# RECONCILING ORGANISATIONAL INTENT AND LOCAL STRATEGIES

## AN IN-DEPTH STUDY OF HEALTH WORKERS IN AN URBAN LEPROSY PROJECT IN INDIA

BY

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For Anja, who makes everything possible.

# పర కాయ ప్రవేశ ము

For those who allowed me to walk in their shoes and see the world through their eyes. For those who dedicate their lives to social service and who work tirelessly to create the conditions in which people can be healthy. We see you.

***I, Kristine Harris, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.***

***Signed*** [redacted]

***Date:*** 16/12/09

## Abstract

There is growing interest in health systems research and implementation studies within public health, yet there is little in-depth research being carried out on the front-line health workers who implement interventions in the field.

This study aims to add to our understanding of implementation processes through an in-depth ethnographic study conducted over a 12 month period of participant observation with field-level health workers in an urban leprosy project. The study employs a multidisciplinary approach, combining anthropological and public health methods and perspectives, and was carried out within one of India's largest leprosy organisations. The research is, in essence, a 'project ethnography' of the work and social identity of health workers, within the context of a rapidly changing policy landscape.

The study argues that health workers are embedded in the structures they work within at the same time as they actively exercise agency within these structures. By understanding how health workers utilise agency within, rather than in opposition to, structure, we can come to understand health workers' social identity, as well as how they reconcile organisational intent with local strategies in the implementation process.

There is a growing realisation within public health that health systems are complex social microcosms in which health workers play a pivotal role. The study argues that the application of social theory, that examines the relationship between agency and structure, will be instrumental in developing research frameworks that truly engage with the process and complexity of health systems.

## List of Abbreviations:

ANM – Auxiliary Nurse Midwife

APMO – Assistant Para-Medical Officer

ATP – Advance Tour Programme

CBO – Community Based Organisation

CHO – Community Health Organiser

DCC – Disability Care Clinic

DDP – Drug Delivery Point

DFID – Department For International Development

DLO – District Leprosy Officer

DMC – District Microscopy Centre

DPMR – Disability Prevention and Medical Rehabilitation

FPP – Frontiers Prevention Project

FSW – Female Sex Worker

HAART – Highly Active Anti-Retro Viral Treatment

HSD – Health Systems Development Programme

IEC – Information, Education Communication

ICCC - Innovative Care for Chronic Conditions

ILO – Indian Leprosy Organisation

ILEP – International Federation of Anti-Leprosy Associations

INR – Indian Rupees

IPC – Inter Personal Communication

MB – Multibacillary leprosy

MC – Microscopy Centre

MCR – Microcellular Rubber

MDT – Multi-drug Therapy

MSM – Men who have sex with men

NCDR – New Case Detection Rate

NGO – Non-governmental Organisation

NHS – National Health Service

NLEP – National Leprosy Elimination Programme

NMA – Non-Medical Assistant

OP – Outpatient Clinic

PB – Paucibacillary leprosy

PMP – Private Medical Practitioner

PR – Prevalence rate

RFT/RFC - Released from treatment/control

SER – Social and Economic Rehabilitation

SET – Survey Education and Treatment

VCCTC – Voluntary Confidential Counselling and Testing Centre

WHO – World Health Organisation

UHP – Urban Health Post

ULP – Urban Leprosy Project

Anganwadi worker - Female community level workers of the Integrated Child Development Scheme

Mahila Mandal - Local women's group

Basti – slum

Ayah – attender

Mela – fair

Chappal – sandal

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## Introduction

This study looks at the work of a group of health workers in an urban leprosy project in Hyderabad, one of India's emerging megacities. The research is, in essence, a 'project ethnography', examining the everyday working reality of the front-line health workers and how these impact the process of implementation. The findings are the result of an in-depth ethnographic study conducted over a 12 month period of participant observation with the project's field-level health workers.

This is an interdisciplinary study jointly funded through the Economic and Social Research Council and the Medical Research Council. The study combines the theories and methodologies of several disciplines, primarily anthropology and public health, each with their own particular history, literature and underlying assumptions. As such, the thesis naturally draws from a wide variety of literature and builds on the insights of numerous fields.

The study asks a deceptively simple question: "what is the role of front-line health workers in reconciling organisational intent and local strategies in an urban leprosy project in India?", and aims to address this question by fulfilling four specific objectives:

1. To chart recent leprosy policy change.
2. To investigate how recent policy changes have affected health workers' daily work and tasks.
3. To investigate how recent policy changes have affected how health workers perceive their role relative to organisation and clients.
4. To investigate the potential role of health workers as a link between organisational intent and client perspectives.

The study aims to build understanding of how the work health workers do in the field relates to the guidelines they follow, how treatment is shaped by international discourse but, also, how the health workers' interactions with local communities shape an alternative set of priorities that are often expressed in their work

practices. In order to access this knowledge, the study utilises an in-depth ethnographic approach, employing tools such as participant observation and informal interviewing.

Leprosy epidemiology and leprosy policy have changed drastically over the last two decades. With falling leprosy prevalence rates around the world, and a rapidly aging population of leprosy affected persons, leprosy organisations are waking up to the need for more comprehensive strategies for dealing with this chronic disease. In response to this change, leprosy organisations are striving to reformulate their interventions from a focus on control to care, from health to development, and from service to empowerment. This piece of research was carried out within one of India's largest leprosy organisations, the Indian Leprosy Organisation (ILO), as it faces the changes ahead, and focuses on what impact these changes have had on front-line health workers, service users and the organisational culture of leprosy organisations. The names of the organisation and those who work for it have been changed to maintain confidentiality.

The study describes how discourses, defined as "appropriate and legitimate ways of practicing development as well as speaking and thinking about it" (Grillo, 1997:12), have shaped the way health workers think about their work and their own social identity. As leprosy policy has changed, so has the role of the health workers working within this context. However, we have yet to fully understand the impact of these changes at ground level, either for implementing staff or people affected by leprosy. As the context changes around them, many of the key components of the health workers' social identity remain linked to the old paradigm and the health workers struggle to find a place in the new world order and to create a meaningful role and identity for themselves. As the international discourse changes in response to falling leprosy rates, so the social identity of front-line health workers is brought into question.

