it is often said to be the 'cradle of humanity' (Lonely Planet, 2003: 15). With a land area of 1,098,000 square kilometres, Ethiopia measures five times the size of Britain. Topography is diverse ranging from twenty mountains peaking above 4,000 metres to one of the lowest points on the earth's surface; the infamous Danakil Depression, which lies about 120 metres below sea level. There are two principal geographical zones: the cool highlands and the hot lowlands.

**Figure 4.1** Map of Ethiopia and Locator Map



The mountains are the source of four river systems, the most famous being the Blue Nile which is joined later in Sudan by the White Nile. The other principal rivers are the Awash, Omo and Wabe Shebele. The Rift Valley bisects Southern Ethiopia diagonally; it averages approximately fifty kilometres in width and runs down to Mozambique (Lonely Planet, 2003: 29).

The population of Ethiopia, still largely rural based, was expected to reach 113 million in 2005, with half of this number less than twenty years of age (Lonely Planet, 2003: 37). Addis Ababa, the capital city, has a population of some 5 million people (Lonely Planet, 2003: 103). Like many other African countries, Ethiopia is multi-ethnic with approximately 83 languages and 200 dialects. The main language is Amharic. English is the most widely spoken foreign language (Lonely Planet, 2003: 37). The local currency is Ethiopian Birr which at present has an exchange rate of approximately US\$1 = 8.85 Ethiopian Birr. The economy suffers from two major and persistent weaknesses: food insecurity and a near total dependency on coffee for foreign exchange earnings.

## **LEPROSY IN ETHIOPIA**

Ethiopia has suffered for centuries from leprosy and is said to be one of the countries most seriously affected by it (P. Mérab in Pankhurst, 1984: 57). Francisco Alvaers, a sixteenth century Portuguese priest was the first foreigner to write that Ethiopia “was inhabited by many lepers” (Beckingham and Huntingford in Pankhurst, 1984: 57). According to Pankhurst (1984: 57), there were numerous observers in the nineteenth and early twentieth centuries indicating leprosy remained a problem. It was claimed by one twentieth century author “that some of his Ethiopian friends believed that many lepers concealed their disease” (P. Mérab in Pankhurst, 1984: 58). This indicates that leprosy-related stigma existed at that time.

According to Pankhurst in pre-nineteenth century Ethiopia, possibly due to Biblical ideas or legend, leprosy was a theme of miraculous cures and this recurs in Ethiopian literature. Cures are attributed to Christ (Budge in Pankhurst, 1984:60); the Virgin Mary (Budge in Pankhurst, 1984:60); and to various saints (Budge in Pankhurst, 1984: 60). One saint to whom prayers were frequently offered was Gabra Krestos, due to popular belief his skin disease was leprosy. Legend has it that the saint, wishing to ‘live a blessed life’, gave ‘all his wealth to the poor people



and asked God to give him leprosy to suffer like Jesus Christ'. The Lord accordingly 'gave him leprosy', and as a result Ethiopian people with leprosy revere him as their patron saint <sup>15</sup> (Budge & Schneider in Pankhurst, 1984: 68).

Today the people of Ethiopia often believe leprosy is 'God-given', possibly due to high respect for Orthodox Christianity which is their main religion. Often they consider leprosy is a punishment for an evil committed in the past. However, there are other beliefs about leprosy, including its relationship to witchcraft; that it is a visitation of sins from a past life; it results from eating certain kinds of foods; or that it is a hereditary disease (ENAELP 2001). There is no question that the stigma surrounding leprosy today is intense with leprosy-related disabilities exposing an individual to harsh treatment from their community, sometimes even murder (ENAELP 2001). Such societal reactions have a negative impact on people's dignity, with a subsequent development of anger, distress, and aggression, and they may live away from those who know them, often in an area with other leprosy-affected people (Field Notes. 2004). The relationship between culture and health related beliefs and behaviour is complex. Personal experience, family attitude and group beliefs interact to provide an underlying structure for decision-making during illness. People who have had leprosy talked of visiting traditional healers, going to holy water, and visiting general health clinics before seeking modern leprosy treatment (Field Notes.2004). However, if people sought treatment early in the areas where treatment is available, rather than delaying for short-term social advantage, they could prevent much of the disability caused by leprosy. There is evidence that of the people whose initial and early contact was with leprosy related health services, many were saved from disability. Conversely, those who went initially to traditional healers, only seeking help at a leprosy clinic or hospital when the disease worsened or the treatment was obviously ineffective, were left with permanent disability (Amenul, et. al. 2000).

Of significance is ALERT Leprosy Hospital and Training Centre (All Africa Leprosy and Rehabilitation Training Centre) in Addis Ababa. ALERT was established in 1965 by a group of international anti-leprosy NGOs (including The Leprosy Mission International) all of whom are

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<sup>15</sup> Though all traditions assert that Gabra Krestos suffered from some kind of skin disease the written texts do not actually specify that it was leprosy. See his life, *Gadl Gabra Krestos be Ge'ezena ba Amareñña*, Addis Ababa, 1958, Ethiopian Calendar.

members of ILEP<sup>16</sup>, along with the Ethiopian Ministry of Health. ALERT's purpose was to provide leprosy training for health workers from all over Africa. It evolved from the Zenbework Memorial Hospital, one of two leprosy hospitals in Ethiopia at that time<sup>17</sup>, and was located on the same site. People with leprosy were attracted to the Zenbework area of Addis Ababa for more than a century to wash in the local spring which was considered holy. In 1944, after returning from exile, Emperor Haile Selassie established the Zenbework Memorial Hospital, naming it after his daughter Princess Zenbework. A leprosy community grew around the hospital made up of people who had come from all regions of Ethiopia; many people stayed after concluding their leprosy treatment because they felt unable to return home. This community quickly grew with new arrivals from around Ethiopia and new generations born into the area. Today a conservative figure of some 20,000 people live there. Leprosy has significantly disabled at least 3,000 of these people and indirectly it affects nearly all of the others in some way (ENAELP, 2001). Notably, the local Orthodox Christian church in the Zenbework community is named Gabra Krestos, after the so-called 'leprosy' saint.

Some forty years ago, in an attempt to limit the size of the Zenbework community, the government forcibly moved many people with leprosy to remote, isolated areas where they were left to survive the best they could in difficult situations. Two examples of this are when in 1954 some 1,000 people were sent to Addis Hiwot and Tesfa Hiwot in Oromiya desert region: this settlement now numbers more than 5,000; and during the 1950s some 7,000 people were settled in Kuyara near Shashamane and this settlement now numbers some 35,000 (ENAELP, 2005).

The people remaining in the Zenbework area relied heavily on ALERT and the facilities it provided, and it is reasonable to say a dependency attitude formed with local leprosy-affected people enjoying access to free, on-demand healthcare. Within the leprosy community itself there was less stigma than in public city areas, so for some years even though they lived in very basic housing and had to beg to survive, many of their health needs were met. However, ALERT began change its *modus operandi* when donors changed policy and this meant fewer benefits for

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<sup>16</sup> ILEP: International Federation of Anti-Leprosy Organisations. See [www.ilep.org.uk](http://www.ilep.org.uk)

<sup>17</sup> Harar was the location of Ethiopia's first leprosarium, founded by the local governor, Emperor Menilek's cousin Ras Makonnen in 1901 (Pankhurst, 1984: 71).

the leprosy community, and the people did not like it. This proved to be a catalyst from which ENAELP emerged.

### **ENAELP: A CASE STUDY**

ENAELP is a secular, non-profit membership organisation made up of people affected by leprosy. The name ENAELP is an acronym for Ethiopian National Association of Ex-Leprosy Patients. ENAELP's membership totals more than 15,000 people spread throughout seven regions of Ethiopia. The gender ratio is approximately 60% male and 40% female. Members pay a fee of between Birr 6 - 12 per person, per year, depending on their financial position and ability to pay.

### **Formation of ENAELP**

The formation of ENAELP began in 1992 when a group of leprosy-affected people living in the Zenbework leprosy settlement on the outskirts of Addis Ababa became upset and angry by changes made to medical services provided by ALERT Leprosy Hospital where they had enjoyed free healthcare for many years. ALERT's donors found they had to restructure their funding arrangements because the system they were operating was costly and unsustainable, but the leprosy-affected people could not understand such problems and wanted the healthcare to continue without change. They also wanted greater recognition socially in order to gain equal rights with other Ethiopian citizens, especially in relation to employment opportunities. This resulted in the group visiting the Minister of Health, the first time such an endeavour was possible, following the fall of the *Derg*<sup>18</sup>. Prior to 1992 Ethiopian people had lived under governments that did not allow people to speak out, particularly against government policy.

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<sup>18</sup> The *Derg* (or Committee) came to power in Ethiopia in 1974 after teacher, student and taxi strikes broke out in Addis Ababa. The Prime Minister and his cabinet resigned and a new one was appointed with the mandate to carry out far-reaching constitutional reforms. But it was too late, and an increasingly powerful and radical military group had emerged, the *Derg*, who replaced the Prime Minister with their own. Gaining in power they arrested nobles and close confidants of the Emperor, and finally with skillful use of the media they undermined the Emperor himself, and his divine right of rule, finishing the century-old imperial dynasty forever. The *Derg* declared a socialist state in December 1975 and began carrying out revolutionary reforms. There was opposition to the *Derg* in various forms from its inception and this culminated in an unsuccessful *coup d'etat* in 1989. Opposition parties during this time consisted of the Marxist EPRP and various ethnically based regional liberation movements, including those of the Afar, Oromo, Somali and Tigrayan people. In 1984-5 another famine followed a drought, in which hundreds of thousands more people died. Failed government resettlement campaigns, communal farms and 'villagisation' programmes aggravated the disaster. Opposition groups united to form the Ethiopian People's Revolutionary Democratic Front (EPRDF), which in 1989, began its historic march towards Addis Ababa. After the war of liberation from the *Derg* a transitional charter was endorsed in 1991, with extensive economic reforms beginning in 1992, mainly along linguistic-ethnic lines. In August 1995, the Federal Democratic Republic of Ethiopia was proclaimed, a series of elections followed, and the second republic in Ethiopia's history was inaugurated (Lonely Planet, 2003:27-28).

Informal advice from the Minister of Health was to form an association and apply for registration as an official entity in Ethiopia. Thus, the Addis Ababa Association of Ex-Leprosy Patients was born. According to the first Chair of ENAELP, it took more than a year to prepare the application required by the Ministry of Justice which included drawing up Bye-Laws for the new organisation (Field Notes. 2004). By 1996 the Addis Ababa Association felt it had developed sufficiently to become a national organisation so they began moving into regions where it was believed more than 80,000 people were living with the disabling effects of leprosy. As a result, the ENAELP came into being and the Ethiopian Ministry of Justice officially registered ENAELP as a non-government organisation in 1996, certificate number 338.

## Figure 4.2 ENAELP Objectives

### ENAELP Objectives:

- To advocate for equal opportunity and full participation of persons affected by leprosy in their community.
- To create awareness in society about leprosy, and persons affected by it, and to bring about a change of attitude in collaboration with government organisations and NGOs.
- To rehabilitate persons affected by leprosy by breaking cultural, social and economic shackles so they can become productive citizens in society.
- To work in partnership with government organisations and NGOs in the fight against leprosy and leprosy related problems.

**Source:** ENAELP Annual Bulletin: 'The Truth': No. 4 January 2003, p.37

## Leadership

ENAELP's original Chair, Ato<sup>19</sup> Arega Kassa, a telecommunications technician, realised he had leprosy in 1963 at 27 years of age. There was no fully effective cure for leprosy in his early years, and Ato Arega was initially unaware of disabilities relating to leprosy and how they would affect his life. He fought to retain his position in Ethiopia's Telecommunications Authority, where he worked for 36 years, and suffered very much from leprosy-related stigma. Over time he became a double amputee, but even with artificial legs, continued to walk as well as any able-bodied person. Latterly he lost much of his sight, a disability caused by leprosy bacteria destroying eye

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<sup>19</sup> Ato is Amharic for Mr

muscles: without blinking, the eyes become dry, dust particles cause damage, and in the long-term, sight is compromised or lost completely.

Ato Arega gave me copies of eleven letters marked “Top Secret” and “Urgent” sent between 1972 and 1989 by his employer to the Medical Board of ALERT Hospital repeatedly asking for medical examinations and proof that his “condition” was not communicable and he was no threat to other employees. Although initially Ato Arega’s treatment was Dapsone, known as mono-therapy, tests showed it had arrested the leprosy bacteria in his body and doctors at ALERT Hospital responded appropriately with official documentation each time they received a letter. However, Ato Arega continued to be harassed by his employer for the majority of his working life. This tenacity is what he brought to ENAELP in its early days when he, as one of the original group, was duly elected Chair, a position he held until 2001.

As Chair, Ato Arega prepared ENAELP’s first constitution, achieving this by referring to copies of constitutions from two other disabled associations in Addis Ababa. In addition he requested and received helpful advice from other agencies; in particular, ALERT Hospital provided technical advice; the German Leprosy Relief Association (Ethiopia) provided financial advice; and the Ministry of Labour and Social Affairs (MOLSA) gave support with general advice. It was Ato Arega’s opinion that MOLSA gave invaluable advice, which combined with that from other professionals working for organisations involved in leprosy or disability, enabled them to prepare the formal documents they needed to set up as an organisation.

During Ato Arega’s time as Chair, ENAELP employed their first fulltime professional staff member. Together they traveled throughout Ethiopia, setting up new Regional and Local Associations. During my interview of Ato Arega, he said, “It was a great challenge traveling throughout the country with such disability as a double amputee and with poor eyesight” (Field Notes.). There is no doubt this man’s energy and dynamism contributed hugely to ENAELP’s growth and to their visibility as an indigenous organisation in Ethiopia. Ato Arega’s experiences of ongoing stigma throughout his working life, plus the level of leprosy-related disability he faced on a daily basis, produced within him a fighting spirit to work towards changing public attitudes towards the disease.

Sadly the very strength and determination which was so positive and essential in ENAELP's formation became a vice as Ato Arega became an increasingly dictatorial leader. His time as Chair ended with a coup d' état by members at the General Assembly in early 2002 who replaced him with the Vice Chair, a tiny energetic woman named W/ro<sup>20</sup> Birke Ngatu. By all accounts this was a difficult time for ENAELP because some six months prior their senior professional staff member had resigned due to difficulties working with Ato Arega. At the time of this case study, participants who had been part of these traumatic events still spoke of them with huge amounts of feeling and emotion: it seemed this may have had the potential to damage ENAELP irreparably. Comments from participants included, "We don't want a one-man leadership"; "Even though we are uneducated we want participation and democracy"; "A one-man say is not an association"; "It is not right for one person to make all the decisions"; "We need common decisions, a Chair should be a co-ordinator and reflect the people's voice".

The new Chair, W/ro Birke Ngatu, with strong leadership qualities appears to genuinely promote full participation of members. In particular she seeks to provide meaningful opportunity for women's involvement at all levels of ENAELP. Having had leprosy since age six, and being abandoned by her family, she has not only experienced discrimination and stigma, but has permanent disability caused by the disease. She said:

The problem of leprosy affected people is my own problem. I don't want to see them begging, living isolated from their families. I want them to develop confidence to ask for their rights and to be free from discrimination. I want them to be able to work in employment so they can contribute to our country just like anyone else" (Field Notes.2004).

While W/ro Birke has a soft heart for leprosy-affected people, she is also feisty and strong in spirit, well able to lead ENAELP by example, but not allowing anyone to mistreat or exploit her as she does so. Her strong Orthodox faith in God appears to be a major factor in her life and one which provides her with the ability to remain steadfast in all that comes her way. From my

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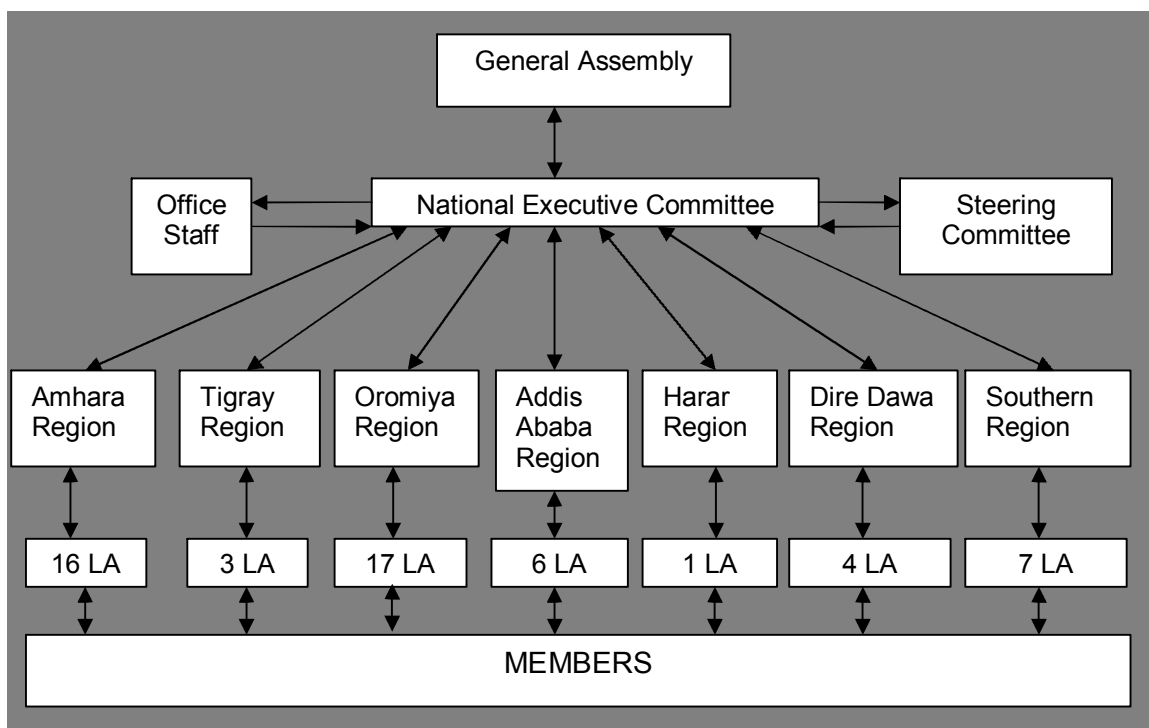
<sup>20</sup> W/ro is Amharic for Mrs

knowledge of her over the last few years and again through this case study, I know she has been through turbulent times. Recently widowed and now sole provider for herself and three of her four daughters, life for W/ro Birke hasn't got easier. But rather than find a paying job, or resorting to begging, she insists on remaining ENAELP's Chair, in an honorary capacity.

### Structure

ENAELP's structure (see Figure 4.3) prior to 2005 included a General Assembly, National Executive Committee and Steering Committee supported by office staff based in the national office in Addis Ababa. In addition there are seven Regional Associations, all of which have varying numbers of Local Associations (fifty-four in total) in their region.

**Figure 4.3 Organisational Structure of ENAELP**



**Source:** ENAELP Evaluation Report, 3 May 2004.

*LA = Local Association*

A positive view of leprosy settlements is that people with leprosy in Ethiopia are grouped in communities rather than being scattered, as is the case in many other African and Asian countries. Hence it is relatively easy for ENAELP to identify and meet with potential members and continue meaningful and regular contact with them. The Chair, staff and various members

of the Executive Committee travel quite frequently to these settlements as it is vital for good communication between the national office and branch members.

As a follow-up to recommendations made in an Evaluation of ENAELP (ENAELP, 2004b) undertaken from 1– 13 February 2004, ENAELP began a review of its structure. I discuss this further in the section on Governance.

## **Staff**

Staff numbers increased with ENAELP's growth and at the time of this case study there were five fulltime professional office staff in paid employment: (male) Managing Director (Degree in Agricultural Engineering from Alamaya University in Harar); two (one male/one female) Project Co-ordinators (BA); (male) Office Co-ordinator (Diploma holder); (female) Office Secretary (Certificate holder). In addition, six (four male/two female) Social Promoters (high school graduates) based strategically in the regions to undertake fieldwork. Also high school graduates, based at the national office, are one female cashier; one male store clerk; one male driver. Other staff, with minimal education: one female cleaner; and four male guards, are based at the national office.

Of the professional staff, two have a leprosy background with parents having had the disease<sup>21</sup>. All six Social Promoters have a parent or relatives with the disease. In addition, all eight of the remaining staff (cashier, store clerk, driver, cleaner and guards) have had leprosy and have varying degrees of disability from minimal and unnoticeable to extensive and very noticeable.

The current Managing Director, Ato Menberu Adane, returned to ENAELP in July 2004, having resigned his position in mid 2001 during the time of Ato Arega, the original Chair. In the period between mid 2001 and early 2004 another male professional was in fulltime paid employment as Managing Director, although the title pre July 2004 was that of Senior Office Co-ordinator. In the two and a half years he was at ENAELP's helm the organisation appeared to drift because of minimal leadership and in early 2004 it became apparent his lack of initiative was causing ENAELP to miss opportunities. The Leprosy Mission New Zealand, a funding

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<sup>21</sup> This includes the Managing Director whose father had leprosy and the Office Secretary whose mother had leprosy.



partner, noticed this problem because of late reporting and an almost nil response to email and telephone communication.

The routine Evaluation (ENAELP, 2004b) conducted by The Leprosy Mission International from 1-13 February 2004 also identified problems in regard to the senior professional staff person. Tensions were identified between the Executive Committee (governing body) and staff, and the working environment in the national office was difficult with de-motivated staff being a major negative finding. Also identified was a lack of office protocols and management systems, no position descriptions for the professional staff, and a lack of capacity and motivation to meet the expectations of the regional and local associations. In addition, some of the paid staff (cashier, store clerk and one social promoter) were simultaneously on the Executive Committee causing a mixing of roles and responsibilities between operations and governance, the end result being one of mistrust. With the senior staff person apparently negating his role the Executive Committee believed they were responsible, by default, for giving orders to the staff. It remains an unanswered question as to whether the Executive Committee, with the mix of some of them also working in the national office as paid staff, in fact contributed to the breakdown of the operational systems and the ensuing negligence of the senior professional, or whether it was the other way around. The Executive Committee asked the senior professional to leave the organisation, and a process according to Ethiopian Labour Law was set in place with the help of a Steering Committee member. He left in April 2004.

Since the return of Ato Menberu Adane as Managing Director in July 2004 there have been a series of inherited issues for him to deal with, mainly in the area of delineating where operations and governance best sits and how the formal setting up of operational and governance policy can enable ENAELP to grow. As it turned out, during the time of my field visit in October 2004 there was again a period of tension for ENAELP as they came to terms with these issues. I discuss the process they went through, and the outcomes, in the section on Governance (below).