Both the health workers' social identity and working practices impact on their relationship with service users and organisational structure and, as a result, influence the implementation of interventions. There is ample research

demonstrating the importance of utilising community strengths and capacities in implementation and planning of health policy in order to maximize the impact of policy on people's living conditions. In addition, there is a large body of operational research arguing for the potential role of regional and national organisations to influence international disease policy, in order to disseminate the lessons learnt from local implementations to other agencies and situations. However, there is a great paucity of work on how organisations or implementing agencies would access local perspectives and how these in turn could be transmitted through the organisation to a wider policy audience. This research aims to address this gap, by investigating the potential role of health workers in reconciling client perspectives and organisational intent. Through the careful application of anthropological tools and theory, to a field which normally falls within the scope of more traditional public health methods and perspectives, this study aims to add to our understanding of the role of field-level health workers in the implementation of health policy.

This approach is not entirely novel, and took inspiration from the work of Arce & Long (1993), amongst others, who carried out an in-depth study of a fieldworker as a means of understanding wider discourse, since "the fieldworker embodies the contradictions between local interests and the state-led development programme (...) The strength of this case is that the contradiction between the structuring effects to the development discourse and the interests of the peasants is analysed through the person of the intermediary, thus giving meat and bone to the process" (Nustad, 2001:480). The approach was also inspired by Row's (1999) work on the meeting between outreach workers and the homeless as 'boundary encounters'.

This study examines the role of front-line health workers in the implementation process and describes how their working practices are shaped by both international and local discourses. All implementation is carried out by field-level health personnel, yet their role and actions are often poorly understood. This thesis aims to contribute to addressing this gap by examining how front-line health workers, within an urban leprosy project, carry out their daily work in a rapidly changing policy landscape; how they understand their role and how this role has changed over the last few decades; how they create, maintain and utilise their

social identity; and how they are both products of the wider policy discourse and utilise their understanding of their role in order to exercise agency within this structure.

As carriers of organisational discourse, front-line health workers are representatives of the health system and the organisational culture they work within, however, their daily interactions with the communities they serve, and their physical connection to the field and the lived reality of clients, also means that they have an in-depth understanding of the lived reality and challenges of their clients. As a result of this insight, and, as a result of their particular understanding of the intent of the interventions, the health workers frequently go beyond their remit and rely on both judicious and manipulative agency in service provision, actively circumventing the very system they subscribe to in order to provide the services they believe the community needs.

In its heavy emphasis on ethnographic research and focus on the social identity of health workers, the thesis might seem purely anthropological, however, that would be to underestimate its commitment and potential contribution to public health. In addition to being a 'project ethnography' of an urban leprosy project, this study aims to provide insights that have application beyond the narrow field of leprosy services. There is growing interest in implementation and health systems research in the public health field and in-depth ethnographic studies like this one, alongside the considered application of social theory, can provide valuable insights and explanatory models that can further our understanding of health systems.

This research recognises that the meeting between health workers and local community represents the interface between health system and service user and, thus, constitutes the corporeal expression of this relationship. Most service users are oblivious to the wider processes, policies and structures that determine the care and service they receive but, rather, perceive the front-line provider as the personification of the wider health system. As a result, the actions of front-line health workers become de facto health policy on the ground. However, for the front-line provider themselves, their role is often less clearly defined. On the one

hand, as trained professionals, they are part of an organisational structure with a clear agenda and set targets and, on the other hand, they interact daily with the ever changing demands and needs of service users and their wider community. Application of social theory to the study of health systems can allow us to move beyond descriptive studies to forming an understanding of behavioural models and underlying motivations.

The thesis is ambitious in scope and depth and this is reflected in its structure. Chapter 1 outlines the theoretical approaches and literature that underlies my study and describes how the conceptual framework evolved during the process of my fieldwork. Chapter 2 outlines the methodology utilised in the study, discusses the impact of the researcher's presence in the field and addresses some of the ethical dilemmas I encountered during my fieldwork. In recognition of how important the richness of the context was to my research, Chapter 3 describes the context and tries to convey a sense of the environment within which I conducted my field work.

Chapter 4 introduces the group of health workers who constituted my primary informants and demonstrates the extent to which health workers are embedded in the structure and discourse within which they work, whilst Chapter 5 attempts to outline this context and analyses how leprosy policy is influenced by national and international discourses.

Chapter 6 examines how these changes have impacted the health workers' working reality and how they perceive themselves and their role within ILO. Chapters 7 & 8 aim to demonstrate that, despite being deeply embedded in organisational culture and leprosy discourse, the health workers still exercise considerable agency, both directly and indirectly, in their everyday working practices. Chapter 9 focuses on how organisational culture is created and maintained, what the primary barriers to communication are within the organisation and what the implications of these limitations are for the potential for further dissemination of health workers' perspectives to a wider policy audience.

As this thesis consists of an unorthodox combination of anthropology and public health, its findings fall into two distinct camps, one which is concerned with theoretical issues within anthropology and the other which attempts to illustrate the utility of research such as this for future public health and health systems research. Chapter 10 argues for more anthropological studies that go beyond a dichotomised view of agency and structure, whilst Chapter 11 argues that, ultimately, understanding the way in which health workers exercise agency within structure has implication well beyond the leprosy field. Insight from social theory and ethnographic studies can help us better understand the intricacies of health systems and health system processes.

The study argues for an increased reliance on anthropological theory and perspectives in public health, and for more focus on the process of implementation rather than on outcomes. By drawing more extensively on social theory, we can work towards an ethnography of implementation that will enable a more complex understanding of the process of implementation and, thus, start to bridge the gap between local strategies and organisational intent, allowing us to move towards more effective interventions.

Without further ado; what follows is the story of a researcher, a disease, an organisation, nine health workers, a city and the complex expression of implementation and the 'social service' that constitutes most people's experience of health systems. It is an attempt to understand the process through which public health outcomes, which we are usually content merely to measure, are created. But more than anything, it is the story of the messy reality that is the everyday working life of fieldworkers everywhere, their efforts to satisfy multifarious competing demands and their endless navigation between structure and agency.

# 1. Framing the research question

This is in many ways an unconventional thesis, in that it attempts to bridge the gap between anthropology and public health. Anthropological investigations often fail to consider how they might be useful to public health policy and interventions. Conversely, public health often conflates anthropology with its methodology and thereby fails to recognise the other strengths the discipline can bring to the field of public health. This research not only utilises mixed methods, but approaches its subject matter from a multi-disciplinary perspective.

This research was funded by a joint studentship from the Economic and Social Research Council and the Medical Research Council specifically aimed at promoting multi-disciplinary work. Combining the two fields is not always easy, as they carry with them implicit assumptions and theoretical approaches that are not always compatible. The social constructivist approach of much of anthropological research often clashes fundamentally with the axiomatic position of biomedical knowledge within the field of public health. However, in the last few decades, as a result of growing interaction and the recognition of a shared desire to relieve human suffering, the two disciplines have grown closer. Though anthropology has traditionally been more interested in client perspectives, in experiences of illness and the incorporation of traditional systems of medicine into primary health care, there is now a growing interest in implementation of health services and, especially, the role of health workers and NGOs in health provision. Within public health, there is a growing interest in the role of health systems and a shift away from an over-reliance on quantitative outcome measures towards building a qualitative understanding of the process of implementation.

This research is based on extensive literature reviews in both anthropology and public health, and incorporates the insights from both these fields in framing the research question and analysing the results. Rather than providing the reader with an exhaustive literature review, this chapter aims to outline the bodies of literature and theories upon which my study builds, in order to provide a summary of the

academic traditions that frame this research. Other, more specific literature reviews will be dealt with in later chapters.

### 1.1 Anthropology, Health Workers and Leprosy

Approaching the field of leprosy control from an anthropological perspective the first thing that becomes apparent is the dearth of anthropological research into the field. As summarised by Carcianiga & Herselman:

> "In a multi-disciplinary study which reviewed the literature on leprosy, it was found that out of 126 articles reviewed, 74% could be categorised as 'medical', 22% as 'psycho-social' and 4% as 'cultural'. The same study revealed that in Volume 1-15 of the *Journal Social Science and Medicine* published between 1967 and 1981 no article on leprosy appeared." (Carcianiga and Herselman, 1999:162)

What research there is can be divided into three main categories. Firstly, there is some anthropological work, primarily that of Mary Douglas (1991), analysing leprosy as a mechanism of social exclusion, focusing on the historical construction of the term and its application as a means of social control. Secondly, there is a body of literature predominantly concerned with issues surrounding stigma as a social constraint in modern day leprosy services (Waxler, 1981, Carcianiga and Herselman, 1999). Lastly, there is some, if not a lot of, work carried out on the social identity of persons affected by leprosy. The work of George Drakos in Greece (1992) and that of James Staples (2003) in India, both of which focus on the construction of the social identities of persons affected by leprosy, stand out in this area.

In general there is very little anthropological work focusing on the social impact of leprosy control programmes, in India or elsewhere. Jane Buckingham's (2002) historical analysis of leprosy policy in colonial South India deserves a mention, as does Eric Silla's (1998) work on leprosy identities in colonial and post-colonial Mali. Both authors demonstrate the extent to which leprosy policy is the result of interactions between international and local discourses, and the extent to which

this policy is crucial in the formation of social identity, not only for those affected by the disease but, also, for those who work in the field.

James Staples' work focuses on how people affected by leprosy are constructed by their social context and how they, in turn, creatively engage with the social context and NGO/government policies as social actors using every-day strategies. The research demonstrates that association with the disease leads to social as well as physical disabilities but also argues that this association can create a basis for the construction of identities and communities with shared experiences and concerns (Staples, 2003). Staples argues that NGOs and people affected by leprosy approach interventions with diverging intentions and agendas. Thus, NGOs are often presented with a 'flattened' image of leprosy affected people and their desires as they are 'told what they want to hear' (Staples, unpublished).

In addition, Staples argues, the disability discourse on which interventions such as Social and Economic Rehabilitation (SER) are premised represent a particularly European construct, which is preoccupied with ideas of equality and a denial of difference (Stiker, 2000 [1982]) and which, thus, embodies a 'reification of ideas of normality' (Oliver, 1990) that is not always equally appropriate to different cultural settings (Ingstad and Whyte, 1995). It is therefore becoming increasingly important that we try to understand how people affected by leprosy construct their identities and communities, through innovation and recombination of elements, through local synthesis and innovation, resistance and accommodation, as a cultural struggle over meaning as much as socio-economic resources (Escobar, 1992). This insight ties in with more fundamental issues surrounding 'development' that will be discussed in greater detail in Chapter 5, suffice to say here that, though I recognise that development as a concept can be an ideological tool in global power relations, I think it equally important to recognise that, for NGOs and those who work for them, the term also "describes a set of activities, relationships and exchanges" that are very real to those who engage with them (Lewis and Gardner, 1996:2).

Leprosy is often seen merely as a medical problem with negative social consequences. This view carries with it the inference that, if the medical problem is

treated, the physical and social problems will be resolved (Staples, 2004). The disease itself is a logical focus for a bio-medically oriented intervention. However, people affected by leprosy conceptualise their affliction as an illness rather than a disease, an experience which is in large part determined by social, economic and cultural factors that are difficult to conceptualise as long as the focus remains firmly on the disease itself (Kleinman, 1981). Barrett's study of self-mortification amongst leprosy affected persons argues that epidemiology, medicine and the social must be seen as interconnected, mutually constituting components in the construction of the illness and that attempts to separate "the bacteria from the burden" conceal the true nature of the disease (Barrett, 2005). In addition, for many people affected by leprosy, the disease is a key element in their sense of identity and community (Staples, 2003, Silla, 1998). Therefore the very same condition that is stigmatising is also strategically deployed as a sign of difference rather than a failing (Gussow and Tracy, 1970) and as a platform for collective claims to rights (Reismann, 2000).

If we accept that the defining principles of some internationally formulated and locally implemented interventions correspond poorly with the self-identification and strategies of people affected by leprosy, it becomes clear that there is a need for a better understanding of the locally specific lived experiences of people affected by leprosy in order to develop more appropriate and locally sensitive interventions.

Exciting and insightful as much of the anthropological work on leprosy is, it is, primarily, limited to a focus on the experiences of people affected by leprosy as service users. If we accept that people affected by leprosy are not passive recipients of services and that the interaction between NGOs and people affected by leprosy must be viewed as an interactive process where each party acts in order to further their respective interests, we must also accept that NGOs, or health systems, are not homogenous entities mirroring international policy. NGOs are composite and complex organisations made up of a heterogeneous mix of individuals who, ideally, share a set of values, targets and underlying assumptions. Recognising that NGOs, as well as service users, have their own agenda, begs the question, how are these differences reconciled in practice and what can we learn

from these everyday acts of reconciliation that may be carried forward into future policy/intervention formulation? And, last but not least, what is the role of front-line health staff in these negotiations and what could be their potential role in carrying these lessons forward?