## **Governance**

The National Executive Committee is the governing body of ENAELP, made up of elected members from Local Associations. Elections take place at the Annual General Assembly. With

ENAELP originally set up as the Addis Ababa Association of Ex Leprosy Patients, elected National Executive members heavily represented the Addis Ababa region, and in particular, one Local Association. This disproportionate representation, as well as three elected members from the same Local Association also on staff, meant there were key issues with which ENAELP had to grapple: not least that the Treasurer was also on paid staff as office cashier. Following negative experiences National Executive Committee members had had with the previous Chair and senior staff person, it was not easy for them to trust the new Managing Director. Although he had formerly worked well with them and had a history of leprosy in his family they needed to place their trust in him if ENAELP was to survive.

With allegations of misappropriation of funds, The Leprosy Mission New Zealand felt obliged to intervene, saying that unless a resolution was reached they were unable to remit further funding to ENAELP from NZAID / VASS<sup>22</sup>. It was only when the National Executive Committee understood the significance of this that a process of change began. For The Leprosy Mission New Zealand, it was a difficult time as they did not want to be ‘the funder with a big stick’. For the new Managing Director it was a difficult time, because he felt he was Managing Director in name only, with no authority to undertake his work. For the National Executive Committee, we cannot underestimate the difficult period it was for them also, because ENAELP was *their* organisation and as people badly marginalised by leprosy, they wanted to retain their newly found positions, any prestige they had acquired, and to continue to be part of a credible growing organisation. Word got around and many stakeholders, including members in the regions, heard ENAELP was in crisis. They knew that if this organisation was to survive, it needed urgent and transparent change.

Many discussions took place, and W/ro Birke, Chair, and Ato Menberu, Managing Director, worked together providing clear role models and encouraging an environment of trust. These two individuals not only spent many hours with the Executive Committee and other ENAELP members around Addis Ababa, they also traveled extensively to the regions talking with the membership. It was a remarkable feat: they managed to explain the situation and outline their proposed methods of change in such a way that the majority of ENAELP members (some 15,000

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<sup>22</sup> VASS (Voluntary Agency Support Scheme), a programme of New Zealand Aid from which New Zealand non government organisations can access development funding if projects meet certain criteria.

people), accepted the proposal. The key difference was to ensure representation of members in the regions and every Local Association applauded this recommendation.

To achieve these changes, ENAELP's Bye Laws needed revising. The first revision was in relation to representation and elections at the Annual General Assembly. It was agreed two people (one male and one female) should be elected from each of the seven regions to make up the National Executive Committee, with only office bearers (Chair, Vice Chair, and Secretary) being resident in Addis Ababa. In addition, Ato Menberu and the National Executive Committee reviewed and amended sections in the Bye Laws referring to finance, purchases, property administration and personnel guidelines. Submission of ENAELP's new Bye Laws to the Ministry of Justice was the final part of this process.

Also of significance was the drawing up of an official Position Description for the Managing Director which meant that for the first time since his appointment Ato Menberu had authority to conduct his duties and responsibilities. To support these changes, members of the newly elected National Executive Committee underwent training in governance issues, and agreed they should not be involved in the day to day running of ENAELP.

During the above period an additional issue began to emerge although it appears that members of the National Executive Committee may not fully appreciate its significance: it relates to the fact most have had minimal, if any, education. This is often a dilemma for membership organisations when members at grassroots are elected onto a governing body because there is inevitably a knowledge gap between them and the professional staff. A large measure of trust is needed if such a gap is not to become a major problem and this is not always easy for a group of despised, marginalised people. Although it is *their* organisation, because of their minimal levels of expertise they need to *trust* the Managing Director and others, who bring to them much needed expertise. However, they fear in doing this they will lose their organisation. Ultimately, this could prove to be a factor on which such an organisation either fails or thrives.

## **External Relationships**

### *Steering Committee*

ENAELP's relationship with the Steering Committee, set up in early 1998, appears to have been fraught from the start. The very strong personality of Ato Arega combined with a Steering Committee membership comprising strong representation from four other organisations involved in leprosy, disability or both, was a recipe for ongoing tensions. At the time ALERT Hospital<sup>23</sup> was going through a crisis relating to the Ministry of Health and ILEP<sup>24</sup> members who had different opinions on how to interpret the former constitution regarding the ownership and status of the establishment (Both, 2000) with the Government of Ethiopia wanting to take it over. The ILEP agencies, jointly responsible for ALERT, failed to find a plan acceptable to the Government of Ethiopia. Politically, this was a very drawn-out complicated problem and dissension was rife. It was into this environment ENAELP's Steering Committee was born.

Within this environment it became relatively easy for Ato Arega, ENAELP Chair, to play off one agency against the other, as they were not easily communicating together. In addition, it seemed some ILEP agencies had a special agenda where ENAELP was concerned (not helped by Ato Arega) trying to ensure control over this fledgling organisation. Although the Steering Committee was to have an advisory role and monthly meetings were set up, it appeared this happened only for the first year or so. From the Minutes of meetings from 1999 to 2000 it seems they went further becoming involved in day to day management decisions. Meetings of the Steering Committee continued on an irregular basis until June 2003 and, although not formally disbanded, it seldom met after that date. In July 2002 ALERT Hospital came under the jurisdiction of the Government of Ethiopia and in the time since, tensions eased. ALERT management, now under the Ministry of Health, is very supportive of ENAELP and its vision.

Since 2003, several Steering Committee members have continued to provide encouragement and technical advice to ENAELP when necessary. For this case study I interviewed six of the remaining Steering Committee members (four males and two females): Sociologist, Deputy Representative & Programme Officer for Education, Christian Blind Mission Ethiopia (male); Medical Director, Ministry of Health ALERT Centre, Addis Ababa (Female); Administration and

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<sup>23</sup> ALERT Hospital owned and managed by a group of ILEP agencies.

<sup>24</sup> ILEP: Umbrella organisation for anti-leprosy agencies, including The Leprosy Mission International (TLMI), German Leprosy Relief Association (GLRA), Netherlands Leprosy Relief (NLR), ALM.

Finance Head, Ministry of Health ALERT Centre, Addis Ababa (Female); Country Representative, German Leprosy Relief Association (Male); TB/Leprosy Acting Team Leader, Ministry of Health Ethiopia (Male); Disability Team Leader, Ministry of Labour and Social Affairs Ethiopia (Male).

One of the Steering Committee members had been on the Evaluation Team for ENAELP's Evaluation in February 2004, which meant this person had an in-depth knowledge of ENAELP from this recent perspective. It was his observation that one of ENAELP's major problems was the lack of boundaries between the governing body and day to day operations which was causing confusion and conflict, plus the professional staff had no clear hierarchy of management from which to work. According to him, at the time of the evaluation feedback, they discussed this at length with the National Executive Committee and Senior Office Co-ordinator. However, in my case study interviews with each National Executive Committee member, held separately, this fact was not provided to me by any of them. It was the opinion of this person that despite ENAELP's internal problems, they had become clearly visible as an organisation of influence and were helping their members to integrate with so-called "normal" people. His caveat would be that members in the regions were not benefiting as much as members in or close to Addis Ababa and this was a key finding of the Evaluation Team. Claims were made to the Evaluation Team by members in the regions that the National Association did not provide them with enough support, including financial support. He experienced accusations from members of the most distant Local Associations, saying the intensity of their feelings had surprised him. They had become members with great anticipation of things to come, and in fact little had happened for them. Their lives were still the same; they were still living in isolated, squalid conditions with little or no leverage to try gaining a better deal from the outside world. A means of countering this would be greater communication links, and possibly the inclusion of leadership training for regional and local leaders. He believed the professional staff could provide such training once policy had been developed and implemented in the National Office. His comments regarding the Steering Committee were interesting: it was his opinion ENAELP had outgrown the mandate of the Steering Committee, and a Technical Committee could replace it. He believed continuation of the Steering Committee in its original form would have a disempowering effect on ENAELP. He said, "ENAELP is growing in terms of capacity and maturity: seven years back it was an

immature organisation and had a charity mentality. Now they feel they can do things to liberate themselves. This must be encouraged and strengthened” (Field Notes.2004). It is interesting to note a Technical Committee was established in 2005 with a mandate to provide technical advice to ENAELP when requested.

Another Steering Committee member also highlighted problematic issues of governance and management. It was his opinion that because of these issues, ENAELP was at a critical point in its organisational growth. He felt if the issues were dealt with appropriately, and the Bye Laws amended to reflect the changes needed, the current conflicts could recede. However, if this did not happen, he was not hopeful for the future of ENAELP saying, “These people will eat themselves and then the central area will collapse” (Field Notes.2004). He said the Executive Committee need to realise the Managing Director is not trying to replace them, his role as a professional is different to their role, and is a major support role imperative to them if ENAELP is to grow. Without a qualified professional giving trustworthy, passionate leadership, it was his opinion ENAELP could not survive. He called the problems organisational growing pains, and if addressed well and suitable monitoring mechanisms put in place, it would not be long before ENAELP is ready to institutionalise and, as such, begin a process to ensure sustainability.

During my interview with another Steering Committee member I heard concerns largely echoing those above, but an additional comment was made in relation to the origins of ENAELP: it was his view that because the organisation had started locally in Addis Ababa, and decided at a later date to expand to the regions, this was a weakness because it needed more than merely changing the name to National Association to get buy-in. He believes the National Association needs to represent the regions more strongly so grassroots members in the regions truly feel part of the organisation and know they are benefiting by being members. Conversely, it was his opinion that ENAELP had achieved a great deal in Addis Ababa especially in regard to their visibility in the city with awareness raising programmes, such as the World Leprosy Day street march. However, he said it is vital for them to keep up to date with modern media and contemporary ways of presenting their message because they are vying for attention in a very competitive market.

Two other Steering Committee members were both supportive of ENAELP saying they felt it was growing and maturing as an organisation. One said “they are now thinking beyond themselves...in the past they seemed to have a dependency attitude, understandably, but this mindset is changing...it is a very positive feeling” (Field Notes.2004). However, this was tempered by adding that at times the members perhaps created obstacles by not fully understanding issues or what needed to happen. Again it was said the Steering Committee’s involvement should diminish because ENAELP needs to become strong, which cannot happen if Steering Committee members continue to have frequent involvement.

### *Donors*

ENAELP had three international donors at the time of this case study (German Leprosy Relief Association, The Leprosy Mission New Zealand, and the Sasakawa Memorial Health Foundation), and was entering into partnerships with two further international donors (The Leprosy Mission England & Wales, and The Leprosy Mission Northern Ireland). They also receive small financial contributions from within Ethiopia, including local government, companies or other organisations<sup>25</sup>, for some of their advocacy and World Leprosy Day events.

The Leprosy Mission New Zealand, together with government funding from NZAID’s VASS matching funds, is currently supporting ENAELP’s core funding through capacity building projects. An initial five-year project concluded in December 2004, with 2005 being an interim year in which a new Strategic Plan was developed. With the Strategic Plan prepared it is intended that a new five-year capacity building project will be implemented in January 2006 .

### *IDEA (International Association for Integration, Dignity and Economic Empowerment)*

IDEA is an international membership organisation, based in Seneca Falls, New York State, USA, for individuals who have had leprosy. IDEA also accepts as members grassroots membership organisations made up of leprosy-affected people. ENAELP, as an organisation, is a member of IDEA. While IDEA claims to fully support ENAELP the relationship is somewhat problematic and strained: Ato Arega (ENAELP’s former chair) remains the IDEA representative in Ethiopia,

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<sup>25</sup> This includes: Ministry of Health, Armauer Hansen Research Institute (AHRI), DKT Ethiopia, Ethiopia Tire & Rubber Economy Plant Private Ltd, Ambo Mineral Water Factory, and Handicap National.

even after removal from office by a coup d' état set in motion by ENAELP members. It appears odd that IDEA's representative is not part of ENAELP which has a membership of some 15,000 leprosy-affected people.

### *ILEP (International Association of Anti Leprosy Organisations)*

According to ILEP, co-ordination is their cornerstone allowing members to engage in the campaign against leprosy with united front and in an ordered manner. Over the years ILEP has proved to be a useful vehicle when governments of some leprosy endemic countries have tried to manipulate various anti leprosy organisations. However, even best intentions can go awry: whether it is due to interpretation of rules and regulations by individuals from member agencies, or that ILEP is now a powerful western federation of fifteen non-governmental anti-leprosy organisations, smaller players such as ENAELP appear to be affected by control tactics. ENAELP is not a member of ILEP, but because they receive funding from ILEP members, it appears they are expected by some to comply with ILEP processes.

ENAELP's Managing Director spoke of his frustration with ILEP in relation to funding they were receiving from an international donor: ILEP requested the funding be sent to ENAELP through the account of the ILEP Co-ordinator in Ethiopia. The ILEP Co-ordinator forwarded the funds to ENAELP, along with funding from their own organisation; however, they did not make clear there were two donors. This proved an embarrassment to ENAELP who thought one of their donors had not fulfilled a funding commitment and followed them up accordingly. ENAELP staff said, "We are not a project. We are an organisation. But ILEP treats us like we are a project" (Field Notes.2004).

### *Local Disabled Organisations*

There are five associations for disabled people based in Addis Ababa<sup>26</sup> that make up the Ethiopian Federation of Peoples with Disabilities (EFPD), of which ENAELP is a founding member. Because all of these organisations face various forms of discrimination, they decided in 1996 to form an umbrella body. The rationale was to provide support to each other and give additional solidarity and strength as they combine efforts in their fight for human rights.

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<sup>26</sup> Ethiopian National Association of the Blind (ENAB); Ethiopian National Association of the Deaf (ENAD); Ethiopian National Association of the Physically Handicapped (ENAPH); Support Organisation for the Mentally Retarded (SOOM).



## **Members and their leprosy experience**

Without exception, each person I met who had experienced leprosy was worse off in every way because of the disease: they had lost family and friends, suffered in employment or lost their job, experienced financial hardship, become visibly disabled and socially excluded. Undertaking this case study allowed leprosy-affected people to express how they feel in their determination to gain full human rights in Ethiopia, which is why they joined ENAELP. In various ways all thirty Articles making up the Universal Declaration of Human Rights (United Nations, 1948) have been violated: this was evident as I heard firsthand incredible testimonies of deprivation, degradation and humiliation. But these people have survived.

### *Our right to a voice*

Of the Executive Committee members, seven of the nine people I interviewed had not heard of leprosy before their diagnosis with the disease. This was possibly attributable to the fact some were children as young as six or seven. Leprosy was not always the first diagnosis with local healers generally being the first port of call, and only after the condition worsened were medical diagnoses sought.

One woman (aged 29) said as a child of six she ran away from home and slept under some trees, and a devil from the river came and gave her leprosy. Her grandmother, with whom she lived, believed this was the cause of leprosy. Treatment from the witchdoctor was very frightening: he washed her all over with cow's blood, some getting into her eyes. She thought she would go blind the stinging was so bad, but she said: "Thanks to God it did not destroy my eyes" (Field Notes.2004). A couple of years later, with worsening symptoms, her father took her to ALERT Hospital. When she saw the disabled people there she was terrified and refused treatment but her father insisted she comply. She and her father never went home again, preferring to remain in the leprosy settlement bordering ALERT. Her father, by this time, knew he too had leprosy. Now, some twenty-one years later, she has married and has a two year old son. Her husband has not had leprosy, which is most unusual. This was her target, she said, to mix life. It was her way of making a difference. Sadly though, she believes unless more change occurs "it will be hard for my son to marry because his mother had leprosy. Until that changes we [ENAELP] cannot stop" (Field Notes.2004).

Another woman (aged 30) was seven when she first had leprosy symptoms but the local healer did not diagnose leprosy. His treatment consisted of chewing *jud* (a local leaf with addictive narcotic qualities) and then spitting it over her. There was no improvement and she began developing nodules on her skin: it was then local people said she might have leprosy. Her father took her to Addis Hiwot leprosy settlement where she obtained leprosy treatment. She lived there for several years before moving to the leprosy settlement near ALERT in Addis Ababa, where she has now been for fifteen years. According to her, discrimination is their major problem. Joining together in a group means their united voice will be heard as they try to gain their rights. She has seen some changes, for example, when she catches the bus from the city to home, people may come and sit on the seat next to her. She said, “For a long time if I sat on a seat, no one would sit next to me” (Field Notes.2004).

A man (aged 45) talked of his early years with leprosy, and how he had inadvertently made his disabilities worse because he did not understand the importance of taking care of anesthetic hands and feet<sup>27</sup>. Now his damaged hands tell everyone he has had leprosy. He always used to put his hands in his pockets so no one could see them but since being involved in ENAELP, he is regaining confidence and said, “I don’t always hide my hands in my pockets now” (Field Notes.2004).

When another man (aged 63) was about twelve he spent a lot of time swimming in a river. He described how his skin would normally be moist and shiny when he got out of the water, but gradually he noticed a change and his skin was rough and dry – even after swimming. Visits to the local healer were not helpful, and eventually his family took him to Bory Meda Hospital at Desie (according to him, some 400 kilometres from Addis Ababa) where they diagnosed leprosy. He only knew of one other person with leprosy, and he “passed the night with him”, so suspects that person infected him. When he was fifteen he traveled to ALERT in Addis Ababa, and has remained in the leprosy settlement there ever since. He said, “I feel free among people like me” (Field Notes.2004).

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<sup>27</sup> Leprosy causes anesthetic limbs, which can be badly damaged, even destroyed, because the person does not experience pain which would normally alert them to the fact they are causing an injury.

Ato Andarge Kinfu, sprightly for his age (76), talked of his experience of leprosy. As a boy he went with relatives to a local healer who “did some sort of implantation under the skin on my arm” (Field Notes.2004). But when this and other treatment failed he traveled to Addis Ababa where leprosy was diagnosed. He began treatment which at that time was mono-therapy consisting of one drug called Dapsone. By then he understood his problem because he had recognised it on other people. I saw a letter he requested from the Ministry of Public Health Skin Diseases Control Service, dated February 5, 1963, in order to gain employment. It read, “This is to certify that Ato Andarge Kinfu has been under treatment for 16 years (1939-1955) in Princess Zenbework Hospital. His disease is completely checked and there are no medical grounds whatever to prevent his accepting any type of employment”. This enabled him to work and have an income. Some years later he qualified as a teacher, his Teacher’s Certificate provided by the Ethiopian Provisional Military Government, Ministry of Education, stating he had successfully completed a three-year national in-service Teacher Education Programme which authorised him to teach in any elementary school in Ethiopia. This was an astounding feat. Several publications have used his quote, “Leprosy must be second to everything, second to me being a man, a teacher, a human being” (ENAELP, 2004). Although he achieved much given he had leprosy, this unfortunately was not so in every aspect of his life. Sadly he said he must remain anonymous as far as his adult children are concerned, the reason being his three sons and one daughter have gained professional employment and if people got to know they had a leprosy-affected father, “I may be a trauma to them” (Field Notes.2004).

Trauma was commonplace in another man’s childhood. Now aged 45, he remembers being unable to join friends at school. This seriously affected him and he became very depressed. Even now his emotions are close to the surface. His family recognised he had leprosy because relatives had suffered from it. Associating leprosy with evil, they took him to witchdoctors for holy water but this was of no benefit and he became very disabled. In spite of this, life moved on and he set up his own business, a petty trading shop, and became self-sufficient. Leprosy still haunts though because he is sure any contact with his siblings would negatively affect them. For this reason he did not attend his brother’s wedding: he was afraid people in the community where his brother lives would isolate his brother if they knew there was someone with leprosy in his family.

*“If people know, I don’t mind, but I don’t announce it...”*

A teenage girl (age 18) spoke about her membership of ENAELP: still at school, no one knows she has leprosy. To her advantage she has no obvious disability because a member of ENAELP’s Local Association recognised her symptoms and she was able to begin treatment immediately. Even though she said “if people know, I don’t mind, but I don’t announce it” (Field Notes.2004), she alluded to the possibility that if people did discover she had leprosy it may affect opportunities for her future.

I was at a focus group of ten people (8 male : 2 female) on the other side of Addis Ababa city in a small leprosy settlement that has little contact with those in the larger settlement next to ALERT, mainly because of distance and costs to get there. Group members were pleased to host a visitor (me) saying they usually feel left out because any visitors to ENAELP generally go to ALERT and the Zenbework area. One of the members was part of the original group who went to the Ministry of Health protesting about the perceived decrease of services available to them at ALERT: he is very proud to be one of ENAELP’s founders. This Local Association has contact with the National Association on a three-monthly basis, and on an annual basis their Chair attends ENAELP’s General Assembly. The Secretary visits the National Association office every two weeks, mainly regarding documentation for membership fees and loans. Group members have been benefiting from loans made available by the Sasakawa Memorial Foundation.

This brought us to a more general discussion about employment opportunities; unemployment in Addis Ababa is high and it is difficult to find work, especially for people affected by leprosy. They referred to ENAELP’s education and vocational training project, in which three of their teenagers had participated, graduating after two years. One spoke of her daughter who had completed a two-year woodwork course, only to discover the training institution was not recognised and her certificate was of low value. This was a huge blow to the family. She did, however, find employment, but at Birr 200 per month (approximately US\$20) it was difficult to cover her living expenses as well as transport costs to and from work each day.

A woman (age 47) told of her success with a loan of Birr 500, repaid in one year by making and selling bottles of local drink. With a huge smile she said she is much better off and can live on

the income. Approximately 80 people have small income generation loans in this settlement. As a group they have prepared a project proposal for a common income generation cottage industry project in which many would work. The National Office has provided assistance with this, and the proposal was to be ready for an external donor in 2005. Group members are proud of this achievement and are keen to progress to the next stage.

One group member complained ENAELP was not living up to expectations, but the others responded saying they did not agree with him. They said weaknesses do exist, but this was not the right time to be critical of National Association leaders who have worked very hard with limited capacity. Their desire was to continue working together and contributing fees (Birr 6 – 12 per member per year) to ENAELP because being part of such a group is important to them. It was their belief society in general is more accommodating of them and the stigma is decreasing. Their goal of a discrimination-free society, and one in which they have equal rights for employment and other opportunities, remains firmly in place. If it is not possible for them, they will continue for the sake of their children and grandchildren.

#### *Strength comes from solidarity*

This Focus Group grew so large it became almost impossible to function with some 50 people wanting to participate. Although specific people were invited, word got around, and due to the sheer size of the leprosy settlement many turned up wanting to contribute and out of curiosity. The settlement area included several Wereda<sup>28</sup> and Kabele<sup>29</sup> which meant a number of Local Associations were involved.

Members in these Local Associations were among the first ENAELP recruited in its early years as the Addis Ababa Association. Of ENAELP's membership it seems these people who have been members longest have had the greatest opportunities for involvement. They talked about their early lives when leprosy isolated them, in many instances their families also, and how they struggled to come to terms with the loss of dignity, social exclusion, loss of education and employment opportunities. Conversely, they went on to say how being part of the leprosy

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<sup>28</sup> Wereda: Administrative unit equivalent to a District

<sup>29</sup> Kebele: Lowest administrative unit

settlement and then joining ENAELP and being part of a group where they all understood each other was so important to them.