Since the primary focus of the study is the health worker, as opposed to leprosy, we must also look to anthropological studies of community health workers and studies of the interaction between service users and providers. The community health worker has been a central figure in public health since the late 1950s and, naturally, the body of anthropological work examining the role of front-line health providers is more extensive than that addressing leprosy-related issues. Much of the anthropological work on community health workers has focused on identifying shortcomings in the conception or execution of programmes, with the aim to improve services, and many of these offer valuable insights to current questions surrounding the provision of leprosy services.

Community health workers have been extensively utilised in health systems all over the world, with varying results, and this has raised questions about programmatic as well as conceptual concerns. Several studies have questioned the quality of services provided by community health workers, with Berman et al (1987) questioning their effectiveness, Kelly et al (2001) raising concerns over their level of clinical skill, and Matomora (1989) criticizing the selection of community health workers before problems and solutions are properly identified. These are important insights but perhaps of greater importance to this study are the conceptual issues raised by some researchers.

Leslie (1985) argues that a failure to include indigenous medicine and ethnographic work on medical practices into the planning and implementation of community health worker schemes limits their impact on the ground and Cornwall (2003) argues that too little consideration is given to issues of gender and participation. Kloos' (1998) study of the effectiveness of community health workers under three different political regimes in Ethiopia demonstrates the importance of properly understanding the impact of the wider political situation, whilst Bastien

(1990) argues the importance of understanding wider cultural issues by illustrating how the role of the community health worker does not fit into the leadership structure of either modern or traditional medical regimes in Bolivia.

Finally, Justice's (1986) study in Nepal argues that primary health care in general is adapted to bureaucratic rather than grass-roots needs or cultural conditions on the ground. She argues that only through social science studies of the needs of local communities and the mechanisms of health bureaucracies can health bureaucracies develop and become sensitive to the rural village culture they seek to serve (Justice, 1987). More specifically, she argues that the front-line health worker's job description often underestimates their input and that they often function as unofficial cultural interpreters for patients and work to provide the services the villagers themselves define as most needed. She argues that, though the health workers receive no recognition or remuneration for this work, it is pivotal to service experience and health outcomes, as health organisations have limited "scope for incorporating social reality into the planning process (...) and often chart a course of action which has more to do with meeting organizational needs than serving those who need health care"(Justice, 1983:969). These are all issues that are of utmost importance to our understanding of front-line health workers and their role in leprosy implementation.

Finally, since this study aims to say something about the health worker's role in reconciling organisational intent and local strategies, it is crucial that we try to understand the relationship between organisations and their clients. Ogden (2000) argues that there needs to be a shift in perspective from control to care, and from supervision to support. She argues that social sciences can help programmes and policies to more effectively meet communities' health needs by shifting the focus from the bio-medical and epidemiological reality of a disease to the ordinary life of people who are affected by it. NGOs often represent just such a medicalised view of leprosy, a view which can lead to a gap in perspectives and aims between service providers and their clients.

As Carcianiga & Herselman (1999) point out, the symptoms of leprosy, the characteristic loss of peripheral body parts, nerve reactions, and trauma to anaesthetic limbs, does not go away with time. As bio-medically oriented public health interventions have focused on curing the disease and eliminating leprosy, the experience of those affected by leprosy has often been overlooked. The main manifestation of the disease, as experienced day-to-day, is its 'side-effects' rather than its bacterial load. Suffering from disabilities, painful reactions and complications, despite having been medically cured, is as real an illness to the sufferer as the presence of the bacteria in their body is to the medical practitioner. Moreover, the community views these symptoms as evidence of the presence of disease and, thus, it is difficult to engage meaningfully in social and economic rehabilitation projects without addressing them. Approaches that fail to address the illness as experienced by people themselves, that fail to consider the larger context within which the disease manifests itself and that fail to consider the needs, desires and resources of people as they interact with their illness on an everyday basis run the risk of being inappropriate or, potentially, counterproductive to the health of those affected by the disease (Staples, 2004).

Much anthropological work has been carried out to understand the needs and resources of the target populations of interventions (Conticini, 2007, Mosse, 2003), demonstrating clearly that the 'recipients' of interventions do not sit quietly by and wait for the intervention of outsiders. They actively engage with their context, their lived reality and the possibilities and limitations this reality imposes on their lives. By understanding their everyday strategies, we could build interventions that draw on the strengths, and address the weaknesses, of these everyday strategies and, thereby, build interventions that are more appropriate, meaningful and feasible to those affected by the disease. In line with the growing "realization that international guidelines (...) are *necessary but not sufficient*" (Ogden, 2000:136), Conticini's (2007) work on street children in Bangladesh agues the importance of a thorough understanding of the local context in order to recognise the impact of changes which may seem insignificant by international yard sticks but can have a significant impact on the lives of people locally. He advocates building interventions "(...) that,

while trying to reach universal goals, [are] built upon local opportunities for action and beneficiary strengths" (Conticini, 2007:26).

The importance of understanding the strengths and capacities of local communities has started to trickle through to official leprosy policy discourse, as exemplified by the Workshop Reports from the International Leprosy Congress in Beijing in 1998 (Smith, 1999), as well as the ILEP guidelines on Social and Economic Rehabilitation (Nichols et al., 1999). However, little research has looked at the extent to which the inclusion of such perspectives is actually happening in reality, the extent to which local strategies are compatible with organisational intent or the extent to which the channels of communication needed to access these perspectives exist within implementing organisations and institutions.

### 1.2 Public Health, Health Workers and Health Systems

On the public health front, recent operational research carried out on management and decision-making within ILO, in collaboration with researchers from LSHTM, has demonstrated the potential role of NGOs in up-stream information flows from local to international arenas. The research demonstrates the extent to which decision making is conducted at an international level, with limited input from local NGOs, thereby limiting their operational manoeuvrability (Porter et al., 2004). The research argues that, as a result of the close interaction between NGOs and communities, the opportunity arises to collect information on the needs and capacities of individuals and communities, as well as generating a feeling of social responsibility for ensuring that this information is translated into policy. It emphasises the potentially pivotal role of NGOs as channels of communication, linking grassroots perspectives with international policy (Lush et al., 2003, Harper, 1997).