The annual World Leprosy Day activities give a major source of satisfaction to ENAELP members because the solidarity they have in numbers speaks for itself when they march in central Addis Ababa. They also involve speakers including city leaders, dignitaries and government officials. Their slogan is for human rights, “Full participation and equal employment for people affected by leprosy”. Of credit to younger members is the band which plays traditional Ethiopian music to accompany traditional dancing. All of the musicians and dancers have had leprosy; some are significantly disabled. The band opens opportunities for advocacy in unusual situations and places where previously members were forbidden: for example, participation in a concert at the Sheraton Hotel; dancing and playing in the foyer of the main Addis Ababa offices of the Bank of Ethiopia; and involvement with other disabled groups in prime city locations raising the profile and special needs of socially excluded people.

Women spoke about their handicrafts business. They buy bags of raw cotton to spin and weave, then embroider Christian Orthodox symbols onto it turning out items such as shoulder bags, table runners, pot-holders, and bedspreads into a local and international market. Many said this work had improved their income and given them a purpose as they work together daily. The handicraft business is located on a plot of land which is the base of the Addis Ababa Regional Association. Members built rough corrugated iron buildings to accommodate other businesses including buying and selling of *teff*<sup>30</sup> and other grains such as wheat and corn, plus dried chillies. Some of the women make injera on site and sell to local people. In addition there is a small transport operation consisting of two donkeys.

### *Knowledge is power. Or is it?*

I met with a focus group of fifteen people (8 women : 7 men), participants for some two years in an income generation project, externally funded, but implemented by the National Association office. One woman who opened a small trading operation in the market said “it has changed my life” (Field Notes.2004). Another said the income earned meant she could send her children to

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<sup>30</sup> Teff is a very fine wheat from which the Ethiopian staple food *injera* is made.

school because they no longer needed to beg to help support the family. A man said, “I used to live on begging then I got a loan so now I can live on my own [support myself]” (Field Notes.2004). He went on to say he would like a second larger loan to increase his business. Another said the loan criteria needed revising, for example, the initial loan amount is small and the repayment duration is short. He would like to buy a cow, but a cow would cost more than he would be allowed to borrow, and raising a cow would take at least a year, so the loan time should be set to accommodate that. Buying a cow also meant making repayments on a monthly basis would not work, but could be made at the time of the sale of the cow. He appreciated the loan he had, but felt a review of the rules would give scope for greater entrepreneurship.

A Focus Group with ten young women who had received educational grants / loans proved interesting. Initially I was aware of ten pairs of empty-looking eyes staring at me. This was in stark contrast to other interviews and Focus Groups. It took some time and a lot of gentle questions to elicit responses, but eventually I began to get the picture. Five of the ten had completed vocational training courses but had not been able to find employment after graduation. The reason: it appeared the ENAELP Executive Committee was being over zealous in its project oversight saying they would not give students their certificates until they had repaid the loan portion of their assistance. But without the certificate (photocopies were not acceptable to prospective employers) they were unable to secure positions. On further questioning, none of the graduates had seen their certificates and after two years of training they were depressed about the situation. On top of this, it seemed the Executive Committee had ‘allocated’ students to vocational training centres without taking into account their interests; as a result some had simply defaulted through mis-matching of interests and skills. Even worse, some had discovered when seeking employment that the vocational training centres where they had trained were unrecognised officially and their chances of finding employment with the certification they had received were minimal. No wonder they were depressed. At this point I asked Ato Menberu to join the Focus Group and he discussed the situation with the young women. They asked if they could organise themselves into an income generation group because they desperately wanted to work. They also indicated concern about their ability to repay the loan component of their educational training. Ato Menberu gave them his reassurance, which W/ro Birke endorsed, that they need not worry and ENAELP would resolve the issues.

*Do human rights apply to everyone?*

I visited the isolated Addis Hiwot<sup>31</sup> Local Association in the desert some 150 kilometres south of Addis Ababa. Most members wanted to be involved in the Focus Group and as it was not possible to minimise numbers without causing offense we went ahead as best we could, counting some 150 people sitting under the shade of large acacia trees. I had been there on previous visits to Ethiopia and met the people, who all wanted to meet with me again. The government had resettled them in 1962 from the leprosy settlement near ALERT in Addis Ababa. Their ethnic composition shows originally they came from all over Ethiopia. At the time of their resettlement the government 'gave' them a large plot of land and the Swedish Philadelphia Mission helped them set up an irrigation system with water from the Awash River. This made it possible to establish an orchard which for many years produced good quality fruit.

When the *Derg* came to power it decreed foreign agencies leave Ethiopia so the Swedish Philadelphia Mission, along with many others, left the country. Maintenance of the irrigation system continued until it became impossible to find spare parts and gradually it fell into disuse and the orchard died. Remnants remain, always seeming to taunt as we stepped over pipes and around taps which have seized. Water is the most precious commodity of all in Addis Hiwot. The only source is the Awash River but even this is difficult to reach, and for leprosy-affected people with a high degree of disability it is treacherous. The walk of thirty to forty minutes each way to collect water is yet another hardship for these people.

Members told me of their increasingly desperate situation, trying to live on a benefit from the government of Birr 20 per person per month which is insufficient to cover basic needs. Looking around me I could see evidence of this as the houses, such as they were, were dilapidated and barely standing. They had mended roofs with plastic sheeting but in the rainy season they leaked. The non-leprosy affected people nearby were never happy that the government forced the resettlement of these people on them, shunning and constantly complaining about them.

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<sup>31</sup> Located in the Oromia Region, Arsi Zone.



The people of this Local Association spoke of their frustrations. ENAELP had developed a new irrigation project following an extensive Participatory Needs Analysis (PNA), and an international agency had provided funding. However, contrary to formal authorisation from Central Government that the land legally belonged to the leprosy-affected people, the Oromia Regional Government is questioning this following de-centralisation of government departments. I heard of 'developers' gaining the title to land all around the Local Association's plot, often helped with the provision of 'incentives' in the form of additional funds. But the Local Association cannot supply incentives so the regional government does not clarify their situation. Ato Menberu and W/ro Birke explained to the members with passion that they had visited the Oromia Regional Government many times but without conclusive results. One of the women responded saying they are really suffering; many of them have two or three teenage children who have no education and no prospect of employment. Others spoke of their anger that the government had forcibly dumped them there in the first place, and now it appeared they could be dumped again. The combined voice of the Local Association was that as members of ENAELP they are strong and know their rights: bad treatment is unacceptable and they vowed to fight. When asked if they would like another project rather than the irrigation project, they declined, wanting to see the land situation through to natural justice.

Ato Menberu later told me his visits to the Oromia Regional Government are never easy; the people with whom he has to communicate mock and humiliate him because he is from ENAELP and associated with leprosy. He said, "They don't say yes and they don't say no. They just keep us waiting and do not take us seriously" (Field Notes.2004).

#### *Isolation, separation, remoteness*

I met with a focus group at Tesfa Hiwot, some fifteen kilometres from Addis Hiwot, with a very rough, dusty road linking the two places. The focus group consisted of 37 people (25 men : 12 women) representing another of ENAELP's Local Associations. The people were resettled in this area by the government in 1967. Recently ENAELP undertook a PNA with funding from an international partner, and an Income Generation Project was to begin in 2005. There was excitement about this, and it was clear that membership of ENAELP was providing a sense of solidarity and giving them new hope with the imminent start of the project. However, as in

Tesfa Hiwot, the people in Addis Hiwot are afraid of developers that are visiting the area and are fearful they will be moved. Discussion in the Focus Group was in turn animated with anger and flat with despair, as people talked of their fears and concerns saying they feel like garbage which is dumped out of the way until the dumping ground looks good to someone else, then they are dumped again, out of the way. Ato Menberu and W/ro Birke, plus people from Addis Hiwot, will continue lobbying the Oromia Regional Government to clarify the situation.

### *When is self-help not self-help?*

On the outskirts of Shashamane<sup>32</sup>, near Kuyera General Hospital, some 250 kilometres south of Addis Ababa, I met with a Focus Group representing a large Local Association of approximately 75 people (13 female : 60 male). The Local Association has been in existence eleven years, and has a strong committed membership drawn from fifteen leprosy villages. The Local Association leadership meets twice per week (Chair, Secretary, Treasurer, Board members and Social Worker), and the members meet together twice per year. Kuyera General Hospital was established in 1953 and amongst its services was a leprosy clinic which was held in a separate building. The first people to come for treatment stayed in the area and formed the first leprosy village. As the years went by more people came for treatment and stayed. In addition, from 1962 onwards, Emperor Haile Selassie resettled people there from the leprosy settlement near ALERT in Addis Ababa. Two further groups of people were resettled in 1987 and the final group in 1991.

A strength of these Local Associations is their support of some 48 Self Care Groups which meet on a regular basis. Their purpose is for accountability between peers regarding staying ulcer-free: because it is so easy to damage an anesthetic limb, extreme care is needed or serious injuries and ulcers result. Weekly meetings mean each member is keen to stay healthy or they receive the ire of the group for being careless. It was with pride they spoke about visits from groups of students at ALERT Training Centre who come to learn more about the Self Care Group concept which began with them. This concept is now being used in other African countries, and in Asia, where leprosy is a problem.

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<sup>32</sup> Also in Oromio Region

### *Human degradation and hyenas*

A focus group near Awassa city <sup>33</sup> was quite different to others in composition because it included both leprosy-affected and other-disabled<sup>34</sup> people, all of whom are members of a new Local Association. During the focus group they spoke of their grim situation: previously they lived together in the nearby city but a developer ‘acquired’ the land on which they were living and evicted them. The 54 households were resettled on the outskirts of the city on a floodplain. Although the developer helped them build mud houses he left them with no clean water and electricity, both of which they previously had. What they didn’t have before, but gained after moving, were hyenas each night at dusk. The hyenas prevented everyone from leaving their houses until morning, so toileting, washing, or any other outside activities were not possible after dusk. Another severe problem was the malaria-ridden mosquitoes with several of the group having recently died from malaria. Sitting with these cruelly oppressed people in such squalid, cramped conditions, was the most moving experience of my visit to Ethiopia.

The group was pleased that with support from ENAELP they had successfully gained the use of clean water from a tap a few metres from their houses at a reasonable cost, as opposed to the two kilometre walk, each way, they had to take earlier. They were frustrated with the local government who said they would connect electricity because the connection fee of Birr 3,000 made it impossible. Even the able-bodied among them were competing for daily labour at about Birr 10 per person per day; the others were forced to beg. ENAELP put pressure on the local government with Ato Menberu and W/ro Birke advocating to have the fee waived. The electricity was connected.

## **Achievements**

### *Belonging*

The sense of belonging was one topic which surfaced in every situation, no matter where I directed questions. Members everywhere were adamant ENAELP is their organisation, proudly asserting their ownership of it. If members from outlying Local Associations felt ENAELP’s National Association was not paying due attention to them or their area they clearly said so. This is positive on one hand as it means ENAELP has priority in members’ lives. However, with

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<sup>33</sup> Awassa is in the Southern Peoples Nations Nationality Regional Government State (SPNNRGS), near the Oromia Region border.

<sup>34</sup> Other disabilities included blindness, lameness due to polio, mental retardation, and accident victims.

limited capacity at national level to deal with multitudes of issues it also seemed at times as though those in the National Association office felt overwhelmed. Balancing belonging and ownership with the needs and wishes of members, and assisting them to help themselves is a fine line to achieve. This is especially so when members are severely disabled, which combined with their restricted worldview and lack of experience due to isolation, means they are possibly needier than most people in poverty. Many members say, “ENAELP is now my mother and my father. ENAELP is ours. I belong to ENAELP. ENAELP will not abandon me” (Field Notes.2004).

### *Advocacy for rights*

ENAELP’s registration in 1996 as an Ethiopian non-government organisation was a landmark. Not only is it an organisation set up to advocate for despised and socially excluded people, it came into being through the extraordinary efforts of some of these very people. There is evidence ENAELP is now well recognised at the highest levels in Ethiopia, with them having fostered alliances and partnerships with heads of various government departments, for example, the Disability Team Leader from the Ministry of Labour and Social Affairs Ethiopia, and the Minister of Health. Unfortunately the decentralization of government to the regions has meant that more alliances with people at regional levels need to be developed, and this clearly stretches ENAELP’s capacity. It is important though when considering the land issues that are arising and the clear direction members are giving to ENAELP to prioritise this concern. ENAELP’s staff and governing body, plus members at Local Association level, are learning more about advocacy and how to gain successful outcomes. The sense of injustice they keenly feel, and which has grown over generations and become part of their history, is clearly a driving force for change and given the solidarity coming from membership of ENAELP they are prepared to make waves to ensure change.

### *Choice and opportunities*

In many areas where ENAELP has Local Associations there are new choices and opportunities for members. While income generation activities are popular and provide additional income and a greater sense of wellbeing to beneficiaries and their families, the vocational training opportunities have been of less value due to the arbitrary rules and regulations imposed by the

National Executive Committee. This has been a significant learning process for ENAELP, showing how the organisation may harm people if at governance level they become controllers rather than facilitators, and if they do not run the organisation in a participatory way. The fact they were replacing one hierarchy of controls and power with another, themselves, was a revelation. Issues of power in the organisation are now a topic for discussion and debate.

#### *Access to benefits*

Members of ENAELP's Local Associations situated closest to Addis Ababa, and the Local Associations around the Zenbework community in particular, have access to the most benefits. However, as ENAELP's capacity strengthens it is developing projects in the regions. With additional funding partners committing themselves to new projects more leprosy affected families and communities are benefiting. In accordance with ENAELP's gender awareness the projects have gender analysis built in and mechanisms ensuring there is equity in the distribution of benefits, especially for women.

#### *Gender and women*

Women are important within ENAELP's membership, with evidence of their value shown by involvement in decision-making at all levels of the organisation. The fact that a woman holds the most senior position in ENAELP, as Chair, gives a strong message that ENAELP is a gender-aware organisation. ENAELP has also developed its structure to ensure equal representation of men and women on the National Executive Committee, and regional executive committees. There appeared to be no male resistance to this change made during the recent review of the Bye- Laws, a change strongly supported by the Managing Director. The flow-on effect is evident in the regions as female members of Local Associations are not afraid to speak out in mixed meetings. W/ro Birke visits the regions on a regular basis, and as a disabled leprosy-affected woman herself, she easily empathises with female members and encourages them not to remain victims in their situation, but to actively advocate for change for themselves and their families.

## **Challenges**

### *Maintaining grassroots ownership*

ENAELP is a membership organisation existing for its members; however, there are grey areas between governance and management of day-to-day activities which have caused dissension. Because ENAELP is totally grassroots, its origins coming from leprosy-affected people themselves, there is a gap between the membership and its understanding of how organisations work and grow. This was evident when misunderstandings emerged between National Executive Committee members and professional staff. Finding ways of retaining meaningful grassroots ownership and valuing input from grassroots level, while at the same time giving space for professional staff to grow and consolidate the organisation, is a major challenge. It requires an environment of trust which must be nurtured by all stakeholders or seeds of doubt and mistrust will feed suspicion leading to a breakdown in critical relationships. The difficulties experienced recently show how this can slow or restrict organisational growth and contribute to member dissatisfaction, and potentially withdrawal of memberships. This is a critical issue for ENAELP.

### *Dependency on external funding*

Given Ethiopia is one of the world's poorest countries, ENAELP does well in accessing finance in-country for small projects such as World Leprosy Day remembrance activities. The challenge is accessing core-funding for the organisation as it develops and grows. Alongside core-funding needs is project-specific funding, which should increase as ENAELP's capacity increases. While ENAELP has a policy of including National Office administration in project budgets to cover some of the core-funding costs, it will take some years before there are sufficient projects to cover core-funding. Until such time ENAELP will remain dependent on external funding, both core-funding and project-specific funding, which leaves it in a vulnerable position. Given its starting point which was totally grassroots and self-generating, undertaken by severely disabled, leprosy-affected people who had nothing and were nothing in the eyes of the public, their journey to independence may take longer than for other membership organisations. But this should not be a surprise. Their goal is to become self-sufficient so while external funders should encourage this they should also be realistic with the timeframe.

## **CASE STUDY CONCLUSIONS**

There are four general observations of ENAELP relevant to the understanding of its emergence as a grassroots organisation.

Firstly, there is clear evidence of positive change occurring through members' collective action and solidarity, and that for the first time in their lives people are achieving in various measures social inclusion and empowerment.

Secondly, a significant gap left by many of the traditional western anti-leprosy organisations whose focus was primarily medical, meant ENAELP's social emphasis and highlighting of human rights issues was welcomed by people who were 'cured' from leprosy, but did not feel cured. Integration of disabled and socially excluded people into the general community is visibly part of ENAELP's mandate.

Thirdly, growing pains are evident within ENAELP as they try to develop a coherent organisational understanding of what a grassroots membership organisation is, and how it should work in practice. They are redefining the delineation between governance and day-to-day management issues and are learning to accept the governing body has a limited level of ability.

Fourthly, ENAELP is trying to develop and maintain meaningful alliances with national and international organisations which are sympathetic to the leprosy cause. While they have developed some strong partnerships, relationships with other organisations can be tenuous from time to time, especially when an external organisation operates with a welfare approach. ENAELP resists this, and rightly so, as it clashes with its own philosophy of self-determination and empowerment.

Given ENAELP began from a very disadvantaged position and has encountered major obstacles great achievements have been made. There is evidence ENAELP is maturing and learning from mistakes and problems which is a sign of a growing, learning organisation. Even though it has been challenging, ENAELP has shown that a group of significantly underprivileged people can

join together in solidarity and challenge deeply embedded social traditions and human rights violations, and as a result gain social inclusion and empowerment for the first time in their lives.



## CHAPTER 5: HANDA and Leprosy in China

*“Leprosy stigmatised our family and relatives so some people thought it best to just ‘eliminate’ the existence of their family members to protect the rest”.*

*Feng Ke Teng <sup>35</sup>, People’s Republic of China*

In this chapter I give a brief introduction to southern China followed by a short concise background to leprosy in China. Then I present a comprehensive overview of HANDA Rehabilitation and Welfare Association and its work as a grassroots membership organisation made up of people affected by leprosy. This exploration of HANDA illustrates the similarity of its features to general grassroots membership organisations which I discussed in Chapter Three. Members of both organisations are typically poor and underprivileged, with the major differentiation being the degree to which members are disadvantaged; generally leprosy-affected people endure more degrading and debilitating living conditions and experiences. This chapter provides an opportunity for some socially excluded leprosy-affected people to tell their life-stories which illustrate the desolation they suffered through many years of enforced isolation.

As part of Chapter Two about leprosy I explored social exclusion issues, and in Chapter Three regarding grassroots membership organisations I discussed issues of empowerment. Chapter Four is a case study of ENAELP, an Ethiopian grassroots leprosy organisation with a membership of disabled leprosy-affected people. It shows that a disadvantaged membership such as ENAELP’s can indeed attain measures of social inclusion and empowerment. Now, in Chapter 5, a case study of HANDA, another grassroots leprosy organisation in the different context of China, adds credence to the results from ENAELP: HANDA members are also reclaiming hope for their future as they challenge deeply embedded social exclusion and uproot internalised oppression. In answering the thesis question, is social inclusion and empowerment possible for members of grassroots leprosy organisations, it appears that results from the case study of HANDA concur with and reinforce case study results of ENAELP in Chapter Four. Therefore, both case studies seem to be indicating the answer is yes.

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<sup>35</sup> Feng Ke Teng: HANDA member

## **INTRODUCING SOUTHERN CHINA**

The proximity of China's Guangdong Province to Hong Kong makes it a major gateway into China. In the 1970s Guangdong was seen as an economic middleweight, but the high level of economic integration between Guangdong's Pearl River Delta and Hong Kong has led to record economic growth, with some economists referring to the area as Greater Hong Kong. Now it is said to be the country's most affluent province. Guangzhou, also known as Canton, is the provincial capital of Guangdong, and is one of the most prosperous cities in China (Lonely Planet, 2002: 593). The Chinese currency is Renminbi (RMB): the basic unit of RMB is the *yuán*. At present there is a rate of exchange of approximately US\$1 = RMB 8.1 (Lonely Planet, 2002: 75). The local people are Cantonese, the population of Guangdong is 86.42 million and it covers an area of 177,901 square kilometres (Population Census, 2000). Guangdong's topography, unique dialect (Cantonese) and remoteness from traditional centres of authority, coupled with a longstanding contact with foreigners, has created a strong sense of autonomy and self sufficiency (Lonely Planet, 2002: 593).

## **LEPROSY IN CHINA**

Leprosy has "run rampant" in China for more than 5,000 years (Lili,1998). It is believed leprosy spread from India to China around 500 BC with the disease being endemic for more than 2000 years (Nordeen in Chen, et. al. 2001: 306). Historically in China, the endemicity of leprosy was much higher along the coast and in the Yangtze valley. From the earliest records, leprosy was associated with fear and disgrace centering chiefly on the thought that it was related to sexual excesses, supported by its mutilating effects and by the belief that it was hereditary and largely incurable (Skinses et al, 1985: 305). People frequently lived in poverty in overcrowded situations, surviving on poor nutrition and battling poor health (Chen et al, 2001: 306).

In the early twentieth century, prior to 1949, foreign missionaries operated the majority of leprosy hospitals (Skinses et al, 1985: 307). In 1950, one year after the founding of the People's Republic of China, the Ministry of Health initiated the leprosy control programme and implemented vertical programmes from national to county levels health (Chen et al, 2001: 306).



**Figure 5.1 Map of China and Locator Map**

Repeated mass or general surveys seeking leprosy-affected people took place in 1956-58, 1964-66, and 1971-73 in most areas of the country. The programme was well organised and records showing data of leprosy patients are clearly documented from 1949 onwards. The aim was to control leprosy infection during the first stage (1949-1981) and elimination of the disease during the second stage (1981-2000). The highest detection rate was in 1957-58, perhaps due to the accumulation of undetected cases in the early years of the programme. Controlling leprosy infection was by enforced isolation in leprosy villages; this practice was discontinued in 1982 when the three drug combination, Multi Drug Therapy, was introduced as an authoritative cure for the disease.

Life in leprosy villages was hard; the law forbade residents to leave the villages and ensured complete separation from society. Families were split, mothers and children were separated, causing long-term psychological difficulties from which many did not recover. Anecdotal evidence is that suicide was an option which some took, especially women (Field Notes.2004). Residents in leprosy villages who were able to work engaged mainly in agricultural work and raising animals (Shumin et al, 2003b: 227); this increased their income slightly and helped fill their days. The experience that a leprosy village could be run by residents and subsidised by the government, combining farming activities and medical treatment, was first recognised as successful in Shandong Province by the mid 1950s, so the concept was extended to other areas in China (Shumin et al, 2003b: 223).

Today it is possible for most residents of leprosy villages to move in and out at will, and a small number have even left to rejoin family. However, these are the fortunate few. For most, their families prefer not to acknowledge them, and as they have been isolated in a village for so long, most of their life in fact, the thought of moving out permanently and looking after themselves away from their 'leprosy family' is distressing. The government has permitted residents to stay and while they do their small monthly pensions will continue, only ceasing if they move out. Due to age and disability there is no way most of them could work or earn a living, so their freedom to leave is not really freedom at all (Field Notes. 2004).

Only in 2000 was the Chinese Marriage Law of 1950 revised and the word 'leper' deleted along with the clause that prevented people diagnosed with leprosy from marrying. While this may be a factor for more men than women living in leprosy villages, traditionally in other leprosy endemic countries, more men than women are diagnosed with leprosy, and there appears to be no reason why this should not be the same in China. It is generally due to the greater mobility of men, which means men contracted the disease in greater numbers than women.

Today in China there is little information available regarding the socio-economic needs of leprosy-affected people<sup>36</sup> and no clear strategy for prevention of leprosy disability and rehabilitation, "due to the fact that the decision-makers and programme managers in leprosy

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<sup>36</sup> Both residents in leprosy villages and people diagnosed with leprosy post-isolation policy in China.

control programmes are medical doctors, which could mean more attention [is] directed towards treatment aspects and less towards rehabilitation activities especially for social and economic aspects” (Shumin et al, 2003a: 218). With an apparent decline in diagnosis of new leprosy cases there is no doubt that social and economic rehabilitation of people affected by leprosy is now the most important task in the leprosy control programme and without such rehabilitation the prevention of disability programme is unsustainable (Shumin et al, 2003a: 220).

Rehabilitation should address problems associated with daily living, but more details on actual needs are necessary to define who needs what kind of help. At the very least a programme, perhaps co-ordinated with governmental and non-governmental agencies is needed from the point of view of human rights and justice (Shumin et al, 2003a:221). People in leprosy villages have literally been abandoned, spending most of their lives in poverty and segregation with little being done for them. In order to meet their most basic needs higher budgets are necessary (Shumin et al, 2003b:228), but in China’s new consumer society now open to outside competition and which is on a predominantly neo-liberal path (Peterson, 2003), the welfare expenditure needed to maintain the leprosy villages and their residents appears unsustainable.

### **HANDA: A Case Study**

HANDA Rehabilitation & Welfare Association is a secular, non-profit membership organisation dedicated to work with and for people affected by leprosy standing by the policy and guidelines of the Chinese Communist Party (HANDA Constitution, 2003). The name HANDA is derived from Hansen’s disease (HAN) and Father Damien (DA) the famous Belgian priest who gave his life for people affected by leprosy on the island of Molokai in Hawaii. HANDA’s membership totals more than 1500 people in two southern provinces (Guangdong and Guangxi), with a ratio of approximately 75% men and 25% women.

### **Formation of HANDA**

Dr Yang Li-he is the quiet, unassuming founder of HANDA, who spent his life working with people affected by leprosy after studying medicine in China’s north eastern city of Dalian.

During training Dr Yang's class was introduced to a young man whose skin was covered in red patches, lesions, and bubble-like nodules. The lecturer said the man had leprosy and as there were no effective drugs he must be isolated. With no cure available until 1942 and the one effective drug from that time being hard to obtain in China, people with leprosy became outcasts with most turning to begging and many committing suicide in despair. This encounter with leprosy haunted Dr Yang and he decided to make defeating leprosy in China his lifelong aim.

After graduation Dr Yang joined the Institute of Dermatology in Beijing where he met an American-born physician, George Hatem, known in his adopted country of China as Ma Hai-de (Williams, 2003). Ma's strategy for combating leprosy involved the creation of leprosy villages where people could live and be cared for, while not spreading the disease. In 1958 he sent a team headed by Dr Yang to establish a village in southwest Guizhou province and two years later Ma sent him to Chaoan county in eastern Guangdong province to carry out a study on leprosy. Dr Yang surveyed the county in 1960 and found 1,700 people with leprosy, isolating them all into one village. He used a blend of Dapsone, to kill the leprosy bacteria, and Chinese medicines, to treat symptoms and complications such as high fevers, skin eruptions and nerve pain, all sporadically experienced by people with leprosy.

Returning to Beijing in 1966, Dr Yang worked in general epidemiology, including leprosy, until 1971 when the Institute of Dermatology moved to Nanjing. He then focused on leprosy and began traveling throughout much of China as a teacher in workshops organised by Ma. Through these workshops Dr Yang spread his experience and expertise to barefoot (rural) doctors who joined a nationwide leprosy control network. In 1985, the National Department of Public Health established the China Leprosy Control and Research Centre in Guangzhou and a few years later Dr Yang became Deputy Director where he remained until his retirement in 1994. During his working life Dr Yang visited every province in China and made three trips to Tibet.

Dr Yang knew without a doubt that the suffering experienced by people with leprosy didn't end when medication cured the disease. Most continued to suffer lingering nerve damage, deformities and disabilities, plus stigma and isolation. They remained outcasts with no job, no home, and unwanted by their families. Although an epidemiologist by profession, Dr Yang was

always the most sensitive physician and a strong proponent for not only addressing the medical needs of people affected by leprosy, but social needs also.

In September 1994 Dr Yang attended the inauguration of IDEA <sup>37</sup> in Brazil (IDEA, 1996a:2) where he was deeply impressed with their intention of becoming an international membership organisation for people affected by leprosy. Approximately fifty people from six countries, (Brazil, Korea, India, Cuba, United States of America, and China) participated and agreed to officially register as a non-government organisation in the United States of America. On February 22, 1995, IDEA achieved this goal.

It was significant that three leprosy-affected men accompanied Dr Yang to IDEA's inauguration. They were the first people with leprosy ever to obtain a passport and travel out of China. All three had lived most of their lives in a leprosy village, isolated from family and friends. Also of significance is the fact they were allowed entry into Brazil. On their return to China, they sent a letter to 600 leprosy villages describing their very positive experience.

Another important event for Dr Yang was China's First National Workshop on Socio-Economic Rehabilitation which he organised in Guangzhou in March 1996. The Sasakawa Foundation, The Leprosy Mission International and the American Leprosy Missions jointly funded the initiative, and it was attended by some 70 people from eight countries and fourteen provinces within China. For people affected by leprosy in China this represented a major step in the restoration of dignity, reintegration into society and economic advancement.

A recommendation from the workshop became the Guangzhou Declaration and furthered IDEA's objective of fostering a network of support throughout the world for people affected by leprosy.

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<sup>37</sup> IDEA: International Association for Integration, Dignity and Economic Advancement. See also External Relationships in this chapter.

## GUANGZHOU DECLARATION

We, the participants in China's "First workshop on Socio-Economic Rehabilitation of Persons affected by Hansen's Disease"<sup>38</sup>, held from March 25<sup>th</sup> to 30<sup>th</sup>, 1996, in Guangzhou, People's Republic of China, make the following declaration and recommendations:

**Whereas** Hansen's Disease affects not only a person's physical body but also, in many cases, a person's social and economic situation and self-image;

**Whereas** much less progress has been made in eliminating the physical disabilities, poverty, stigma, and social isolation historically associated with the disease than has been achieved in reducing the number of active cases of Hansen's Disease;

**Whereas** persons affected by Hansen's Disease have an essential role to play in the elimination of the disease and its consequences;

**Therefore**, as persons directly affected by Hansen's Disease and as professional health and social workers dedicated to assisting them, we as participants in the workshop jointly recommend:

1. **That** governmental and non-governmental agencies treat persons affected by Hansen's Disease in a holistic manner, focusing attention and funding not only on the elimination of the bacilli from their bodies, but also on the prevention and cure of the physical, social, economic, psychological and spiritual problems which so often affect them and their families;
2. **That** words like 'leper' and 'hanseniano' which define people by their disease be eliminated from our vocabulary, and that expressions such as 'leprosy patient' or 'Hansen's Disease patient' no longer be used to describe persons once they have been medically cured of the disease;
3. **That** legal restrictions on the movement and socio-economic activities of persons affected by the disease be removed;
4. **That** persons affected by the disease be encouraged to overcome their sense of helplessness and shame in regard to Hansen's Disease and to take a pro-active role in preventing and solving the physical, social, economic, and psychological problems they confront;
5. **That** persons affected by Hansen's Disease be encouraged to join and work together with disability organisations and other community, national and international groups in seeking integrated solutions to common problems;
6. **That** the 'International Leprosy Association' (ILA) be encouraged to broaden its membership to any person actively involved in any of the aspects in the fight against the disease;
7. **That** organisations focusing on Hansen's Disease be encouraged to involve persons affected by the disease in planning activities and to use them more effectively as counsellors, teachers, spokespersons and lobbyists;
8. **That** through both word and deed the public be made aware of the true nature of Hansen's Disease;
9. **That** final victory in the fight against leprosy only be declared when there are no more persons to be cured, no more disabilities to treat, no more discrimination to overcome, and when persons once affected by the disease lead normal, integrated lives with the same opportunities, rights, and duties as their fellow citizens.

IDEA...(1996 b).

**Figure 5.2 Guangzhou Declaration**

<sup>38</sup> Hansen's Disease is another name for leprosy.



Although Dr Yang was keen to see IDEA come to China the law prevented registration of international organisations. Instead, HANDA was born: China's own membership organisation for people affected by leprosy. HANDA was registered with the Provincial Department of Civil Affairs in 1996, with endorsement from the Provincial Department of Public Health.

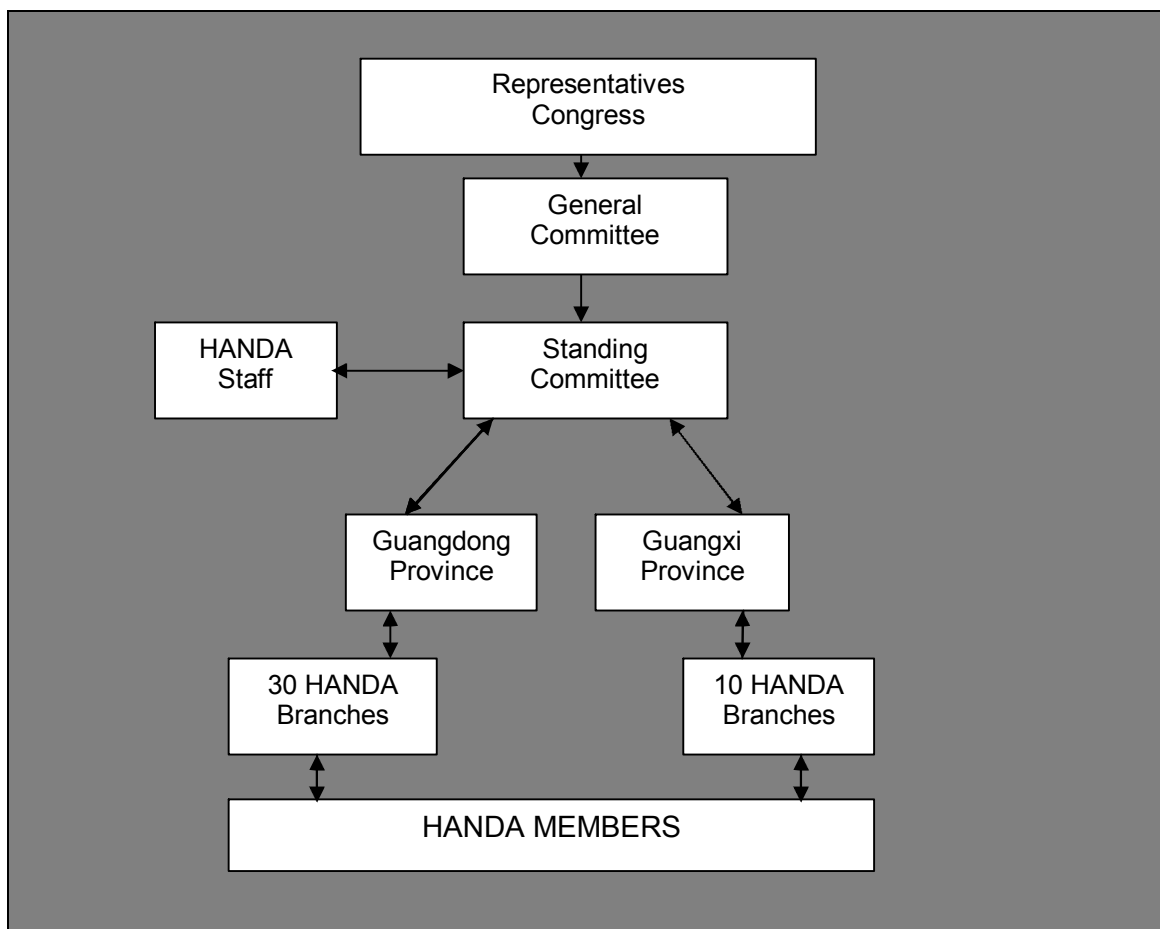
The formation of non-government organisations became possible in China around this time when the first environmental NGOs coincided with the government's desire to see the 'greening' of the country. This led to alternating politics of tolerance and strict control (Ho, 2001: 897-898). The earliest regulations by the Chinese communist government on social organisations date from September 1950, when the former Ministry of Internal Affairs announced the Temporary Measures for the Registration of Social Organisations. The term 'social organisation' there meant a non-government organisation (Wang, in Ho, 2001: 902). However, directly after the communist take-over the central state exerted increased strict control over voluntary civil organisations with a virtual absence of civil society during the collective period (1956-78). This gradually began to change with the start of economic reforms which in turn unleashed great social changes initially unforeseen by the government. In the decades of economic reform to date, there has been an explosive growth of social organisations (Ho, 2001: 902). HANDA's emergence was made possible because of these changes within China.

There remains in many situations, however, a lack of separation between government and society, which is said to be affecting the development of grassroots organisations. In order to obtain government support or recognition, administrative intervention is often accepted with the result that many Chinese scholars or policymakers are critical of NGOs in China saying they are not worthy of the name NGO: instead they are called GONGOs, or 'government organised NGOs'. To reduce intervention in the civil sector, in 1994 the central government issued a ban on concurrent leadership functions by the state and party officials. This was reiterated in 1998 but the effect this has had on the development of NGOs remains uncertain (Ho, 2001: 904). In HANDA's situation, there appears to be a clear separation, although their Constitution does state it must work 'under the leadership of the Chinese Communist Party' and 'abide by China's national constitution, laws, regulation and policies...' (HANDA Constitution, 2003).

## Structure

HANDA's structure includes a Representatives Congress, General and Standing Committees, supported by staff based in the national office in Guangdong. In addition there are members, the majority of whom reside in 30 leprosy villages (out of a total of 63 leprosy villages) in Guangdong Province; and in 10 leprosy villages (out of a total of 40 leprosy villages) in Guangxi Province. HANDA is working strategically towards covering all leprosy villages in both provinces, and eventually moving into neighbouring provinces. They also welcome as members people who have been diagnosed with leprosy since the government's isolation policy was abolished. I discuss the operation of HANDA's structure in Governance (see below).

**Figure 5.3 Organisational Structure of HANDA**



**Source:** Field Notes. 2004.

## **Governance**

HANDA's Representatives Congress is the highest authority and main governing body of the organisation, made up of elected members. It meets annually and representatives from each branch attend: an election process at local Branch meetings identifies representatives. Regular Branch meetings are held, usually in leprosy villages. The Representatives Congress elects a new General Committee of fifteen members every five years, and this represents as many HANDA branches as possible. At present one woman and fourteen men make up the General Committee. The General Committee sets up a Standing Committee of seven members, five selected from its own membership, the other two being ex-officio members: General Secretary (Dr Chen) and one of the Honorary Presidents (Dr Yang). HANDA has two Honorary Presidents: Dr Yang Li He and Mr Lin Zhi Ming. At present the Standing Committee consists of men only. It meets every two months, usually for one or two days. The Standing Committee generally makes routine decisions. However a consultation process takes place with all members prior to major decisions if these need to be made outside of the annual Representatives Congress. Directing and managing policy is also part of the Standing Committee's role.

### *Standing Committee*

I met with four male Standing Committee members in a Focus Group. All talked of devastation when forced into isolation and how they had spent most of their lives in a leprosy village. When asked how they coped, they didn't know. They had to live one day at a time. Even today leprosy stigma is still strong:

Since 1968 I have only visited my home town twice. It is only 50 kilometres from where I live. My father died in 2002 and my mother in 2003. I was very sad because I received a message from my family saying not to go to their funerals. Leprosy stigmatised our family and relatives. Some people thought it best to 'eliminate' the existence of their family members like me to protect the rest (Field Notes.2004).

When asked to identify the most exciting thing about being a member of HANDA there were four animated replies: "It has helped change my life"; "We have suffered from stigma and discrimination, but now we can communicate with many people"; "My generation suffered a lot,

now we can see some justice and have peace and happiness”; “My heart is full of joy, I used to be a leprosy patient, but now HANDA treats me as a normal person” (Field Notes.2004). However, underlying these responses is sadness because their families still fear them. Stigma will only be fully gone when families can welcome home their leprosy-affected members again.

The men’s goal is to set up additional HANDA Branches in Guangxi and other provinces. They will use advocacy activities to increase both membership and the numbers of volunteers who are willing to support HANDA. To achieve this professional staff are necessary; they are pleased HANDA has an excellent team which has grown steadily since the organisation began.

There is concern about three leprosy villages which now have only one person living in each as the other residents have died. It is the Standing Committee’s wish to move these people to villages where they will have the company of other residents; however, these moves are not allowed. The reason? Local governments are paid to administer the leprosy villages and if they are closed down that money would cease and the government would have to find the staff new positions elsewhere. This indicates people affected by leprosy are not always the real beneficiaries of funding and other resources. In this situation it is the local government staff who benefit, illustrating yet another form of exploitation.

When I asked why there were no women on the Standing Committee, and only one woman on the General Committee, one man replied that “women had smaller brains than men and were not able to think as well” (Field Notes.2004). This appeared to be a completely acceptable explanation to which they all agreed.

### *Growing Pains*

Dr Chen spoke about the fast growth of HANDA, which appears to be highlighting an increasing lack of capacity in the governing bodies, ie, the General and Standing Committees. He readily acknowledges HANDA is a membership organisation and elected grassroots members should be involved in governance; however, with current elected members increasingly out of their depth, it is an escalating problem. Members of the two committees are committed to the organisation but their minimal education and limited worldview is beginning to compromise good decision-

making. The challenge ahead, according to Dr Chen, is how best to continue growing HANDA as a grassroots organisation and keep governance in the hands of members when they appear to have reached their level of competence, or possibly exceeded it. Dr Chen said this is one of the most critical challenges HANDA has faced to date.

### **Leadership**

Dr Yang was instrumental in the emergence of HANDA as a Chinese non-government organisation. He all but single-handedly developed HANDA to the point where professional staff were employed. Although never having had leprosy himself there can be little doubt Dr Yang would have experienced the stigma of leprosy, simply because of his involvement with the disease. Leprosy is not a clever career move in any society, and not least in China.

Dr Chen, a dermatologist, took up the senior professional position of General Secretary in 1999. At the time of his graduation in 1985 Dr Chen met Dr Yang and they became good friends. Dr Chen learned much about leprosy from Dr Yang, considering him “a very good role model” (Field Notes. 2004). Prior to taking up the position with HANDA, Dr Chen worked with leprosy in a government role and this experience held him in good stead for his HANDA appointment.

### **Staff**

Staff numbers increased with HANDA’s growth and at the time of this case study HANDA employed twenty-one people. Along with the General Secretary there are: Office Manager (female), Office Assistant (female), three Project Co-ordinators (one male : two female), Accountant (female; father had leprosy), Cashier (male, has had leprosy), Publications Assistant (female, has had leprosy) two social workers (one male : one female) all based at the national office in Guangzhou. In addition an Eye Team consisting of two doctors (both male) and a nurse (female) travels extensively around the provinces undertaking eye surgery<sup>39</sup> in an especially adapted vehicle. A Wound Care Team of two nurses (both female) also visits the provinces. Due to a large number of amputees living in leprosy villages the Wound Care Team also organises production of prostheses at HANDA Prosthetics Workshop near the national office where three

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<sup>39</sup> Leprosy affects eyes: M.leprae destroys the eye muscles so blinking and shutting eyes is no longer possible. Without the protection of blinking and shutting the eye when sleeping, the eye dries out and is damaged by dust and other particles.

technicians (all male and all having had leprosy) make high quality artificial limbs. HANDA has two drivers (both males affected by leprosy).

### *National Office*

HANDA's offices are located in a multi-story apartment block which is used both as office space and housing. Their offices are bright and airy inside, well laid out with modern facilities and technology. The Office Manager was employed in 1999 soon after the appointment of Dr Michael Chen as General Secretary. Her role includes administration of scholarships, small loans, skills training and the communal fund plus membership management. Although she has not experienced leprosy herself, the Office Manager is committed to HANDA. The Project's staff are all university trained; none have been affected by leprosy. Their main work is with HANDA's nine international donors, of which two are from Hong Kong, developing project proposals and preparing reports.

The two social workers each have a social work major from university and heard about HANDA through advocacy by the General Secretary in his bid to raise public awareness of leprosy needs in China. These positions are based half-time in the national office and half-time helping people in the leprosy villages. Travel is often rugged including climbing mountains by foot and crossing rivers by small boat to reach remote isolated areas where leprosy villages are situated. Due to the subordinate place of women in China and the fact women have generally been less involved in HANDA's activities, a female social worker was employed specifically to deal with this delicate gender issue. Recently trips to Guangzhou have been organised for leprosy village residents who are able to travel. This was the first time many had been out of their village for decades.

On the other hand, it is also the role of the social workers to organise opportunities to speak at universities and other venues, taking HANDA members with them to tell their story. This is not for fundraising, which is not permitted within China, but rather to encourage people to volunteer their time to help renovate some of the old, dilapidated buildings making up leprosy villages. The social workers play a key role in coordinating these activities.

The accountant, who graduated from the Technical School for Accounting, has had personal contact with leprosy because her father had the disease. However, it was only in 1998 she discovered this as her father kept it a secret due to the stigma their family would have otherwise faced: his decision enabled his children to undertake professional training. The cashier had leprosy and due to government law was isolated in a leprosy village in Jiangxi Province from 1972 until 1998. At that time (1998) local policy in Jiangxi was different to that in Guangdong (where people were not permitted to leave the villages, or to transfer to another village), so he was able to leave his village and move to Guangzhou to take up his position with HANDA. Although his role is called cashier, he actually does a variety of small jobs around the office, including getting water and making tea. The Publications Assistant had a very difficult childhood due to leprosy, and never knew her family as she grew up.

#### *Medical Teams*

The nurses, not affected by leprosy themselves, travel extensively to leprosy villages around Guangdong Province working with disability needs, eye and wound care, protective footwear and prevention of disability. Because large numbers of people are waiting for artificial limbs which were not previously available, the nurses' workload is heavy. They also work with leprosy-affected people living outside the villages; these are people who have been diagnosed with the disease since 1982 when prior to this enforced isolation in leprosy villages was mandatory. Most of the people with whom they work speak Cantonese, but there are some isolated groups who have different dialects and this makes verbal communication difficult. One of the nurses said; "This does not matter, we can communicate with our heart, they can feel our heart" (Field Notes. 2004). The nurses also visit local Dermatology Clinics which are part of the government primary health care system. Nowadays this is where leprosy diagnosis takes place so it is important for HANDA to keep in regular contact with staff as there is nothing in the nursing training curriculum about leprosy.