Studies often speak of 'provider' and 'client' perspectives. However, studies in organisational anthropology have shown that organisations (or 'providers') cannot be seen as homogenous entities but must, rather, be seen as complex structures

governed by the competing interests of actors, both inside and outside of the organisations (Emmet and Morgan, 1982, Wright, 1994). The stated organisational intent of facilitating upstream information flow must be understood in relation to power relations between different actors within organisations, as well as between 'provider' and 'client' (Foucault, 2000). These power relations may have significant consequences for the nature of the information transferred and the manner in which it is communicated (Cooke and Kothari, 2001, Chambers, 1997, Hickey and Mohan, 2004). In most cases, the relationship between 'client' and 'provider', as well as that between health worker and management, has a hierarchical nature that influences communication. However, our understanding of organisational behaviour is limited by a lack of studies of the 'shop floor', of how things actually happen within organisations (Czarniawska-Jorges, 1992) and of the 'middle ground' (Nichter and Kendall, 1991, Leppard, unpublished). As of yet, no studies have looked in depth at these relationships within leprosy organisations and at what impact organisational culture and internal working relations might have on the possibility of bottom-up communication of grass-roots perspectives.

This research focuses on the experience, social identity and impact of a group of leprosy healthy workers. Having already discussed social sciences perspectives on health workers, we also need to acknowledge that there is a vast body of literature within public health surrounding the role of the community health worker and, primarily, their role within primary health care. Community health workers have a long history in public health, from the early barefoot doctors of China in the mid-50's (Zhang and Unschuld, 2008), to their central position in the concept of primary health care enshrined in the principles of the Alma Ata declaration (WHO, 1978). In fact, many signatories to the declaration considered community health worker programmes tantamount to primary health care in general (Mburu, 1994). Then came the economic recession of the 1980s and community health workers fell from popularity, as they were seen to have failed to deliver, largely due to problems such as "unrealistic expectations, poor initial planning, problems of sustainability, and the difficulties of maintaining quality" (Gilson et al., 1989).

The literature review for this study is complicated by the role of my research subjects, as they straddle the categories between professional workers and community health workers. In addition, the public health literature applies a wide variety of definitions of community health workers in studies and programmes, as well as describing a varied remit from project to project and country to country. However, there are already several excellent systematic reviews summarising this research from a public health point of view, such as Gilson et al (1989), Bhattacharyya et al (2001), Abbatt (2005), Lehmann et al (2004), and, most recently, Parasad and Muraleedharan's (2007) SWOT analysis and the WHO (2007a) review.

The 2007 WHO review "*Community Health Workers: What do we know about them?*" reviews 250 journal and grey literature articles pertaining to the role and work of the community health worker, to provide an up-to-date review of points of consensus in the literature. The review emphasises the potentially valuable contribution community health workers can have on improving access and coverage of services, even if the quality of their services is not always assured. Therefore, in order to be effective, community health worker must be carefully selected, appropriately trained and carefully supervised. The review concludes that community health worker should be firmly embedded in their communities in order to retain legitimacy and acknowledges that the issues surrounding remuneration remain unresolved and controversial. Finally, the review stresses that, though community health worker programmes can be an effective means of reaching populations that are not reached through other health services, they are not an inexpensive fix or a panacea for a weak heath system.

Despite discussing issues surrounding the role of community health workers as social agents, the WHO report retains a pragmatic perspective, focusing on the performance, management and governance of community health workers. The report focuses on issues such as staff retention (Bhattacharyya et al., 2001), impact effectiveness (Swider, 2002, Lewin et al., 2005), cost-effectiveness, training, supervision, community participation, relationship to wider health services (Doherty and Coetzee, 2005) and the controversy surrounding the efficacy and

ethics of incentives (Bhattacharyya et al., 2001). In addition to these pragmatic considerations, the report acknowledges that the outcome and efficacy of community health worker programmes is to a large extent dependent wider trends, economic resources and political commitment (Haines et al., 2007)

> "Although this concept of community health worker continues to focus on their role in community development and bridging the gap between communities and formal health sector, their role as advocates for social change has been replaced with a predominantly technical and community management function. Over the years, and in the prevailing political climate, this pragmatic approach to community health workers has gained currency, and undoubtedly today constitutes the dominant approach, although the fundamental tension between their role as extension workers and change agents remains" (WHO, 2007a:5-6)

In addition to looking at health workers, this study focuses specifically on the health worker's role in implementation. Implementation studies can be said to look at "what happens between policy expectations and (perceived) policy results" (DeLeon, 1999:315) (Ferman, 1990) and have long been polarised around top-down and bottom-up views of implementation.

Top-down approaches, such as that proposed by Van Meter and Van Horn (1975), tend to see implementation as a question of the proper management and administration of plans and policies that have been determined higher up in the hierarchy. These top-down approaches tend to be reflected in the structures of governance of public health institutions and organisations, where the levels of politics and administration are kept carefully separated and access to the political level is controlled by hierarchy and authority (Barrett, 2004). In this perspective, the role of ground level implementers is that of a lackey (Werner, 1981), limited to the proper application of the policy objectives formulated by policy makers and proper implementation, of course, is only possible under 'ideal' conditions (Hogwood and Gunn, 1984). As a result, innovation is seen as dangerous, as it implies an un-controlled deviation from the policy plan. Epistemologically, implementation is seen as objective and agency has limited or no role to play, legitimately.

Conversely, bottom-up approaches, like those proposed by Hanf (1982) and Hjern & Hull (1982), tend to approach implementation as subjective and, thus, see innovation and agency as crucial in the implementation process. Bottom-up approaches take ground level implementation as the starting point of analysis and tend to focus on the micro-politics within institutions. Such bottom-up approaches emphasise the role of field-level implementers and the extent to which their actions in the field constitute policy in practice, as opposed to the carefully laid plans of policy makers. Taken to the extreme, implementer becomes liberator (Werner, 1981), as they are seen to take on the role of advocates. Having said this, most bottom-up theories approach implementers from a more pragmatic perspective, such as, for example, Michael Lipsky's (1983) account of 'street level bureaucrats'.

In general, implementation studies have fallen out of fashion in recent decades, and what work there is often fails to fully analyse the perspective of ground level implementation staff themselves and the power relations that enable and/or limit bottom-up communications within and beyond the organisational setting.

### 1.3 Implications and Applications

This research should be read both as an in-depth ethnography of an urban leprosy project and the health workers who work there, at a time of drastic changes in the leprosy policy landscape, and as an attempt at furthering health systems theory and public health understanding of interventions, through the directed application of social theory. To speak of health systems, we must recognise the complex implications of understanding 'systems' and how people interact within them. Social sciences have spent the last centuries developing theories aimed at understanding how systems shape people and how people, in turn, shape systems. If we are to truly understand and strengthen health systems, we must draw on these insights. If we can reach beyond 'multi-methodology' towards the recognition of the potential of true multi-disciplinary collaborations, at a point in time when the approaches of anthropology and public health are closer than ever,

we have a real chance of drawing on the strengths of both in order to improve health delivery to service users.

This research springs out of a public health reality which is faced with a global shortfall in human resources, it comes at a time when we are beginning to realise that we will not be able to achieve the Millennium Development Goals without fundamentally rethinking our approach to health provision, and at a time when the public health world is revisiting the primary health framework set down in the Alma Ata declaration as a potential solution to these challenges. Investment along these lines would necessarily involve a major investment in front-line health workers. Parallel to these developments, there is a growing interest in health systems and in interventions focusing on health systems strengthening. There is also growing acknowledgment of the fact that health provision is not merely a question of the number of health providers, or the clinical skill of these providers, but that it must be seen as an expression of the functioning of the health system as a whole. These are the perspectives that frame my research interest into front-line health workers and their impact on interventions.

Within the wider field of health systems research, health workers are often ignored or forgotten, as policy makers focus on the more macro level influences or on the more technical aspects of health systems. Although there is growing recognition of the importance of human resources in health systems research, most of this still retains a very pragmatic focus on worker density, incentive structures (both financial and other), training and skill levels (Hongoro and McPake, 2003). Recent health systems research has recognised that there are a number of factors that influence the performance of health systems but that these are rarely accounted for within traditional explanatory input-output frameworks (McPake et al., 2006). In addition, the pivotal role of front-line health workers is slowly being recognised, as is the impact of their 'discretionary' behaviour on health system outcomes (Walker and Gilson, 2004). Research has focused on the different elements that influence the outcomes and mechanisms of health systems, such as the particular political and cultural context (Atkinson et al., 2000); power (Atkinson, 1997, Gilson, 2005); policy change (Walker and Gilson, 2004, Penn-Kekana et al., 2004, Buchan,

2000); trust (Gilson et al., 2005); motivations (Franco et al., 2002, Franco et al., 2004); intervention history (Schneider et al., 2006); and, organisational issues (Atkinson et al., 2000, Blaauw et al., 2003).

Though these all describe aspects of the informal mechanisms of health systems, there have been few attempts at building frameworks that examine these informal mechanisms in relation to the formal structures they exist within. One notable exception is the *'Dynamic Responses Model'* framework developed by the Health Systems Development Programme (HSD) (Balabanova et al., 2006), which attempts to at least outline the relationship between these different mechanisms, and examine the role that health workers play in their execution. Though my research does not explicitly utilise this framework, as I did not become aware of this impressive body of research until the latter stages of my research, it was encouraging to find that, though the HSD and I have approached the issue from very different perspectives and with very different methodologies, we had still reached very similar conclusions.

In its current manifestation, and by its own admission, the HSD framework lacks theoretical sophistication. The theoretical perspectives it requires are ones that I believe the social sciences already possess and, therefore, this study must also be understood as an attempt at incorporating anthropological methods and social theory into the study of health systems, in order to build a greater understanding of the role of health workers in implementation. The details of the HSD framework, recent trends in health systems research and exactly how my research fits into this wider trend within public health will be discussed in Chapter 11. Suffice to say here that it is within this trend that I hope the findings and methods of this research can have an impact on public health.

We need to recognise that health systems are complex social systems and engage with "the complex inner-workings of the system, the everyday organisational reality of health workers and managers (...) Significant resources and energy have been directed at fixing the 'hardware' of the system, while the 'software' – the organisational culture, the social networks, the values – has been largely ignored

(...) [As a result] our understanding of the complex social world of health systems is limited and fragmented. Current perspectives rely on simplistic assumptions about human behaviour" (Blaauw et al., 2003:39). To address this, health systems researchers must draw more extensively on social theory to develop appropriate explanatory models and to build more appropriate interventions in the future.

This thesis is, as stated above, an attempt to combine the insights from anthropology and public health in order to better understand the role of health workers in the implementation of leprosy services in a rapidly changing policy landscape. The combination of two disparate disciplines is always difficult and the application of anthropological findings to public health is often especially so due to the very different nature of the questions asked and the results produced by the two disciplines. To find that, in this case, the two disciplines share a desire, a framework and an interest, in the complex and unpredictable impact of human resources on health system outcomes, suggests a real space for anthropological research within the wider public health agenda.

What this research is not, is an attempt at suggesting a framework or a particular social theory, but rather a demonstration that there are a number of social theories out there capable of illuminating the dialectic relationship between agency and structure in a way that could significantly advance health systems analysis.

Hopefully, this research can inspire others to carry out similar studies in different cultural, political and health care settings. For when it comes to health systems research and human resources, just as Atkinson notes for studies of decentralisation, there is a need for better local knowledge: "Although the requirements of ethnography are demanding both in cost and time, such studies are of vital importance to build up a base of knowledge about the context of health systems development as a complement to the international work on how to assess quality of health services. Without a body of work documenting the realities of policy implementation in context, we have no record of what is really being changed, we do not know what we are monitoring through quality indicators and

we cannot assess relevance of regional and national experiences from one context to another" (1997:635).

### 1.4 Defining a Conceptual Framework

So, to summarize, there is a general paucity of research on leprosy within anthropology and a voluminous, yet divided, literature on community health workers, both in anthropology and in public health. On the one hand, we have anthropological research demonstrating the desirability of utilising local strategies in implementation and policy planning and, on the other hand, we have operational research arguing for the potential for translating such experiences up the policy ladder and influencing the formulation of policy at international level. Despite these two areas of research demonstrating the desirability and potential of such approaches, there is a lack of research on how local strategies can be accessed by organisations and by which processes they can be brought to affect the formulation of more appropriate leprosy policy and interventions. Therefore, I decided to construct my study around the investigation of the potential role of health workers in this process, as front-line health workers must be seen to form a crucial part of any health system.

The health workers are both carriers of organisational intent and through their day-to-day interaction with the community, observers of community intent. Therefore, the physical meeting between the health workers and local communities can be seen as a point of interaction between organisational intent and local strategies. Further, this interaction can be seen to constitute a spatial and temporal arena where the negotiation between variant perspectives, that may be insurmountable on an organisational level, may be reconciled on an individual level, through subtle manoeuvring on the part of health workers.