#### *Quilt Project Sewing Enterprise*

Close to HANDA's national office is the Quilt Project Sewing Enterprise, now financially independent. Managed by Elly, a young woman on HANDA's staff, the enterprise involving some twelve or so people, mainly women, produces high quality goods for sale locally and

internationally. HANDA trains leprosy-affected people in sewing, and while most trainees are integrated into the local labour market, some stay on at the Quilt Project to make quilted baby blankets and other items such as place mats, bags of many different types, and more. The premises are in a multi story apartment block, occupying three to four rooms. They have good light and the machines and equipment are modern and well maintained.

#### *Prosthetics Workshop*

Due to the high level of leprosy related disability and subsequent amputations there is a significant demand for artificial limbs. Artificial legs are of high quality and their appearance is as near to a normal leg as one can imagine. In addition, the prosthetics staff manufactures footwear which is specially adapted for leprosy-affected anesthetic feet. Special footwear protects feet so inadvertent damage does not take place when walking, or working on daily activities. The workshop is on the ground floor of a large complex, and is contained in two rooms which open out onto a courtyard. Staff have modern equipment and maintain it well.

#### *Scholarships, Skills Training and Small Loans*

Since 1982 when enforced isolation of people with leprosy ceased, people newly diagnosed with the disease remain in the community. However, stigma still exists and if leprosy is recognised life can be very difficult for the person and family involved. HANDA undertakes small projects to help such people. These include scholarships at varying levels for children whose parents live in hardship because of leprosy; skills training to increase employment prospects; and small loans to help families achieve economic independence. At present there are more people needing help than there are funds available.

#### *Communal Fund*

The Standing Committee manages the communal fund, into which each member pays a small amount per month. It was set up to work like an insurance scheme for people in leprosy villages: for example, if a member has a sudden emergency or health need, they can borrow from the fund. Membership is additional to membership of HANDA, but only HANDA members can join the communal fund. This has given a great sense of security to many of the people living in leprosy villages (Field Notes.2004).



## **External Relationships**

### *Donors*

HANDA had eight international donors at the time of this case study, including the following: Sasakawa Memorial Foundation; American Leprosy Missions (ALM); The Leprosy Mission New Zealand (TLM NZ); Associazione Italiana Amici di Raoul Follerau (AIFO); Handicap International; Hong Kong Medical Mobilisation Co-operation; Rotary Club Hong Kong South District; Casa Ricci Social Services. These organisations contribute on varying scales from small to medium financial contributions for scholarships and small loans projects to core funding partnerships. TLM NZ, together with matching government funding from NZAID's VASS programme, supports HANDA's core funding with a four year capacity building project providing the organisation with opportunities to grow in strength and effectiveness so it can more effectively work with its members. The Sasakawa Foundation appears to have an especially strong, friendly relationship with HANDA, contributing significantly to the organisation financially and with moral support.

### *IDEA (International Association for Integration, Dignity and Economic Empowerment)*

Based in Seneca Falls, New York State, USA, IDEA is an international membership organisation made up of individuals worldwide who have had leprosy. IDEA also accepts as members grassroots membership organisations made up of leprosy-affected people: HANDA is a member of IDEA. It was IDEA which so inspired Dr Yang to set up HANDA as a membership organisation for people affected by leprosy in his own country. While Dr Yang and Dr Chen see HANDA as a branch of IDEA very few of HANDA's members are aware of the relationship between the two organisations: their allegiance is to HANDA. While IDEA is fully supportive of HANDA and its role as a grassroots leprosy organisation it appears many of IDEA's ways of working are embedded in HANDA's structure. It may be that IDEA needs to give HANDA less "support" and allow it more space for self determination.

### *ILEP (International Association of Anti Leprosy Organisations)*

HANDA is not a member of ILEP, but receives funding from some ILEP members, including The Leprosy Mission. There appears to be an underlying tension in the relationships between some ILEP members and HANDA, with varying interpretations depending on who is being

discussed and who is discussing them. An ongoing tension relates to forms of accountability both for funders and implementers of projects. This is an interesting issue which may benefit from further research but is beyond the scope of this thesis. In the meantime it will provide reasons for ongoing vigorous debate.

#### *Other local NGOs*

HANDA is part of a growing network of local NGOs in China and works with them, sharing expertise when possible. For example, if a person from an NGO takes part in training, then that person will in turn share what they have learned with other interested NGOs. While this adds capacity to the other NGOs, it also reinforces the training material in the mind and understanding of the original trainee. Not least, it also helps spread training benefits when funds for training are scarce. This shared training arrangement is working well for HANDA and its counterpart NGOs in Guangzhou.

#### **Members and their leprosy experience**

The experience of leprosy is one which touches every aspect of an individual's life, their family also, and while drugs can cure the medical problem, it cannot be assumed social problems associated with the disease will then cease. I heard many times, "They said I am cured, but I didn't *feel* cured and I didn't *look* cured" (Field Notes. 2004). Time and again their testimonies illustrated the violation of the Universal Declaration of Human Rights (United Nations, 1948) with all thirty Articles being breached in various ways. This research allowed people whose leprosy had been 'cured' to have a voice about their experience and why they joined HANDA.

#### *Listening to their voices*

Without exception, every respondent said that isolation and stigma had been the most difficult aspects of their leprosy experience; often being almost too difficult to bear. Hi Qi's story is typical. According to Hi Qi (aged 89) a diagnosis of leprosy forced him into a leprosy village and he has never been out since entering in 1950. He was a teacher until dark patches appeared on his face, destroying his future when leprosy was diagnosed. Nowadays Hi Qi greatly appreciates his membership of HANDA and the way it has given him a sense of belonging and elevated his self worth. Although HANDA staff have offered to take him out, he says he is too old now, and

scared after so long in isolation. He enjoys meeting people HANDA take into his village to help the residents, saying that after more than fifty years in isolation they give him much pleasure.

Huang (aged 69) was about thirteen years old when diagnosed with leprosy. Until her diagnosis she knew nothing about leprosy so was deeply shocked when the local government forced her into isolation away from family and friends. She said some two hundred people were in the leprosy village when she went there, most of them very disabled. Gradually leprosy disabled Huang also, especially her hands. Treatment became available, but by then Huang was very disabled so although her leprosy was eventually cured, the consequences remained with her. Another challenge for Huang was that children could not be born into leprosy villages. This denied a woman's natural instinct to become a mother, and for many the longing to have a child and not being able to, was too much to bear. Huang first heard about HANDA when Dr Chen and Dr Yang visited with some volunteers to meet her and others in the village, saying they wanted to rebuild their rundown communal kitchen. She was amazed and soon realised this was a good organisation and she wanted to become a member. For Huang, HANDA brought hope for the first time in her lonely isolated life. HANDA's social workers now regularly visit her village, along with outsiders (as she calls them) to spend time with the residents. Huang believes there must have been a major change outside in attitudes towards leprosy because they now have so many visitors to their village.

Jasmine (aged 25) had a difficult childhood due to leprosy growing up not knowing her parents. At nine years her hands became less flexible, eventually locking in a permanent half-grasp, so characteristic of leprosy. Paralysis affected her eyelids, leaving them unable to shut properly. Leprosy was diagnosed when she was fourteen and although two years' drug treatment cured the disease, her hands and eyes remain disabled. She said, "When I was told I had leprosy, I wanted to leave this world. It was too much to bear. No one would touch me. I was alone. My tears fell like heavy rain every day" (Field Notes 2004). Coping with leprosy-related disability is physically challenging, demoralizing and traumatic.

Through a local Dermatology Clinic Jasmine heard of HANDA and she joined HANDA's sewing school in 1997 aged 17. Dr Yang personally encouraged Jasmine and she was delighted when he

asked her to accompany him to the 15<sup>th</sup> International Leprosy Congress in Beijing. There a specialist doctor in leprosy reconstructive surgery said Jasmine's nerve damage was repairable so she agreed to surgery. For some two years prior to this, Dr Yang had searched for Jasmine's mother, which included visiting her father who said he did not know his wife's whereabouts. Eventually, however, he revealed she was in a leprosy village, so Dr Yang went and met her, and brought her to the hospital the day before Jasmine's surgery was to take place. It seemed incomprehensible that a mother and daughter could both have leprosy with the other not knowing and that they could spend years isolated from each other in different leprosy villages. Jasmine has got to know her mother and no longer feels abandoned. The surgery to her hands, which now look normal, has helped her regain self-esteem. This enabled her to attend English evening classes, and she has also completed accounting and computer skills. In 2004 Dr Chen asked if she would like to work in the HANDA office and she accepted this new challenge.

Sam Mai's husband left her when she was diagnosed with leprosy, taking with him their two children then aged 1 and 2 years. She was isolated to an island and depression engulfed her. Only the faint hope of seeing her children again kept her from taking her life. Recently she was able to meet her children, now adults, but she has never seen her husband again. Sam Mai said she cannot imagine anything worse for a mother than being denied access to her children. Although she can now leave the island if she chooses, Sam Mai has chosen to stay because she feels ill-equipped to live 'outside'. She is, however, pleased to be a member of HANDA and plays a major role in HANDA's local Branch Association especially enjoying promoting HANDA by making short visits to people and places near the leprosy village.

Dr Yang wanted to help Zhu learn to farm chickens at his leprosy village so he could train others, and a trip to Korea was part of this plan. A leprosy group in Korea had developed a chicken farm which was proving very successful. But this did not work out because at that time a person with a history of leprosy did not qualify for a passport. Zhu felt his right to an identity was denied him, and he suffered psychologically. Since then Zhu has worked in HANDA's national office where he appreciates the respect shown to him. He has family and sees them occasionally; however, his sister-in-law is still afraid of him so tensions remain about his visits.

Kuen (60) was isolated at nineteen and her family remains afraid of leprosy after all this time. She is an amputee with one leg removed above her knee and has no artificial limb yet <sup>40</sup>. To move around the village she has a small chair which she places ahead of herself and balances her stump on it to walk. There appeared to be a blank look of resignation on her face as she talked. But her eyes lit up a little when she mentioned HANDA, and HANDA's communal fund available for emergencies or unexpected financial difficulties. As Kuen said good bye and moved away using her chair as a walker, another two women passed by, one riding a large tricycle towing a small trailer and in the trailer sat a woman, another amputee without a prosthesis.

*From camaraderie and solidarity...*

I was an onlooker at a three-day Special Member's Meeting set up so members from leprosy villages in Guangxi Province could meet Guangdong members. The two social promoters, with Dr Chen, facilitated the meeting at HANDA's offices. Having previously met members in a leprosy village context it made a huge impact on me seeing them in a neutral environment: it strongly reiterated the fact that people with leprosy are normal people who should be encouraged to speak for themselves and define their own development. Those participating in the meeting were indeed contributing with dignity, self respect, and at times with animation. They unanimously supported HANDA as 'their organisation' and were proud to be members. Coming together to talk about experiences, their roles in various Branches, and offering to help Guangxi members set up HANDA in their own area showed that when people regained self-confidence they are able to contribute significantly to the ongoing growth of the organisation.

*...to anger and rebellion*

During the meeting an animated discussion took place about an incident at the ShiGangZhang Leprosy Village where residents were attacked. A former leader of the nearby town gathered some one hundred people and with knives and sticks they attacked the leprosy-affected people. Due to disability, residents of the leprosy village were unable to escape suffering major injuries. Some were beaten into a coma. The village was left in ruins, including workshop equipment used for generating additional income and the road into the village was destroyed. It is alleged an official from the local dermatology clinic saw the attack, and although he called the police

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<sup>40</sup> HANDA's Prosthetics Workshop has a backlog of approximately 600 prostheses waiting to be made due to the fact that no amputees in the leprosy villages had artificial limbs prior to HANDA's existence. Lack of funds prevents HANDA from outsourcing work; and the communal fund is far too small for purchasing such expensive items.

immediately, was too afraid to take further action. The police took more than an hour to arrive and provided no reasons for their delay. The leprosy-affected people were hospitalised with extensive injuries, giving the attackers further opportunity to occupy the village. The issue remains unresolved.

This situation incensed HANDA members with them saying the attack and subsequent occupation of the village means the residents have become refugees. They fear that if it is not investigated it may happen in another leprosy village. It was agreed HANDA would advocate for the villagers by insisting on an investigation; the arrests of those who inflicted harm on the residents; payment of residents' medical costs; and compensation for loss of earnings from the villagers' business. HANDA's advocacy role is slowly becoming more overt as China's civil society gains added opportunities for freedom of speech, but it is still somewhat tenuous when involving either local or national government.

## **Achievements**

### *Belonging*

The topic that came up again and again, no matter where questioning was directed, was the importance of belonging and relationships within HANDA. To the members this was of paramount importance: HANDA is their organisation. Having known isolation, indignity, poverty, and a total lack of voice, it cannot be underestimated how significant it is for these people to become members of HANDA. They emphasized that belonging to HANDA had given them new hope and they looked forward to the future with anticipation instead of fear, dread and loneliness. While HANDA can never fully replace lost relationships with family, especially children, the fact that it advocates for full rights and inclusion for people with leprosy means that at least life may be different for new generations affected by the disease.

### *Choice and opportunities*

The three men who were the first leprosy-affected people in China to obtain passports to travel abroad saw this as a major triumph. In 1994 when their passports were granted they felt they finally had an identity. No longer were they objects to be discarded, they were people: "We were regaining our humanity in society" (Field Notes. 2004).

Members considered the organisational structure of HANDA a key feature because it reinforces the fact it is a membership organisation and member's voices are important. The appreciation of processes whereby members can contribute to HANDA's decision-making, knowing their voices are heard and respected, cannot be underestimated. This directly contributes to the restoration of dignity, self-worth and self-confidence enabling them to leave behind their trauma, and to become valuable citizens who in turn can contribute to their society.

HANDA's registration in 1996 as a Chinese non-government organisation was a milestone in itself because such a phenomenon in China had not previously been possible. The fact an organisation advocating for the rights of socially excluded people was successful in setting up and gaining registration was a tremendous gain, not just to its members, but to people within the system (Dr Yang in particular) who had worked for the cause for many years. Having recognition and acceptance from the highest level is a benefit which members and staff respect and from which they gain a substantial amount of pride. While this may seem at best somewhat nebulous or subjective to outsiders, or at worst a hierarchy of control, such recognition in this situation appears to directly contribute to a sense of wellbeing and empowerment at all levels.

#### *Access to benefits*

Having no material or monetary benefits, HANDA's Communal Fund, into which each member contributes RMB30 per year, provides a sense of wellbeing because members know that for an emergency, especially a medical emergency, there is a source of funding from which they can draw. As residents in leprosy villages receive a meager pension from the local government (RMB50-250 per month depending on varying factors) many are not in a position to pay for medical care or any extras over and above living expenses. Therefore, the Communal Fund is a major source of security and reassurance for these people who are eking out a survival in volatile conditions. Not least, it is an asset which belongs to them as members, and is administered by them also. This was clearly a major practical advantage of being involved in HANDA.

There is great pride resulting from successfully setting up and administering the Quilt Project Sewing Enterprise and Prosthetics Workshop. Both are providing services for HANDA members, one with training and employment, the other with empathetic staff constructing

artificial limbs and footwear. That the Quilt Project Sewing Enterprise is now operating as a successful business without external funding is a testament to members' involvement and commitment to make it work. Staff receive a salary which is commensurate with similar businesses, and their working conditions (including first-rate lighting) are excellent. The pride and empowerment evidenced by members who had previously known only oppression and isolation was apparent in the confident body language and their willingness to talk about how life for them had changed so significantly. Even when they had to live with disability for the rest of their lives, the fact that their psychological state of mind was so optimistic made their physical disability seem more manageable.

In every situation where HANDA was involved it appeared the sense of wellbeing engendered through membership of the organisation was considerable. 'Choice' was possible for the first time in many members' lives and the affirmation and advocacy espoused by HANDA, plus new and exciting opportunities, were indeed giving hope to generations who had previously had none, as well as to future generations.

## **Challenges**

### *Maintaining grassroots ownership*

Despite HANDA's achievements and significant growth since its inception in 1996, an issue has emerged which has the potential to cause tension unless sensitively and constructively dealt with: how to maintain grassroots ownership of the organisation and continue growing. The fact that members undertake the governance of HANDA gives it a strong 'bottom-up' structure ensuring ownership at grassroots by people sharing a common experience. However, professionals who are empathetic, but for whom most do not share leprosy as a common experience, are managing HANDA. While this has worked well so far, it is a situation which needs careful monitoring so HANDA not only remains in grassroots ownership but also recognises the members in governance positions with little or no education may inadvertently constrain the organisation's growth.

Tackling gender issues is another challenge. Women, when given opportunities for talking in female-only company, opened up significantly more than when in mixed company. It appears



women are often constrained by the prevailing cultural view which supports the dominance of men, and HANDA's current governance structure has no process to ensure equal numbers of men and women are involved in the organisation at decision-making levels. Although Dr Chen, the senior professional, is aware of gender issues and desires a more equal representation of women in the organisation, it is not easy for him to instigate such change and maintain grassroots ownership as the majority of members are men.

### *Relationships*

HANDA members attribute major importance to 'belonging' because of their common experience of leprosy and the relationships they have within HANDA. However, HANDA also has to develop external relationships in order to grow and for funding purposes. Even when attitudes of external partners appear to HANDA (and possibly other organisations) to be patronising or imposing, HANDA needs to explore ways of dealing with such issues as part of its capacity building and growth into a strong organisation. This does not excuse patronising attitudes but rather recognises such challenges exist and pre-empt them by setting strategies in place rather than dealing reactively and defensively.

### *Dependency on external funding*

As it is not possible to undertake fundraising in China, NGOs such as HANDA need to seek external funding. While HANDA's goal of self-sufficiency is commendable, it is currently a fledgling organisation in a country which historically has not encouraged NGO activities. Therefore, commitment to funding for capacity building over a strategic period of time is a necessity, along with empathetic support and mentoring, from organisations with similar aspirations.

## **CASE STUDY CONCLUSIONS**

There are four general observations resulting from this case study of HANDA. Firstly, there is evidence of change occurring through members' collective action and solidarity, and that for the first time in their lives the common experience of leprosy is providing strength and impetus for achieving in various measures social inclusion and empowerment.

Secondly, historically China's dermatology clinics were largely responsible for people with leprosy and they, plus the traditional anti-leprosy agencies working in China, had a largely medical focus in relation to the disease. Thus a gap was left unfilled and HANDA's social emphasis and highlighting of human rights issues is welcomed by people who are 'cured' from leprosy, but do not feel cured.

Thirdly, growing pains are evident within HANDA as the governing body and professional staff grapple with maintaining HANDA's grassroots ownership in a growth stage which may need to move beyond the governing body's experience and level of competence.

Fourthly, HANDA is working hard to develop and maintain meaningful alliances with international leprosy organisations. They have developed some strong partnerships and are working to develop additional partnerships which can further help them achieve their organisational goals. HANDA has a strong commitment to bottom-up participatory development and rigorously applies this, especially when communicating with partners or prospective partners.

Taken together we can see HANDA has successfully become a legitimate grassroots organisation in its own right. Although their beginning was externally initiated, the structure of HANDA provides for members to be involved in decision-making processes. The need for women to be more involved at decision-making levels is an issue they are grappling with, although as yet there are no clear ways forward. Overall, HANDA is showing that groups of people who have faced extreme social exclusion, disability and stigma, can by collective action and solidarity gain measures of social inclusion and empowerment.

## CHAPTER 6: GRASSROOTS LEPROSY ORGANISATIONS

*“If people feel good about themselves, they can start to create change”.*

*B. (Venky) Venkatesh* <sup>41</sup>

What factors influence groups of leprosy-affected people to establish grassroots leprosy organisations? How well do grassroots leprosy organisations fit into the international environment along with other anti-leprosy organisations? This thesis has argued that although drugs cure leprosy medically, many people do not feel cured as they remain socially excluded and disempowered because of disability and the age-old stigmatisation associated with the disease (as outlined in Chapter Two). It also argued (in Chapter Three) that although grassroots membership organisations are set up for varying reasons, they can enable social inclusion and empowerment for members through collective action and solidarity. The question is can groups of leprosy-affected people achieve social inclusion and empowerment through membership of their own grassroots leprosy organisations?

Chapters Five and Six detailed the emergence of two grassroots leprosy organisations: ENAELP in Ethiopia and HANDA in China, and showed the resulting changes in members' own lives, their families, and their communities. These chapters also provided brief insights into experiences between these grassroots leprosy organisations and international anti-leprosy organisations. This chapter will discuss the findings of Chapters Five and Six in relation to the research framework and context outlined in the first three chapters, firstly analyzing the specific reasons for their development; and secondly, identifying whether through membership of grassroots leprosy organisations people can move towards sustainable social inclusion and empowerment. Thirdly, it will briefly discuss the relationships between grassroots leprosy organisations and their larger, more powerful international counterparts.

### FACTORS OF INFLUENCE

A number of factors combined to bring about the grassroots leprosy organisation phenomenon. As discussed in Chapter Two, a key aspect was the medical focus on leprosy by governments and international anti-leprosy organisations which had largely overlooked sociological issues.

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<sup>41</sup> B. Venkatesh, known as Venky, is Director of Action on Disability in India. He has been blind since his teens.

Combined with the WHO focus on the medical treatment of leprosy and a politically motivated campaign for leprosy elimination as a public health problem, which was not a bad thing in itself, the sociological challenges of leprosy were largely ignored. However, sociological issues remained very important to leprosy-affected people as it is from this gap of unmet sociological needs that grassroots leprosy organisations began to emerge: both ENAELP and HANDA fit into this category.

In Ethiopia and China, both countries with large numbers of people living with permanent leprosy related disability, there was little hope of regaining an equal place in society. This was exacerbated by the fact that many leprosy villages existed in which leprosy-affected people had been forcibly isolated by governments and anti-leprosy legislation, which in reality was tantamount to human rights abuse. In both ENAELP's and HANDA's situations, a relaxing of government controls contributed to leprosy-affected people joining together and establishing their own organisation.

### **Characteristics of Organisational Start Up**

As argued in Chapter Three, organisational start-up is a critical factor which defines an organisation's growth path (Nogueira, 1987: 173). Therefore, it is important to compare early characteristics contributing to the emergence of grassroots organisations, and those which specifically applied to the emergence of ENAELP and HANDA. Chapter Three shows there are varying types of organisational start-up, of which two in particular are common: self-generating groups and externally initiated groups. This differentiation usually comes about due to the type of catalytic agent involved.

#### *Catalytic Agents*

ENAELP falls into the category of a self-generating group with its energetic, dynamic founder-leader having the vision to draw together a group of leprosy-affected people who were unhappy with the level of medical services available. Both the founder-leader plus a backlash to the reduction of medical services previously provided by ALERT hospital in Addis Ababa were the motivating factors which gave birth to ENAELP. HANDA was an externally initiated group that began after a leprosy doctor attended an international forum which gave him the impetus to set

up a membership organisation for China's leprosy-affected people. This coincided with a breakdown in services for leprosy-affected people that had previously been provided by the government, and more latterly the barefoot doctor system. Both ENAELP and HANDA needed to go through official procedures for registration of an organisation, and for both this happened at a time when such opportunities were opening in each country after a long period of authoritarian and socialist rule in ENAELP's situation, and communism in China.

### *Membership, Structure and Governance*

Having had different beginnings, ENAELP and HANDA both needed to work out an organisational structure on which they could build and grow, plus governance mechanisms which would define the nature of their organisations. As for grassroots organisations generally, ENAELP and HANDA's membership reflects their *raison d'être*, as the majority are people who have been affected by leprosy and are still living in isolated leprosy settlements or villages.

Grassroots organisations have varying options regarding the type of structure they choose to use, mostly reflecting models of other organisations. Both ENAELP and HANDA decided they would be membership organisations whereby members retain control in the main decision-making body. For both, this is an assembly of elected members representing as diverse a range of the membership base as possible. In ENAELP's case, their original structure was challenged because the organisation, which began as the Addis Ababa Ex-Leprosy Patients Association, went national, so changes to their Bye-laws were needed to better reflect their intent to be as representative as possible. At the time these changes were made ENAELP also took the opportunity to assess their gender situation, in particular, how well women were contributing to ENAELP's decision-making processes. Although by then ENAELP had a female Chair, few other women had significant roles. Their response was to state in the Bye-Laws that the General Assembly needed both female and male representation from each area, with practical and financial provision made to enable this to happen. HANDA's original constitution is still serving the organisation adequately in terms of their structure; however, in terms of gender issues, there are no provisions which would encourage women into decision-making roles.

Although in Chapter Three it was stated Avina (2002:130) felt it was often difficult for self-generated grassroots organisations to recognise the importance of defining whether or not they would be participatory or top-down, this did not appear to be a problem for ENAELP. It was clear from the outset that methodologically they chose to be participatory in style and when their founder-leader, who had become Chair, became dictatorial and used top-down non-participatory methods of working, the membership showed their disapproval by voting him out of office. Similarly, HANDA which was externally initiated, went down the route of participatory methodology although, as some people informed me, it is really only participatory for the male members.

Both organisations have governing bodies made up of elected members, which is a common structure for grassroots membership organisations. While this is good at one level in that it reflects the membership and a voluntary ethos, it also distances the highest level decision-making from the direct professional experience of the staff (Clark, 1991: 66-67). Add to this an ensuing problem whereby the organisation grows substantially, and outgrows the ability of the elected members to govern. This affects self-generated as well as externally initiated groups alike when members from the grassroots are involved in governance. An additional dilemma is that often those on the governing bodies have no idea this is a problem. ENAELP and HANDA are both experiencing these dilemmas. Clark (1991:66-67) offered no help, only stating that achieving the right balance is a major challenge and a problem that few grassroots organisations have overcome completely. For ENAELP and HANDA this is cold comfort although ENAELP may have inadvertently stumbled on a possible solution: trust, nurtured by common experience.

While ENAELP's new Managing Director, a university graduate, has not himself had leprosy, he has personally been affected by it and experienced the stigma of the disease because his father had leprosy. The common experience of leprosy is therefore shared between him and the membership, including those elected onto the governing body. With this common experience providing a strong bond between the decision-making body and the key professional staff member, the possibility of developing an enduring trust between the two is far more likely.

### *External Relationships*

According to Avina (2002:131) in Chapter Three, the type of organisational start-up experienced directly influences the timing and success of establishing external relationships. For self-generating groups it is likely to be a more difficult process as they begin with fewer contacts than externally initiated groups; coupled with the fact they are usually more resource-poor at start-up. This is reflected in ENAELP and HANDA: ENAELP appears to be finding it more of a challenge to contact potential partners, while HANDA with its more advanced starting point along with greater professional capacity and connections appears far more adept at doing so. Other factors also influence this to a greater or lesser degree, including relationships with existing organisations: in ENAELP's and HANDA's situations, with international anti-leprosy organisations. While tensions have been evident, and at times ENAELP and HANDA have felt somewhat threatened, they are both learning skills of diplomacy and negotiation, as well as how and when to stand up for themselves in times of disagreement. The issue here is that it takes strong leadership but also a leader who is willing to learn from experience, especially when it comes to making a decision about whether or not to bite the hand that may in future feed you. HANDA appears to have been more resilient here than ENAELP, probably due to its stronger resource base and the clear benefits of an externally initiated start up.

### **Characteristics of Growth**

Using guidelines identified by Esman and Uphoff (1984:72ff) it appears ENAELP and HANDA are growing organizationally, in character and substance, as well as in membership numbers. The key here is that organisation size should not grow disproportionately to the understanding, experience and capacity of its leaders' and members' ability to handle the growth.

### *Participation: both a process and a result*

Growth, according to Clark (1991:105) happens when an organisation charts its own course, and if done in a participatory way which values the importance of process as much as results (Carroll, 1992:78) it will strengthen organisational capacity. That ENAELP leaders took the recent Strategic Planning exercise to every region in Ethiopia where they have members indicates the willingness of ENAELP to work in a participatory way. As a result, ENAELP is stronger because they now have a Strategic Plan owned by its entire membership. This indicates

ENAELP understands the need for participatory processes if they are to achieve positive results and organisational growth. Similarly, HANDA demonstrated their understanding of participatory processes, and the importance of their leaders and members working together to make plans and set goals, by organising exchange visits between Branch members from different Provinces. The idea here was not only for participants to do planning and set goals, but to share common experiences, to learn from each other, and to join together in sessions of facilitated learning where members learned about advocacy and how they might together raise the profile and needs of leprosy-affected people in the wider community.

### *Conflict Management*

According to Esman & Uphoff (1984: 75) conflict management is second on their list of guidelines, with good handling of conflict indicating organisational ability and adeptness. While they argue that some conflict within organisations should be regarded as normal, ongoing unresolved conflict is debilitating and can be harmful. In this regard ENAELP appears to be a fairly normal organisation, generally coming through conflict situations stronger as a result. This happened at the time the founding leader was voted out as Chair of the organisation. The new Chair settled into the role using a fully participatory model of running the organisation, endorsed by the members, and which enables members to be involved wherever possible. ENAELP's ability to handle conflict is constantly tested, and strengthened, as the previous Chair continues trying to regain his position. While the professional staff and the governing body of ENAELP try to limit the damage this may cause it remains a particularly difficult situation and one which is testing ENAELP's conflict management skills to their limits. In HANDA's situation, if their leaders have had to become involved in conflict management it must have been successfully undertaken internally as I have not heard of it.

### *Resource Mobilisation*

In their own ways, ENAELP's and HANDA's experiences compare well to resource mobilisation undertaken by other grassroots organisations. Both are effectively acquiring local resources even though there are constraints within their respective countries. ENAELP has developed partnerships with local businesses and some government Ministries resulting in additional funding for local advocacy for leprosy-affected people. Although fundraising is not permissible



in China, HANDA has mobilised local people, through advocacy, to join in work teams which are rebuilding and renovating some of the dilapidated houses in the leprosy villages. They also encourage others to visit the leprosy villages to mix socially with the residents and provide interest and encouragement to them. Then there is mobilisation of their own memberships in self-help activities as well as mobilisation of external resources - usually international donors. These are common activities of grassroots membership organisations and ENAELP and HANDA appear to be no different.

### *Resource Management*

As discussed in Chapter Three, Esman and Uphoff (1984: 78) contend that resource management has the highest correlation with overall organisational performance. ENAELP and HANDA appear to bear this out: ENAELP's capacity has been consistently lower than HANDA's in terms of their ability to manage resources; for example, management of projects and the associated funds, which probably harks back to their different starting points. It also relates to ENAELP having fewer resources including fewer professional staff than HANDA, and the fact they had to go through a transition period when the membership voted their strong founder-leader out of office. While many grassroots membership organisations have not been able to change leaders and go through a transition phase successfully, it would appear ENAELP's transition phase was successful. However, in order to increase their capacity to manage resources more effectively and to manage more resources in total, priority is being given to training staff and governing body members as appropriate. They have also been developing new governance and operational policy and procedures to strengthen their organisational base.

### *Being a Learning Organisation*

Organisational growth and maturity is more likely when an organisation has a safe culture for conscious learning (Taylor, 2002:347) because as well as successes there will be mistakes and failures and much can be learned from both. However, grassroots membership organisations do not always have the luxury of choosing to cultivate a safe learning environment as they may have donors who are mainly interested in compliance issues (Uphoff, 1986:192). Carroll (1992: 115) argues strongly for relationships with mutuality; permanent consultation and two-way

information flow, so that a process of empowerment occurs for the grassroots organisation. On this basis, how are ENAELP and HANDA placed in terms of being learning organisations?

Members and staff from both ENAELP and HANDA told me they have a lot to learn, and they wish to learn as much as possible in order to develop themselves personally and also to benefit their respective organisations. Such development is possible, they said, when they have funders who understand these needs and not only provide a budget for training, but also spend time with many of them in a mentoring role. ENAELP clearly appreciates the mentoring role provided by one of their funding partners saying it has been a critically important contribution to their organisational development.

ENAELP and HANDA appear to be typical of growing grassroots organisations. There is a clear and conscious movement within each to implement participatory models of working which recognises processes are as important as results, especially when one of their long-term goals for members is empowerment. Enabling members, who for the most part are extremely poor and many of whom are disabled, to contribute meaningfully and take part in decision-making leads to positive results. Although many are intangible, as identified by the Grassroots Development Framework quoted in Chapter Three, it is most often the intangible results which increase social capital, self determination and self-esteem, allowing empowerment to occur.

### **Common Experience**

As discussed in Chapters Five and Six, without exception, each person I met who had experienced leprosy was worse off in every way because of the disease. The experience of leprosy is one which touches all aspects of an individual's life, and that of their family and community because of the severe stigma associated with it. People remain disabled not only physically but also emotionally as they may lose a spouse, children, family and friends; employment which results in financial hardship; the security of their home; and other traumatic losses. Chapter Two argues that leprosy is a complex disease and should not be seen only as a medical issue: it is a major social issue also. The social consequences of having leprosy are immense and it is this *common experience* which draws people together.

Chapters Five and Six described the historical situations in Ethiopia and China whereby people with leprosy were systematically isolated at diagnosis for the remainder of their lives. Isolation consisted of removal to a remote community or government-run village where only leprosy-affected people lived, and where they had to fend for themselves. While this was extraordinarily tough, and many did not survive or ensured that they personally did not survive, those who did formed a strong bond through common experience.

Experiences were excruciatingly awful. Some as children experienced the devastation of separation from their parents; adults and children alike suffered the pain of parting. They were told frightening myths as to the cause of leprosy, and many suffered witchdoctors' 'cures' which could be anything from being smeared with cow's blood or human spit, to 'surgical procedures' which was nothing short of butchery causing further damage. Men, women and children all suffered the devastation of losing sensation in their hands and feet; they themselves often caused further damage to their limbs by not really understanding the importance of self care, or through being forced to work even with anesthetic limbs because no work meant no income and no income meant no food.

The strength of the bond formed by common experiences shared over many years has played a major part in the formation of ENAELP and HANDA. These people have suffered and survived together. They understand that while the medical experience of leprosy is based on lack of pain or anesthesia of limbs, the social experience of leprosy is the opposite and is far more painful than they can describe. This common experience of really *knowing* the devastation and stigma caused by leprosy is what has formed their collective strength as a group of people. It is this common experience and collective strength which is at the heart of ENAELP and HANDA.

### **Failure of Welfare**

There are strong similarities between ENAELP and HANDA, as shown in Chapters Five and Six, in terms of how the failure of welfare contributed to the emergence of these grassroots organisations. In Ethiopia, many leprosy affected people travelled to Addis Ababa seeking medical treatment from the ALERT Hospital, and they enjoyed access to free, on-demand healthcare for many years. However, there came a point when ALERT's donors began to make

changes to their funding arrangements because the system they were operating was costly and unsustainable. When the leprosy community which surrounded ALERT hospital realised the significance of the proposed changes, they tried to prevent them from taking place, but without success. Then they became angry because they felt they were being victimised yet again as leprosy-affected people. This anger, combined with the creative vision of their founding leader, and the timing politically which by then allowed such an organisation to be formed, were major driving forces which contributed to the beginnings of ENAELP.

Similarly, in China there was an effective leprosy control programme operating which the government ran from national to county levels. Repeated mass or general surveys seeking leprosy-affected people took place and those diagnosed with the disease were sent to leprosy villages run under the auspices of local dermatology clinics. Contributing to this programme were the barefoot (rural) doctors who played a major role in the government's healthcare system. However, in China's new consumer society which began opening to outside competition, the welfare expenditure needed to maintain the leprosy villages became unsustainable and residents were literally abandoned. Dr Yang, who had been involved in leprosy all of his working life, was deeply troubled by these developments so when he heard of an ex-leprosy patients organisation forming internationally, he wanted the same for leprosy-affected people in China. Working within the evolving political framework, Dr Yang brought about one of China's first non-government organisations, known today as HANDA.

Both organisations were born following the collapse of welfare initiatives which were unsustainable. In both situations thousands of people had grown dependent on the welfare offered to them: they saw it as their right and did not expect it to stop. When it did stop it not only left a major gap in services it also left a lot of angry people who felt they were victims and suffering all over again because they had leprosy. Forming their own organisation was, therefore, a very strong reaction to the failure of welfare and the perceived injustices and breach of human rights this caused.

## **Human Rights Issues**

The brief history of leprosy as discussed in Chapter Two illustrated some of the injustices faced by people with the disease through the centuries. Compulsory isolation from society was the norm in many countries, including Ethiopia and China. Other forms of injustice were played out according to government laws which actively discriminated against people with leprosy, as though they were criminals. For example, as stated in Chapter Six, it was only in 2000 in China that the Marriage Law of 1950 was revised and the word 'leper' deleted along with the clause that prevented people diagnosed with leprosy from entering into marriage.

The experiences of social exclusion faced by ENAELP and HANDA members were total, playing out graphic examples of the cultural and moral social bond rupturing between individuals and society (Silver, 1994: 539); and showing how discrimination denies these already poor people participation in every sphere (de Haan, 2001:27-28; Silver, 1994:543). And rather than any hierarchical power relations that may be present in a society providing mitigating factors, (Silver, 1994:539), it showed that leprosy-affected people are always the lowest of the low. As Chapters Four and Five showed, all thirty articles in the Universal Declaration of Human Rights (United Nations, 1948) were violated in Ethiopia and China, as borne out by the experiences of ENAELP and HANDA members.

Chapter Two argues that when the actions of exclusion are repeated over and over again through social relations and practices then this becomes a form of structural violence (Farmer, 2003: 29-50). Even without physical violence, Farmer contends that people may be radically violated because much suffering is structured by historically given and economically driven processes and forces of which gender inequality, racism, poverty and a stratified society are at the heart. Given the disadvantaged position of such people, and the traditional welfare model which many anti-leprosy agencies bought into, Freire's (1989) insistence that oppressed people must struggle for their own interests and not leave their fate to others must have seemed ludicrous to some. However, with his concession that there may be an occasional need for consciousness raising amongst the oppressed so they are aware of their rights and can decide what is in their best interests it becomes less ridiculous and more realistic – and his experience is certainly

believable: that the finest struggles with the best results are those fought by oppressed people themselves.

Thus, fighting for human rights from Freire's perspective means that groups of leprosy-affected people will be more effective and obtain the best results if they join together and take up the fight themselves. ENAELP and HANDA are actually proving this to be true, and are showing that with appropriate consciousness raising, combined with energy resulting from the anger borne from their common experiences, plus the solidarity of collective action, they can indeed decide what is in their best interests and how best to fight for the social inclusion and empowerment they so much desire.

## **SOCIAL INCLUSION AND EMPOWERMENT**

That there has been a movement towards social inclusion and empowerment for the members of two grassroots leprosy organisations, ENAELP and HANDA, has been established. What remains to be established is the extent of the movement, and whether or not it is likely to be sustainable.

### **Movement Towards Social Inclusion**

The fact that members of ENAELP and HANDA believe their membership of these grassroots leprosy organisations has increased their sense of value and dignity through newly gained social inclusion is a very positive finding. In addition, many members indicated their subsequent involvement in projects implemented by ENAELP and HANDA had provided new sources of income and increased their living standards significantly. Of course, the most significant movement towards social inclusion is when discrimination against leprosy-affected people is completely eliminated, so is this really possible and how is such a change measured?

Perhaps one answer is the restoration and healing of the cultural and moral social bond which ruptured between these individuals and society (Silver, 1994: 539). Leprosy-affected people themselves have provided examples which are important to them and these include: access to government officials for discussion and communication; access to the banking system within their country; the right to travel on any type of public transport; having a passport. The measurements may also include a change of conditions enabling leprosy-affected people to do

the same as other people are able to do (de Haan, 2001:27-28; Silver, 1994:543): for example, live in a community of choice rather than in enforced segregation; visit family members at will; enjoy equal employment opportunities; and undertake international travel. Finally, that a disease called leprosy no longer has the power to place people at the bottom of the social hierarchy (Silver, 1994:539) but that they may be seen as individuals of worth because of who they are, not despised because of a disease they have had.

Changes to the law in many countries, including Ethiopia and China, along with increased understanding of the facts about leprosy are certainly reinforcing many of these changes which are occurring. And while there is a long way to go it is evident that ENAELP and HANDA are contributing to change and their members are benefiting. The movement towards social inclusion has begun.

### **Movement Towards Empowerment**

Even though some people now class the word 'empowerment' as development jargon, to actually be empowered remains vitally important to people who have been disempowered. It is useful to look at Moser's (1989) work in gender where she identified the empowerment approach as one which emerged following the failure of other approaches, the first of which was welfare. Having recognised in this thesis that a welfare approach addressing the social issues of leprosy clearly did not work in a sustainable way for leprosy-affected people, it is helpful to see how the empowerment approach has been useful in gender and development. With the empowerment approach advocating for greater self-reliance and self-determination made possible through bottom-up mobilisation, plus the importance of meeting strategic structural needs as well as practical needs, it seems that both ENEALP and HANDA are working within this framework.

It is interesting to compare the progress of ENAELP and HANDA with that of the two grassroots organisations referred to in Chapter Three, DAWN and SEWA in India, both seen as successful, and to note the similarities and differences. DAWN's and SEWA's experiences began by addressing practical needs such as health and employment, but simultaneously and strategically challenging structures, legislation and human rights abuses: ENAELP and HANDA are both doing this. DAWN and SEWA are bottom-up membership organisations for a disadvantaged

group of people (women), enabling them to become stronger through organisation and raised consciousness in order to challenge their own subordination: likewise, ENAELP and HANDA are bottom-up membership organisations for a disadvantaged group of people (affected by leprosy), enabling them to become stronger through organisation and raised consciousness to challenge their situation. If DAWN and SEWA are seen as successful organisations which have enabled the empowerment of their members, even though they acknowledged it was a slow process, ENAELP and HANDA by following the same approach must also be moving towards empowerment of their members. But how can we know for sure, and can empowerment be measured?

As discussed in Chapter Three, the Grassroots Development Framework (Ritchey-Vance, 2002: 308-310) effectively breaks down abstract concepts into more measurable components so that increased social capital can be more adequately measured. This appears to provide a useful yardstick for ENAELP<sup>42</sup> and HANDA<sup>43</sup> with both organisations showing signs of empowerment on the three levels identified: firstly, direct benefits to families and individuals; secondly, organisational strengthening; and thirdly, broad impact in local, regional and national areas. Each of these three areas has tangible and intangible components and ENAELP and HANDA appear to be working within them all. A 'plus sign' ( + ) indicates many signs of empowerment with a 'minus sign' ( - ) indicating remaining negative factors which require more work before they are fully addressed.

## **CHAPTER SUMMARY**

In summary members of ENAELP and HANDA appear to be experiencing varying degrees of social inclusion and empowerment as a result of membership in their respective organisations. As grassroots leprosy organisations, both seem to be functioning in ways similar to other grassroots membership organisations. Key factors contributing to ENAELP and HANDA's establishment are similar to those experienced by other grassroots organisations, and from this it would seem reasonable for ENAELP and HANDA to expect similar results. Certainly, many of their results so far appear to confirm that expectation.

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<sup>42</sup> See Appendix 6 for Grassroots Development Framework: Signs of Empowerment, ENAELP, Ethiopia

<sup>43</sup> See Appendix 7 for Grassroots Development Framework: Signs of Empowerment, HANDA, China



The fact that ENAELP and HANDA are made up of disabled leprosy-affected people means their memberships are severely disadvantaged. However, apart from perhaps taking longer than other grassroots organisations to reach their goals, they appear to be achieving significant measures of social inclusion and empowerment for their members. This may seem somewhat unbelievable to external groups, in particular, some international anti-leprosy organisations that remain committed to a welfare approach because of their assumption leprosy-affected people are simply not able to help themselves let alone others. Perhaps they had not reckoned on the power of the common experience or the motivation fueled by angry reactions to the failure of welfare in Ethiopia and China. Solidarity has certainly brought them power from joining together in collective action. If external groups who are sympathetic to the work of ENAELP and HANDA can continue providing support, and are willing to help elicit their latent capacity and viability, then the resulting energy will continue to be a major development resource within their respective countries.

## CHAPTER 7: CONCLUSION

*“The problem is not how to wipe out all differences, but how to unite with all differences intact.”*

*Rabindranath Tagore<sup>44</sup>*

Through working with two local grassroots leprosy organisations, ENAELP in Ethiopia and HANDA in China, this research has examined whether such organisations can bring about social inclusion and empowerment for their leprosy-affected members. From the perspective of members from both organisations and that of myself, an outsider, local grassroots leprosy organisations (whose aim is advocating for equal opportunities for their members) have indeed made an impact in terms of achieving social inclusion and empowerment. The focus of the case study was attempting to understand how these local grassroots leprosy organisations came about, what they have achieved, and what implications this has for leprosy-affected people and anti-leprosy organisations in the future.

This chapter begins with a reflection on the fieldwork methodology, followed by a brief overview of the thesis tracing key themes that have emerged throughout the research. The chapter moves on to outline the main conclusions of the thesis in the areas of leprosy, social inclusion and empowerment and the changes brought about through common experience, collective action and solidarity, and the role of international anti-leprosy organisations in future partnerships.

### REFLECTIONS ON METHODOLOGY

Using a qualitative approach of semi-structured interviews and focus groups, plus participant observation, was clearly the best option for exploring a relatively unresearched topic. I felt this left the research open for me to investigate additional ways that grassroots leprosy organisations may be contributing to achieving social inclusion and empowerment for their members which is not yet covered in literature. It also proved appropriate culturally in both ENAELP and HANDA, since the people responded better to casual, relationship-based discussions than formality. Despite the apparent informality of conversations, I still worked through a detailed question guide (see Appendix 1), steering conversation where appropriate, and with the help of my translators where needed.