Despite moving closer in the last decades, anthropology and public health are still based on implicit assumptions and theoretical approaches that are not always easily combined. In constructing my initial conceptual framework I had pitted

anthropology against public health, top-down against bottom-up, lackeys against liberators and, even, organisational intent against local strategies, thereby inadvertently creating a dichotomous framework (see *Figure 1*). By constructing such a strongly dichotomised view of the theoretical landscape, I inadvertently came to think of my research subject as a conflict to be resolved. Thereby, as Bourdieu warns, adopting a *"contemplative or scholastic stance that cause her to (mis)construe the social world as an interpretive puzzle to be resolved, rather than a mesh of practical tasks to be accomplished in real time and space – which is what it is for social agents" (Wacquant, 2006:273).* This idea of a dichotomous conflict is even evidenced in the phrasing of my research question, with its focus on 'reconciliation'. Inadvertently, I had pitted organisational intent against local strategies, agency against structure. However, I later found that apparent simplicity often hides great complexity.

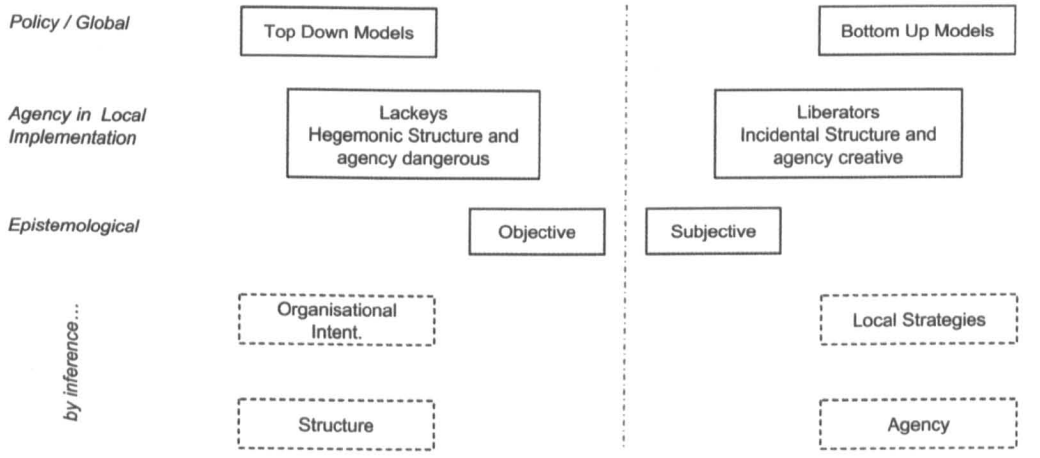



*Figure 1*: Dichotomized view of theoretical approaches.

Once in the field it very rapidly became clear that this dichotomy was an artifice of my mind and a construct of the literature (see *Appendix 1*). It became clear that, to understand how the health workers see the world, and to explain their actions in accordance with their own world view, I would need to move away from the idea of a 'conflict' and allow for a much more complex approach, that takes as its starting point the relationship between agency and structure without dichotomising the two.

In order to achieve this I would need to draw more heavily on social theory, as well as to try to link the theory to recent trends in public health systems analysis.

### 1.5 Refining the Conceptual Framework

The actions of health workers can only be understood if we recognise that the health workers are both limited by the structures they exist within and created by those very same structures. The structures we exist within enable us to make sense of the world at the very same time as they dis-able us by limiting the ways in which we can understand the world (Ortner, 1984). However, as actors in this world, we can also express agency. Though there has been a tendency to see agency only in the expression of opposition to the structures that define us, in the form of rituals of resistance or in the shape of social revolutions, I believe that the existence of agency within structure is a far more radical realisation. By looking at the ways in which agency is expressed within structure, we can begin to understand change within the system.

Moving beyond the initial dichotomy and allowing for complexity in the conceptual framework, I needed to identify a theoretical framework that could transcend the dualism of agency and structure and, instead, focus on the dialectic relationship between the two. The relationship between agency and structure, or micro and macro processes, has been central to post-war social theory (Giddens, 1979) and a number of theorists have proposed more or less successful solutions, from the early work of Berger & Luckmann (1966), through Bhaskar (1989) and, perhaps most famously, Giddens' (1993) theory of structuration, to more post-modern approaches such as Seidman (1997), Williams (1991) or Omi & Winant (1994). All of these offer insights into the dialect relationship between agency and structure but, for the purposes of this study, I found that a combination of the work of Michel Foucault and Pierre Bourdieu offered the greatest insights into the social identity and actions of my informants.

The potential importance of Bourdieu and Foucault's social theories to the study and understanding of public health and medicine has been proposed by many (Samuelsen and Steffen, 2004) and the idea to combine Foucault and Bourdieu's work to aid in the understanding of the interplay between agency and structure has been utilised by others in the past, for example, by Gorringe and Rafanell (2007), to understand the creation of Dalit identities in Southern India; by Bourgois et al (2004), to investigate the everyday violence of hepatitis C among young female injection drug users in San Franscisco; by Agergaard, to investigate sports in Denmark (2005); by Ebrahim (2008), to understand the relationship between NGOs and their funders; or, by Decuteau (2008), to understand HIV/AIDS in post-apartheid South Africa.

Health workers are embedded in a wider structure within which they operate and Pierre Bourdieu's concept of the habitus offers valuable insights into how this structure is structured and maintained through everyday social interactions. According to Bourdieu, social actors can exercise agency within this structure. However, he does not allow much scope for systemic changes as a result of this agency. Similarly, Michel Foucault's approach deals with the relationship between agency and structure. Unlike Bourdieu, however, he opens up the possibility of change as the result of strategic agency. Taken together, the two perspectives can be utilised to look at the relationship between structure and agency as it plays out in the everyday activities of front-line health workers.

Lastly, I found Joan Comaroff's (1985) perspective on policy as the product of a double dialectic relationship useful in conceptualising the way in which the health workers' agency can be instrumental in affecting wider policy discourses. By moving away from a perspective that favours either a top-down hegemonic view or a bottom-up incidental view of policy creation, she argues for a dialectic model of policy formulation. Thus, Comaroff's approach allows us to move away from a view which favours a monolithic, hegemonic international discourse that is imposed on local organisations. Rather, she argues, policy formulation must be seen to be the result of a myriad of voices and perspectives competing for influence at any given time. This is as much true of the local context as it is of the global arena. This

perspective allows us to understand not only how international discourses construct the health workers' world view, but how they can, in turn, be part of constructing this discourse, at least on a local level. By recognising that policy is created by local and global dialectic relationships in a dialectic relationship with each other, Comaroff identifies a mechanism of mutual constitution between the discourses and, thus, opens up the possibility of agency and ground level perspectives influencing the international policy arena.