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<sup>44</sup> Rabindranath Tagore, 1861-1941: Bengali poet from India who won the Nobel Prize for Literature in 1913.

For the research with both ENAELP and HANDA, I discussed with my translators what I wanted to achieve, and went through the question guides with them first. However, I made it clear that chatting conversationally may also be useful to my research and if an interesting issue came up spontaneously then we needed to be free to explore it further, without hurrying. In addition to the translators' language skills, I also relied on them to act as a social and cultural interpreter, especially in leprosy village and community situations for which I had little or no previous experience. In both cases the translators had had such experience and were familiar with the situations concerned.

## **SUMMARY OF THESIS**

This study began with an introduction in Chapter One outlining the research questions: what factors have influenced groups of leprosy affected people to form grassroots organisations; what factors contribute to the establishment and growth of viable and effective grassroots organisations and is this attainable for groups of socially excluded, often disabled, leprosy-affected people; if so, how may they best succeed? And to what extent are grassroots leprosy organisations accepted by international anti-leprosy organisations and is it possible for meaningful alliances and partnerships to develop between them?

Then the study areas were introduced along with the research approach and general methodology emphasising qualitative and inductive learning based on an understanding of the historical context of leprosy and the new phenomenon of emerging grassroots organisations.

Chapter Two showed that historically leprosy and its treatment had been limited to medical issues, even though for centuries severe stigma had contributed to the social exclusion and disempowerment of people with the disease. Revealing the extent of the social exclusion problem and human rights abuses was essential in understanding how much leprosy-affected people have been let down by 'the system' as it were, with traditional anti-leprosy organisations maintaining a medical-only focus for such a long time. The concept of leprosy-affected people themselves determining their own development was introduced and the question posed as to

whether or not grassroots leprosy organisations using a participatory bottom-up model of development can effectively meet the needs of their membership.

Chapter Three explored grassroots membership organisations, concluding there are currently some very effective and well-known grassroots organisations that have empowered their members. The reasons for their emergence, the ways they evolved, and their development approaches were discussed, all contributing to the conclusion that bottom-up participatory development must recognise *processes* are as important as *results* and are necessary for grassroots membership organisations wishing to empower their members.

Chapter Four presents discussion and analysis of ENAELP, a grassroots leprosy organisation based in Ethiopia. The desire of ENAELP's membership to experience social inclusion and empowerment, and the extent to which this is happening, is presented along with firsthand information from members about their experiences of social exclusion and disempowerment, and what this has done to them as individuals, families and communities affected by leprosy. How these experiences have contributed to the emergence of ENAELP is a key factor in this research.

Chapter Five is a discussion and analysis of a second grassroots leprosy organisation, HANDA, based in China. Although the emergence of HANDA came about differently to that of ENAELP, the desire of their membership is the same: to experience social inclusion and empowerment. The degree of success that HANDA is achieving is outlined along with more firsthand information from members about their life experiences. Again, these experiences are key factors in the development of HANDA and make major contributions to this research.

Chapter Six analyses the research data collected from both case studies and compares and contrasts this information with that in Chapter Three. The experiences of ENAELP and HANDA as grassroots leprosy organisations appear to be very similar to those of other general grassroots organisations, which tends to indicate they may reasonably expect similar outcomes. There are some differences, however, which if not addressed may contribute to significant difficulties in the future. This includes the extent to which grassroots leprosy organisations such as ENAELP

and HANDA are accepted by international anti-leprosy organisations and whether it is possible for meaningful alliances and partnerships between them.

## **CONCLUSIONS OF RESEARCH**

There are five conclusions drawn from this research in answer to the questions: ‘What factors influenced groups of leprosy-affected people to establish grassroots membership organisations? How can groups of leprosy-affected people achieve social inclusion and empowerment through membership in their own grassroots leprosy organisation? To what extent are grassroots leprosy organisations accepted by international anti-leprosy organisations and is it possible for meaningful alliances and partnerships between them?’

### **Failure of Welfare Programmes**

Firstly, the failure of welfare programmes in Ethiopia and China were major factors influencing leprosy-affected people to form grassroots leprosy organisations. That, combined with their *common experience* of leprosy and the trauma of *human rights abuses* they experienced were very powerful factors drawing these leprosy-affected people together to work in solidarity to achieve their collective aims.

As discussed in Chapter Two, welfare creates dependency; Moser (1989: 1807) referred to welfare beneficiaries as passive recipients. It is also inherently unsustainable; Moser (1989: 1809) referred to the main method of welfare implementation being through “top-down” handouts, or free goods and services. Therefore, the outcome for leprosy-affected people involved in the Ethiopia and China leprosy programmes prior to the mid 1990s was never going to be one of social inclusion and empowerment. The welfare programmes were satisfactory while they lasted, but were set up to fail because they did not deal with issues of sustainability or the empowerment of their beneficiaries. When the programmes ceased, the ensuing anger and betrayal felt by the people added to the humiliation and disgrace already being experienced, and of living with stigma and social exclusion. Thus, when ENAELP and HANDA moved into the “free spaces” (Carroll, 1992: 174) left by the welfare failure, they were powered from the accumulation of anger that had built up over generations and finally peaked. In order for such a

strong movement to be replicated elsewhere, circumstances would somehow need to prompt the ire of the people, giving them a common cause for which to fight.

### **Participatory Development Approach**

Secondly, there are many similarities between ENAELP and HANDA, and the life cycles of other general grassroots organisations. Their successful *modus operandi* appears to be that of working within a participatory development approach that attributes as much importance to process, ie, a bottom-up model of working, as to results. This cultivates a strong sense of belonging to the organisation, ownership of its work and ideals, plus sustainability of benefits.

It also means that members of the organisations are determining their own future having had sufficient consciousness-raising to set them on the path of their choice so they can fight together. When discussing issues of self determination in Chapter Six, Freire's (1989) work was acknowledged, in particular, his insistence that oppressed people must struggle for their own interests and not leave their fate to others. In the cases of ENAELP and HANDA it is apparent that the self determination process itself is one which is providing significant empowerment for their members. This supports Freire's view that the finest struggles with the best results are those fought by oppressed people themselves.

### **Governance from Grassroots**

Thirdly, the challenge of enabling elected members from the grassroots to provide effective organisational governance is one ENAELP and HANDA are facing. While both are membership organisations that have decided to work with a participatory philosophy, the fact that their governing bodies consist of voluntary members with limited or no education and a diminutive world view, is becoming a problem. Although ownership of an organisation by members may well be strong, and along with the voluntary and participatory ethos proving to be very positive factors, the highest level decision-making being at a distance from the professional experience of the staff stifles growth and strategic leadership. As discussed in Chapter Two and Chapter 6 Clark (1991:66-67) identified this as an issue for grassroots membership organisations in general but one few have overcome. It would seem, therefore, that this is an important topic for further research and examination because it may very well be a key factor on which grassroots

membership organisations either live or die. Any new research should also explore the common experience factor discussed in Chapter 6, with particular reference to ENAELP's situation whereby their senior professional staff member has a personal experience of leprosy, which he shares with the membership.

### **Social Inclusion and Empowerment**

Fourthly, ENAELP and HANDA, as grassroots leprosy organisations, are achieving a measure of social inclusion and empowerment for their members. The importance of both process and results in developing organisational policy, setting goals and defining and implementing activities is a major factor in this achievement. This thesis did not take a static view of social inclusion and empowerment, rather it has analysed changes in terms of how they are moving towards these two inter-related goals.

Although increases in wellbeing are always good in the view of the people concerned, unless it is sustainable it would really be no better in the long-term than the welfare approach that preceded it. Hence, the investigation was carried out in relation to the philosophical approach of each organisation and the opportunities of self-determination for their members. The fact that social, psychological and economic empowerment was occurring meant members were experiencing many practical changes, and in some situations major changes. However, these would not necessarily be sustainable unless what Moser (1989:1803) termed strategic change simultaneously took place. In other words the political and structural context of their societies also needs to change. Full social inclusion and empowerment in its broadest sense is dependent on the external environment.

Looking at the Grassroots Development Framework (Ritchey-Vance, 2002: 308-310) and identifying both the tangible and intangible signs of empowerment taking place at local, regional, national and international levels, it appears that after a somewhat slow take-off momentum and movement is occurring externally. This means the long-term strategic awareness raising and advocacy undertaken is having an impact, in both Ethiopia and China.

## **Meaningful Alliances and Partnerships**

Fifthly, meaningful alliances and partnerships between ENAELP and HANDA and international anti-leprosy organisations are possible, some do exist, but much is dependent on the organisational culture of each anti-leprosy organisation. While some are strongly supportive of ENAELP and HANDA, actively encouraging them to make decisions about their own self determination and destiny, others cling to the assumption such a model is not possible or, for reasons best known to them, is better not encouraged.

The importance of partnerships in development has been emphasised by many writers and researchers (Carroll, 1992; Chambers, 1983 and 1997; Clark, 1991; Cleaver, 2002; Crewe and Harrison, 1998; Fowler, 2002; Harrison, 2002). Authentic partnership is a much debated issue: what is it? Is such a thing possible? Carroll's position on this, as discussed in Chapter Three, is that the secret of non-paternalism is mutuality, in obligations, contributions and benefits, and the right to question or to protest, sensitive guidance (for both partners) so that mutual legitimacy is recognised. When there is such a difference in power relationships, and differing realities from very different parts of the world, not least significant cultural diversity, there are inherent issues for both partners to work through in order to achieve anything like an authentic partnership. Spending time developing a partnership indicates the importance each organisation places on this, but all too often, it does not happen. With the powerful organisations usually coming from the west, it means that developing country grassroots organisations may need to stand firm if it seems to them that neo-colonialism may be emerging, even if it means losing a potential funding source.

## **RELEVANCE: To the wider field of leprosy and grassroots organisations**

This thesis has used the examples of ENAELP and HANDA to show how grassroots leprosy organisations can facilitate social inclusion and empowerment for their members. It has emphasised, however, that these grassroots leprosy organisations came about to a large extent because of the failure of welfare on which they had grown to depend. With the collapse of these unsustainable welfare systems the beneficiaries were left in perhaps an even worse state than before, and were certainly ill-prepared for the hard realities they faced trying to survive post welfare failure. In terms of relevance to wider literature this thesis has shown that welfare-type



programmes implemented without sufficient thought given to issues of sustainability are ineffective long-term. Such programmes should be approached with caution, if at all, since it is clear they have very short-term benefits, if any, and they create dependency which is completely the opposite to empowerment. Organisations that are supporting or are implementers of welfare programmes should seriously question their motivation in doing so.

ENAELP and HANDA arguably have as their membership some of the world's poorest people, the lowest of the low, disabled by leprosy. Yet, as constrained as they are, these people have shown that through the strength of collective action and solidarity they can be change-makers. In terms of relevance to wider literature this thesis has shown that the most oppressed and discriminated of peoples, if given the opportunity and appropriate conscientisation, can indeed make decisions about their lives and their destiny. It affirms Freire's claim, and it supports bottom-up development models which place significant importance on process as well as results and outcomes. This thesis is a significant milestone for grassroots leprosy organisations, as they now have a knowledge-based platform of research which attempts to understand the complexities of both leprosy and grassroots organisations, bringing the two together for the first time.

## APPENDICES

### APPENDIX 1: GUIDING QUESTIONS FOR FIELDWORK

#### Understanding of leprosy by ENAELP/HANDA members:

1. When did you know you had leprosy?
2. What did know about leprosy at that time?
3. What work do you do on the Committee?
4. Had you seen anybody in your family or village with leprosy? If yes, who?
5. Was there a cure for leprosy at that time?
6. What did you know about leprosy disability?

#### Understanding of ENAELP/HANDA by ENAELP/HANDA members:

7. When did you hear about ENAELP/HANDA? How? Tell me about it.
8. Do you know who started ENAELP/HANDA, and why it was started?
9. What was the ENAELP/HANDA vision?
10. What motivated people to join ENAELP/HANDA?
11. Why did you decide to become a member?
12. How long have you been a member?
13. Do you think ENAELP/HANDA is growing? If so, why?
14. Is it the shared experience of leprosy that holds you together as an organisation, or issues of poverty or discrimination?

#### ENAELP Executive Committee / HANDA Standing Committee:

15. When were you elected onto the Committee?
16. Why are you a Committee member?
17. What work do you do on the Committee?
18. How do you think ENAELP/HANDA can best help its members?
19. What would you like to see ENAELP/HANDA doing which it is not doing?
20. What does ENAELP/HANDA do well? And not so well?
21. Has ENAELP/HANDA changed its role over time since it was established?
22. What is your vision for the future of ENAELP/HANDA?
23. How does ENAELP/HANDA find funding for its work?
24. Have experiences with funders been positive or negative? Tell me what you know about them.
25. What do you know about governance and management issues?
26. Does ENAELP/HANDA have a constitution? If so, who wrote it and when?
27. When was ENAELP/HANDA registered as an NGO? How did this happen?
28. Do you feel the professional staff are helping ENAELP/HANDA? If so, how?
29. What have you learned from working with them?

*ENAELP only:*

- 30. What does the Steering Committee do?
- 31. How does this help ENAELP?
- 32. What have you learned from working with them?

**ENAELP Regional and Local Associations / HANDA Branches:**

- 33. Do you belong to a Regional or Local Association / Branch?
- 34. If yes, where? And what do you do there?
- 35. How is the Executive Committee /Standing Committee involved with Regional and Local Associations / Branches?
- 36. Are the members happy with this? Tell me why?
- 37. What have you learned from working with Regional and Local Associations / Branches?

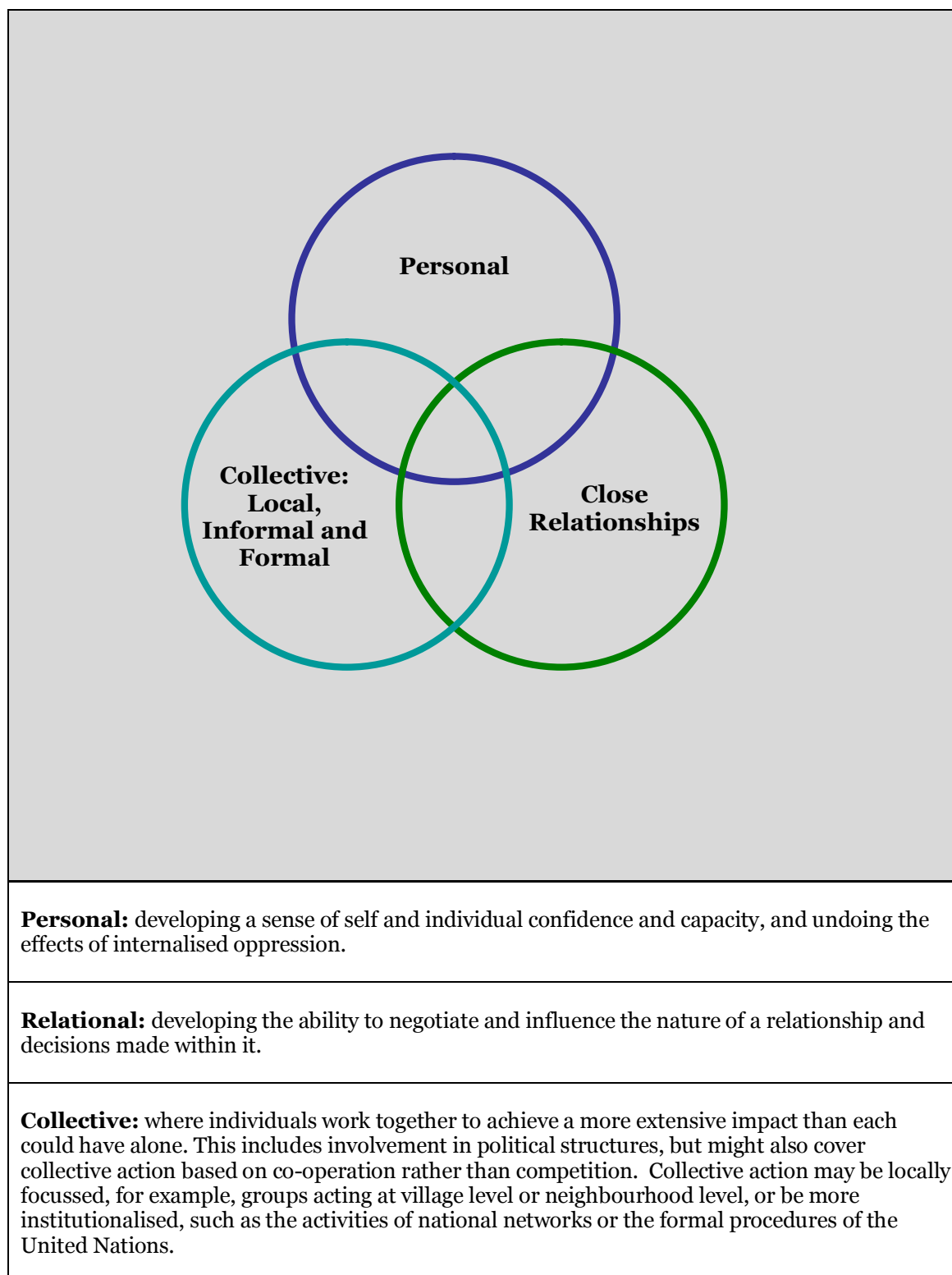
**Professional Staff:**

- 38. What are your professional skills/qualifications/experience?
- 39. Why did you decide to work for ENAELP/HANDA?
- 40. How long have you worked here?
- 41. Do you feel, as a professional staff member, you are helping ENAELP/HANDA?
- 42. What do you do best to help ENAELP/HANDA build its capacity as an organisation?

**General:**

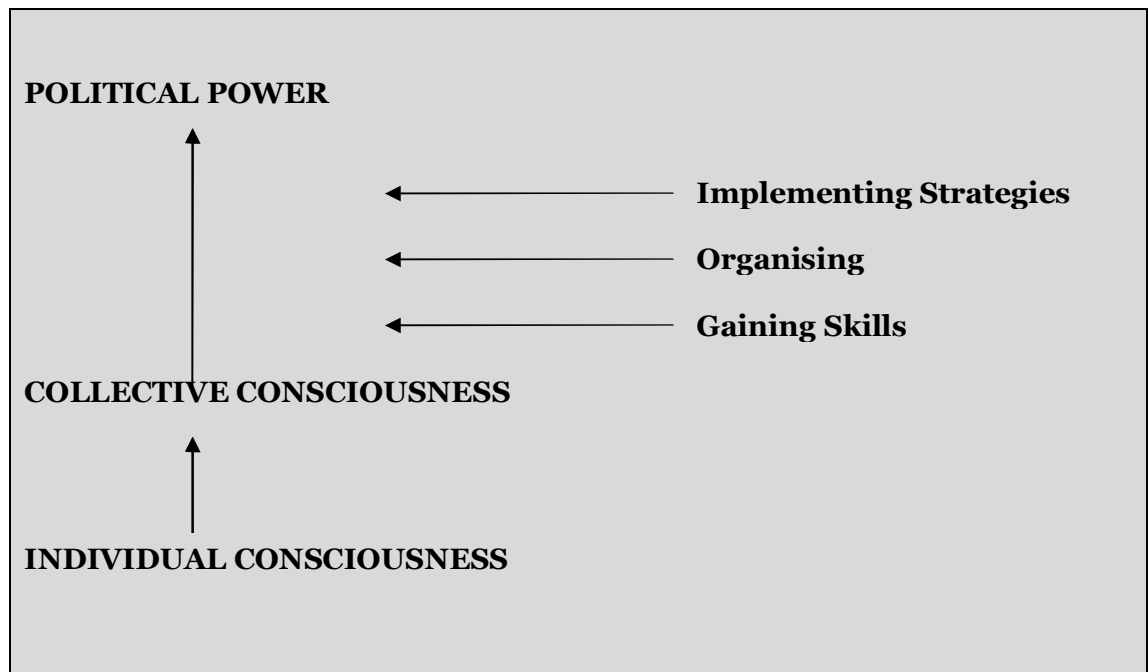
- 43. What changes have ENAELP/HANDA made for people affected by leprosy?
- 44. What does the general public think about leprosy today?
- 45. Have ENAELP/HANDA made a difference to leprosy stigma in the general public?  
If yes, how?
- 46. Is there anything else you would like to tell me?

## APPENDIX 2: THE THREE DIMENSIONS OF EMPOWERMENT



**Source:** Rowlands (1997: 14)

### **APPENDIX 3: MODEL OF LEVELS OF EMPOWERMENT**



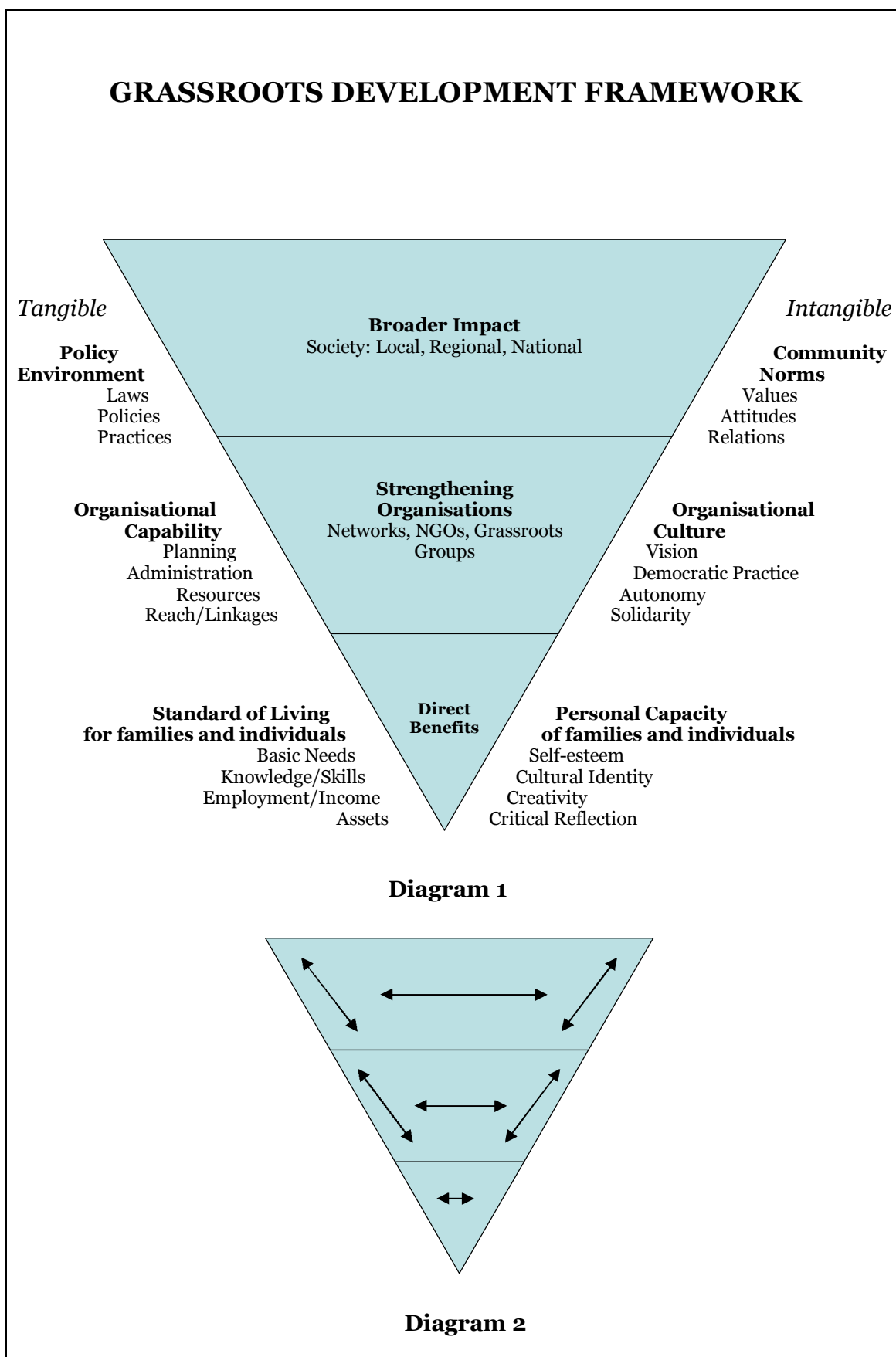
**Source:** Schuler (1986: 33)

## APPENDIX 4: MOSER AND EMPOWERMENT

Policy Approaches to Low-Income Third World Women and Gender Planning					
Issues	Welfare	Equity	Anti-Poverty	Efficiency	Empowerment
<b>Origins</b>	Earliest approach: residual model of social welfare under colonial administration; modernisation / accelerated growth economic development model.	Original WID approach: failure of modernisation development policy; influence of Boserup and First World feminists on Percy Amendment; declaration of UN Decade for Women.	Second WID approach: toned down equity because of criticism; linked to Redistribution with Growth and Basic Needs.	Third and now predominant WID approach: deterioration in world economy; policies of economic stabilisation and adjustment rely on women's economic contribution to development.	Most recent approach: arose out of failure of equity approach; Third World Women's feminist writing and grassroots organisations.
<b>Period most popular</b>	1950-70: but still widely used.	1975-85: attempts to adopt it during and since Women's Decade.	1970s onward: still limited popularity.	Post 1980s: now most popular approach.	1975 onward: accelerated during 1980s, still limited popularity.
<b>Purpose</b>	To bring women into development as better mothers; this is seen as their most important role in development.	To gain equity for women in the development process: women seen as active participants in development.	To ensure poor women increased their productivity: women's poverty seen as problem of underdevelopment not of subordination.	To ensure development is more efficient and more effective: women's economic participation seen as associated with equity.	To empower women through greater self reliance: women's subordination seen not only as problem of men but also of colonial and neo-colonial oppression.
<b>Needs of women met and roles recognised</b>	To meet PGN* in reproductive role, relating particularly to food aid, malnutrition and family planning.	To meet SGN^ in terms of triple role, directly through state top-down intervention, giving political and economic autonomy by reducing inequality with men.	To meet PGN* in productive role, to earn an income, particularly in small-scale income generating projects.	To meet PGN* in context of declining social services by relying on all three roles of women and elasticity of women's time.	To reach SGN^ in terms of triple role, indirectly through bottom-up mobilisation around PGN* as means to confront oppression.
<b>Comment</b>	Women seen as passive beneficiaries of development with focus on reproductive role. Non-challenging therefore still widely popular especially with government and traditional NGOs.	In identifying subordinate position of women in terms of relationship to men, challenging, criticised as Western feminism, considered threatening and not popular with government.	Poor women isolated as separate category with tendency only to recognise productive role; reluctance of government to give limited aid to women means popularity still at small-scale NGO level.	Women seen entirely in terms of delivery capacity and ability to extend working day. Most popular approach both with governments and multilateral agencies.	Potentially challenging with emphasis on Third World and women's self-reliance. Largely unsupported by governments and agencies. Avoidance of Western feminism criticism, means slow significant growth of underfinanced voluntary organisations.
<p><b>PGN*</b> Practical Gender Needs  <b>SGN^</b> Strategic Gender Needs</p>					

**Source:** Moser (1989)

## APPENDIX 5: GRASSROOTS DEVELOPMENT FRAMEWORK



**Source:** Ritchy-Vance in Edwards & Fowler (2002:308)

## APPENDIX 6: SIGNS OF EMPOWERMENT: ENAELP, Ethiopia

GRASSROOTS DEVELOPMENT FRAMEWORK		
SIGNS OF EMPOWERMENT: ENAELP, Ethiopia		
<i>Tangible</i>	<i>Levels</i>	<i>Intangible</i>
<p><b>Policy Environment: Laws, Policies, Practices</b></p> <ul style="list-style-type: none"> <li>+ ENAELP established and registered officially in Ethiopia as an organisation for people affected by leprosy.</li> <li>+ ENAELP has official By-Laws, recently been updated in conjunction with the Ministry of Justice, to reflect growth in membership.</li> <li>+ ENAELP is extending in the regions, strengthening Local Associations and establishing new Local Associations.</li> <li>+ Making an impact and raising ENAELP's visibility through advocacy and awareness raising for World Leprosy Day.</li> <li>+ Managing Director &amp; Chair interact with Ministry of Labour &amp; Social Affairs on disability issues and have a good working relationship with them.</li> <li>+ Campaigning for Human Rights, especially equal employment opportunities for all, with some employers allowing leprosy-affected people to work for them.</li> <li>+ ENAELP Chair has a passport for international travel to promote the cause at various fora and in Geneva at Human Rights offices.</li> <li>+ ENAELP has a growing number of international partners who not only provide funding but also linkages with other organisations.</li> <li>+ Self-care groups are visited by Medical Students training at ALERT so they can see firsthand how this concept works: this is now being used in other African countries where leprosy is a problem</li> <li>+ In some areas leprosy-affected people now use the same</li> </ul>	<p>Broad Impact <b>Society:</b> <b>Local,</b> <b>Regional,</b> <b>National</b> <b>International</b></p>	<p><b>Community Norms: Values, Attitudes, Relations</b></p> <ul style="list-style-type: none"> <li>+ Visible signs of attitude change towards disabled and leprosy-affected people in some places, therefore, inclusion of previously excluded people.</li> <li>+ ENAELP gained additional credibility in the public arena because Chair has a passport and travels internationally on human rights missions.</li> <li>+ ENAELP has become the public face of leprosy and, as such, is increasing awareness about the needs of leprosy-affected people: this is becoming an accepted part of community life locally, regionally and nationally.</li> <li>+ Access to government officials for discussion and communication provides a new sense of social inclusion.</li> <li>+ Recent access to the government banking system provides a new sense of dignity and social inclusion.</li> <li>+ ENAELP seen and accepted by some international anti-leprosy organisations as a legitimate indigenous organisation.</li> <li>- Stigma against leprosy-affected people remains ingrained in many places, including in public policy documents.</li> <li>- Some international anti-leprosy organisations appear to have little respect for ENAELP.</li> </ul>



<p>public transport as other people.</p> <ul style="list-style-type: none"> <li>+ ENAELP is a founding member of the umbrella organisation for disabled people's groups (EFPD) in Ethiopia.</li> <li>+ ENAELP members can now have personal bank accounts which makes practical financial issues much easier for them.</li> <li>- At times various government or community leaders, or other people, will not co-operate with ENAELP on projects they are implementing for leprosy-affected communities.</li> </ul>		
<p><b>Organisational Capability: Planning, Administration, Resources, Reach/Linkages</b></p> <ul style="list-style-type: none"> <li>+ Inclusive, participatory process of decision-making regarding plans for World Leprosy Day and preparations.</li> <li>+ National Office and staff provide a key hub for ENAELP.</li> <li>+ International and national donors provide core funding and project funds for an increasing number of projects.</li> <li>+ A clear vision for the future documented and a new five-year strategic plan developed to achieve it.</li> <li>+ General Assembly of ENAELP takes place annually, with two representatives (one male and one female) from each region.</li> <li>+ ENAELP been through a collective decision-making process regarding gender sensitivity with policy documents reflecting this.</li> <li>+ A group of young leprosy-affected people have their own band and play in places of significance eg, Sheraton Hotel in Addis Ababa, and Bank of Ethiopia main entrance, promoting human rights.</li> <li>+ Elected members of Executive and National Committees to undergo governance training so they can better understand the role they need to play in a grassroots organisation.</li> <li>+ Recognition of the need for mechanisms ensuring there is equity in the distribution of project benefits.</li> <li>+ Leprosy-affected people can</li> </ul>	<p><b>Strengthening Organisations Networks, NGOs, Grassroots Groups</b></p>	<p><b>Organisational Culture: Vision, Democratic Practice, Autonomy, Solidarity</b></p> <ul style="list-style-type: none"> <li>+ Common experience provides a strong bond for joining in collective action and solidarity.</li> <li>+ Strategic Plan process was fully inclusive and involved members from every Local Association.</li> <li>+ Updating ENAELP's by-laws was participatory process and involved as many members from as many Local Associations as possible.</li> <li>+ Opportunities to have a voice and to vote at the General Assembly provide experiences of democratic practice, and give participants a sense of self-worth.</li> <li>+ Provision of a specific place for women in ENAELP's structure has enabled female members an increased sense of belonging to the organisation.</li> <li>+ Having a female chair of ENAELP is a wonderfully encouraging role model for female members.</li> <li>+ Members have freedom to set up women's only groups if they feel these are necessary.</li> <li>+ The Managing Director and Chair ensure processes are followed which will develop trust between them and the members, and between all members.</li> <li>+ Dependency which was so evident prior to ENAELP's establishment is decreasing and members are prepared to try new things to become more independent.</li> <li>+ Having a personal bank account means the individual concerned is now recognised as a human being the same as other people.</li> <li>- Sometimes outsiders see</li> </ul>

<p>now have their own bank accounts.</p> <ul style="list-style-type: none"> <li>- Organisational growing pains are often difficult to deal with: lack of experience contributes to misunderstandings.</li> </ul>		<p>ENAELP as an exclusive group which may become a threat to the community.</p>
<p><b>Standard of Living: Basic Needs, Knowledge, Skills, Employment, Income, Assets</b></p> <ul style="list-style-type: none"> <li>+ Increased income from new businesses (income generation projects).</li> <li>+ Children going to school because of increased family income.</li> <li>+ Leprosy-affected families have educational opportunities previously not available.</li> <li>+ Training utilised for employment purposes.</li> <li>+ Some families reunited after many years of separation.</li> <li>+ Superstition about causes of leprosy dramatically receded and many people now seek good medical care early.</li> <li>+ Personal self-care of anesthetic limbs is undertaken by members of self-care groups where peers provide support (and disapproval when appropriate) to each other.</li> <li>+ Young women who had had a negative experience with vocational training prepared to work together to find solutions to their problems.</li> <li>+ Individuals benefit by having control over the resources which are due to them.</li> <li>- Occasional family conflict, eg, male/female, over control of project resources.</li> <li>- There are still occasions when a person loses his/her job because of a new leprosy diagnosis.</li> </ul>	<p><b>Direct Benefits Families Individuals</b></p>	<p><b>Personal Capacity: Self-esteem, Cultural Identity, Creativity, Critical Reflection</b></p> <ul style="list-style-type: none"> <li>+ Self esteem and personal worth increasing with new employment and income opportunities.</li> <li>+ Education increases opportunity and helps people to integrate into new environments.</li> <li>+ Many no longer feel “labelled” by leprosy and have greater positive recognition socially.</li> <li>+ Through ENAELP people can <i>belong</i> to each other because of common experience of leprosy.</li> <li>+ With increased self-esteem comes liberation as people feel confident to do new things for themselves.</li> <li>+ Individual members of ENAELP’s music band have increased confidence and identity after successful performances in public fora around Addis Ababa. Their creativity is valued.</li> <li>+ Some members recommended changes to the loans for various reasons; this indicates good critical analysis and reflection.</li> <li>+ Some members forcibly isolated by past governments can now visit the region of their birth and re-establish their cultural identity. The leprosy identity is lost.</li> <li>- Some families not yet reunited: older people say they must remain ‘anonymous’ so adult children and grandchildren are not stigmatised.</li> <li>- Depression and charged emotions for some members is still a reality.</li> <li>- People newly diagnosed with leprosy keep it a secret – unless disabilities prevent them from doing this, which means fear of stigma still exists.</li> </ul>

## APPENDIX 7: SIGNS OF EMPOWERMENT: HANDA, China

GRASSROOTS DEVELOPMENT FRAMEWORK		
SIGNS OF EMPOWERMENT: HANDA, China		
<i>Tangible</i>	<i>Levels</i>	<i>Intangible</i>
<b>Policy Environment: Laws, Policies, Practices</b> <ul style="list-style-type: none"> <li>+ China's first National Workshop 'Socio-Economic Rehabilitation,' in Guangzhou, 1996: a forerunner to HANDA's emergence.</li> <li>+ HANDA was one of China's first NGOs to be established and registered at the Provincial Department of Civil Affairs.</li> <li>+ HANDA has an officially recognised constitution.</li> <li>+ HANDA has a growing number of international partners.</li> <li>+ Three HANDA members were the first leprosy-affected people to obtain their own passport and travel out of China. They had entry into Brazil for an international leprosy conference.</li> <li>+ HANDA is strategically extending into new provinces and setting up new Branches.</li> <li>+ HANDA is raising its visibility with advocacy in public places, particularly in universities.</li> <li>+ Improved conditions in leprosy villages where leprosy-affected people have lived long-term.</li> <li>+ HANDA's nurses keep in close contact with local government Dermatology Clinics.</li> <li>+ HANDA staff and members take part in public fora, eg. Beijing International Leprosy Congress.</li> <li>+ Quilt Enterprise links HANDA to prospective international donors for other areas of work.</li> </ul>	Broad Impact <b>Society: Local, Regional, National</b>	<b>Community Norms: Values, Attitudes, Relations</b> <ul style="list-style-type: none"> <li>+ Visible signs of attitude change towards leprosy-affected people in some places, with inclusion of previously excluded people.</li> <li>+ HANDA gained credibility in public arena when three members gained passports to travel internationally on human rights missions.</li> <li>+ Pride at being one of the first indigenous NGOs in China.</li> <li>+ Advocacy undertaken in public places. Some leprosy-affected people are regular advocacy group members, willing to tell their story. This is a powerful testimony, especially in China's universities where many young people are furthering their education.</li> <li>+ HANDA is seen and accepted by some international anti-leprosy organisations as a legitimate indigenous organisation.</li> <li>+ HANDA is accepted as a legitimate and credible organisation by government run dermatology clinics.</li> <li>- Stigma against leprosy-affected people remains ingrained in many places, including in public policy documents.</li> <li>- Some international anti-leprosy organisations appear to have little respect for HANDA.</li> </ul>
<b>Organisational Capability: Planning, Administration, Resources, Reach/Linkages</b> <ul style="list-style-type: none"> <li>+ HANDA's structure includes a Representatives Congress, General Committee and Standing Committee, made up of elected HANDA members for full representation of the people.</li> <li>+ Representatives Congress meets annually for elections and strategic planning.</li> </ul>	Strengthening Organisations <b>Networks, NGOs, Grassroots Groups</b>	<b>Organisational Culture: Vision, Democratic Practice, Autonomy, Solidarity</b> <ul style="list-style-type: none"> <li>+ Common experience provides a strong bond for joining in collective action and solidarity.</li> <li>+ HANDA members have a real sense of belonging to each other which has contributed to solidarity.</li> <li>+ People living in enforced isolation in leprosy villages can now travel to Guangzhou (or other locations)</li> </ul>

<ul style="list-style-type: none"> <li>+ Large well staffed National Office is a key hub for HANDA.</li> <li>+ Fast growth from one staff member in 1996 to 21 in 2004.</li> <li>+ A large number of professional staff, most of whom have never had leprosy themselves, but who are willing to be committed to HANDA's growth and effectiveness as a new NGO.</li> <li>+ HANDA has a specialist Eye Team which travels extensively undertaking eye surgery.</li> <li>+ HANDA's Prosthetics Workshop, staffed by leprosy-affected people who have trained in prosthetics and footwear, is making high quality artificial limbs and shoes.</li> <li>+ HANDA's two social workers (one male, one female) are key players when HANDA moves into new areas and leprosy villages they have not worked in. This means previously isolated people can choose to become HANDA members if they wish.</li> <li>+ HANDA employs qualified nurses to move around the leprosy villages and who also keep in close contact with local Dermatology Clinics.</li> <li>+ HANDA provides reconstructive surgery for members with hands and/or feet damaged by leprosy.</li> <li>+ Quilt Enterprise is a financially independent sewing business, making goods for national and international markets.</li> <li>+ Communal fund, run by HANDA members, is like an insurance scheme from which people can borrow for urgent needs.</li> <li>+ As an organisation, HANDA takes part in training to up-skill staff and members.</li> <li>+ Most people previously forced to live in leprosy villages are now permitted to leave if they wish, or to stay as they choose.</li> <li>+ HANDA organises and conducts joint meetings of HANDA Branches so members can mix and learn from each other.</li> <li>+ Within the limits of NGOs in China, HANDA advocates for members in suffering injustice and human rights violations.</li> <li>- At present only one woman and fourteen men make up the General Committee. Women are reluctant to put themselves</li> </ul>		<ul style="list-style-type: none"> <li>to attend HANDA meetings.</li> <li>+ In most cases, people previously forced to live in a leprosy village may now leave if they choose, or come and go at will.</li> <li>+ Elections for HANDA officers provide a democratic means of choosing leaders.</li> <li>+ One woman was brave enough to stand for election to the General Committee in order to represent other women. She was successful.</li> <li>+ HANDA's employment of a female social worker is helping to address organisational gender issues.</li> <li>+ Quilt Enterprise staff are all leprosy-affected people benefiting from employment, income, and increased self-esteem and dignity.</li> <li>+ The communal fund has removed pressure from HANDA members who know there is a resource available for financial difficulties due to healthcare expenses etc.</li> <li>+ When HANDA is involved in outside training programmes it is usually with other new NGOs: this contact is helping breakdown leprosy stigma.</li> <li>+ The joint meetings of HANDA Branches provides a sense of solidarity amongst members.</li> <li>- HANDA's governing bodies do not have a gender balance; some have no female representation.</li> <li>- A minority of leprosy villages will not yet allow their residents to leave; this is applicable to those with only one person left in the village. Soul destroying for the person involved</li> </ul>
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<p>forward for office in a male oriented culture.</p> <ul style="list-style-type: none"> <li>- HANDA's governing body is made up of members with little education so it struggles with lack of capacity.</li> </ul>		
<p><b>Standard of Living: Basic Needs, Knowledge, Skills, Employment, Income, Assets</b></p> <ul style="list-style-type: none"> <li>+ Some families have reunited, or met leprosy-affected family, after decades of separation.</li> <li>+ HANDA takes groups of leprosy-affected people on trips around their province; for many this is the first time they have been out of a leprosy village since they entered up to 50 years ago.</li> <li>+ People with leprosy can generally take part in public evening classes or other educational opportunities and gain qualifications.</li> <li>+ The communal fund is seen as a personal asset for each member who contributes to it and may need to use it, especially also as it is administered by members.</li> <li>+ Personal self care of anesthetic limbs encouraged by HANDA staff and peers in the villages.</li> <li>+ Workers in Quilt Enterprise are flourishing in a positive setting and while producing high quality goods for sale they are earning a good personal income.</li> <li>+ Individuals benefit from having control over resources which are due to them.</li> <li>- Many families still do not want their leprosy-affected family members to contact them or attend family gatherings such as funerals etc</li> <li>- There remain occasions when a person loses his/her job because of a new leprosy diagnosis.</li> </ul>	<p><b>Direct Benefits Families Individuals</b></p>	<p><b>Personal Capacity: Self-esteem, Cultural Identity, Creativity, Critical Reflection</b></p> <ul style="list-style-type: none"> <li>+ Leprosy-affected people benefit from mobile eye teams. Restored sight improves sense of wellbeing.</li> <li>+ HANDA members who are amputees, or have foot problems, benefit from artificial limbs and special shoes.</li> <li>+ Members take part in group trips in their province for the first time in decades. They are overawed at changes, and seeing the new China is both a devastating and inspirational experience for each.</li> <li>+ Comments from HANDA members in leprosy villages include "People talk to us now with their heart".</li> <li>+ Reconstructive surgery on hands and/or feet means people with leprosy can look normal again. A major contribution to improved self confidence and dignity.</li> <li>+ Undertaking evening classes or other education enables leprosy-affected people to compete on a more even playing field for employment opportunities which is a great boost to self worth.</li> <li>+ Working at the Quilt Enterprise has resulted in confident and happy individuals.</li> <li>+ Some people choose to remain in leprosy villages now they are permitted to leave but benefit psychologically from knowing they have freedom.</li> <li>+ HANDA members are now respected and treated as human beings which gives them an identity of which they are proud.</li> <li>- Leprosy stigma remains strong in many places, thus feeding loss of dignity and self-esteem for many leprosy-affected individuals.</li> <li>- People newly diagnosed with leprosy still keep it secret – unless disabilities prevent them.</li> <li>- Some women still suffer emotionally from not being allowed to give birth to a child.</li> </ul>

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## ENAELP, Ethiopia



**Leprosy affected people, all members of ENAELP:**

- 1) Self-care group checking for possible damage to their anesthetic feet
- 2) A remote leprosy village
- 3) A group of internally displaced families
- 4) A young woman with disabled hands
- 5) Older women who are very disabled
- 6) Local cooking facilities are basic



## ENAELP, Ethiopia



07



10



08



11



09



12

### ENAELP initiatives:

- 7) Vocational training enables young people to work
- 8) ENAELP leaders meeting with partners and potential funders
- 9) Income generation making local handicrafts for sale locally and internationally
- 10) ENAELP Chair
- 11) ENAELP National Office in Addis Ababa
- 12) Income generation making local food for sale in the market

## HANDA, China



Leprosy affected people, all members of HANDA:

- 1) Access to this remote leprosy village is by boat
- 2) Isolation from society in a leprosy village
- 3) Cooking facilities are basic
- 4) Leprosy leaves people very disabled
- 5) Leprosy and loneliness
- 6) Many people are amputees



## HANDA, China



### HANDA initiatives:

- 7) Leprosy villagers enjoy mixing in mainstream society
- 8) HANDA's Prosthetics Workshop
- 9) HANDA's governing body meets
- 10) HANDA's Quilt Workshop
- 11) Networking of HANDA Branches from different areas
- 12) Life has changed for the better