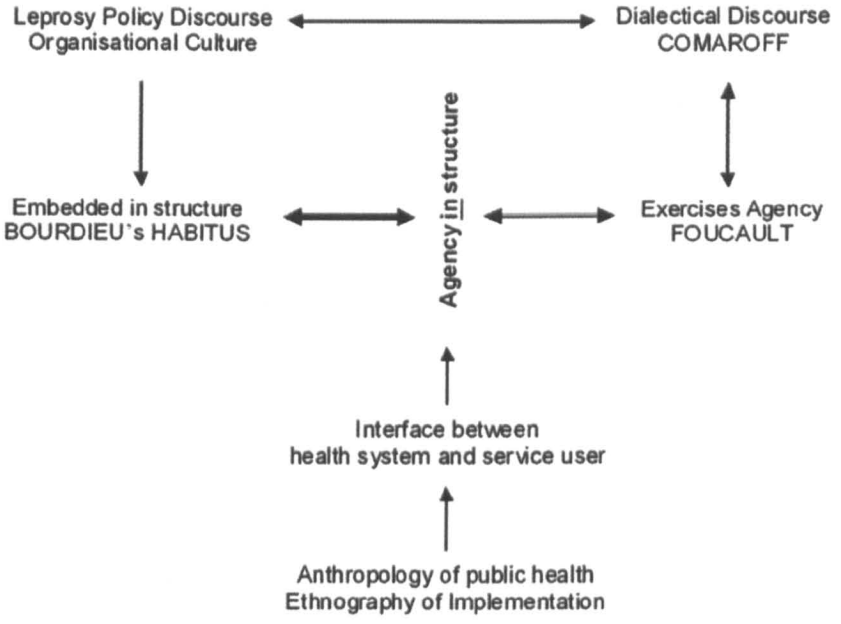



*Figure 2.* Theory re-envisaged. As guide rather than conceptual framework.

The figure above illustrates the social theory utilised in this thesis and is intended more as a guide to reading the thesis than as a strict conceptual framework. The figure sets out the mutually constituting relationship between structure and agency relates this to the applied social theory. In addition, the figure attempts to demonstrate how the dialectical discourse framework might serve as a powerful tool for improving interventions. In recognising that health workers express agency and that this agency is expressed in the everyday working practices of health workers it follows that this perspective will impact on the organisation's culture. The

organisation is a more powerful actor than the health worker and could potentially influence national or international policy. More directly, the organisational culture forms the primary structure in which the health workers are embedded.

The heart of this thesis, and of this figure, is the understanding of agency as expressed within, rather than in opposition to, structure. This perspective could yield insights far beyond this study as it highlights the importance of understanding not only structures but the actors that work within these structures. Within public health there is a growing interest in health systems analysis and a growing recognition that health systems must be understood as complex social microcosms and that health systems are an expression of the interaction between health providers and service users. Through the proper application of anthropological methods along with social theory we can begin to form an understanding of the practice of public health delivery, and the mechanisms of service provision thereby. Only by building an effective anthropology of public health can we truly have effective application of anthropology in public health in order to develop interventions that draw more extensively on the strengths and capacities of health systems and local communities.

## 2. Me and Methodology

Most of the data for this thesis comes from 13 months of fieldwork carried out within a specific project of one of India's major leprosy organisation. Having a background in both anthropology and public health it was clear to me that in order to understand what was going on at ground level in leprosy control I would have to apply the tools of anthropology, in the form of an exploratory ethnographic study of the health workers, to be able to observe and experience firsthand the health worker's relationship with the community and the internal working dynamics of the organisation. Thus, the study relied primarily on a loose set of methodologies described within anthropology as participant observation. The aim of this methodology has always been to reconcile the differences between what people say they do and what people actually do, as well as to, hopefully, enable the researcher to gain access to emic thought patterns by gaining access to the experiential work of his/her subjects by actively participating in the world of his/her research subjects. However, as we seek to immerse ourselves in our subjects world, it is important that we maintain a critically reflexive approach to our own position as researchers vis-à-vis our subject and maintain an awareness of both the perspectives we carry into the field with us and the ethical implications of our presence and actions in the field.

### 2.1 Getting Situated

When I first arrived at the project I discussed my research plans with the project management who suggested I give a presentation in front of all the project staff explaining why I was here, what I wanted to achieve and what my methods would entail. Later I came to realise this was a great idea, as it was the format in which the staff were used to receiving any new information or change to procedure etc. During this meeting I explained a little about my background and my study but placed the primary emphasis on what I wanted from them, how they could help me achieve my goals and what I hoped I could do for them. Even though my talk emphasised the fact that I did not want them to change any of their habits but

merely allow me to work alongside them as they performed their routine duties, and I reiterated this sentiment on an almost daily basis, this was going to prove very difficult to achieve.

The primary hurdle was to be one of communication but not merely one of language. Having failed to find instruction in Telugu in London it was decided that I would concentrate on learning the language in situ. However, upon arrival I was to find that it was in no way this simple. Hyderabadi discourse is a complex and seemingly haphazard mishmash of Telugu, English, Deccani[1], Urdu, Hindi, and Lombardi (or other tribal languages) as well as a score of other Indian languages spoken by the migrant population (such as Tamil, Marathi, and Rajastani). Despite spending every free moment of my first three months in the field studying Telugu, on my own or with the help of the project staff, I never mastered the language beyond the bare minimum needed to follow simple conversations related to common work situations. Thus, I often had to rely on the translation help from the health workers who thankfully all spoke good English. However, their English proficiency was in itself a hindrance to my learning Telugu, as one of the health workers turned to me during an eye-camp we were conducting my very first week in the field and ask in perfect English: "You want us to speak Telugu to you so you can learn? But we also want to learn English."

## 2.2 Participant Observation

Having settled into the field and the flow of the organisation, as well as managing the residual language problems, I settled into the bulk of the data collection, in the form of participant observation with the field-level staff at the organisation. Participant observation has been a cornerstone of anthropology since Malinowski was first stranded in the Trobriand Islands as an unintended consequence of the 2nd World War (2001). Though there is little concrete agreement on exactly what this methodology entails there is an agreement that in its ideal form it "involves

[1] (an amalgam of Urdu, Marathi, Konkani, Gujarati, Kannada, Telugu, Arabic, Persian and Turkish spoken by the Muslim population in South India)

holding the role of 'participant' and 'observer', insider and outsider, in tension so as to ensure that one is close enough to see what is going on, but not so close as to miss the wood for the trees." (Bate, 1997:1151).

The majority of my fieldwork was spent working alongside the Community Health Organisers (CHOs) as they went about their daily duties, spending mornings in the field and afternoons in the project's outpatient clinic or doing paperwork. For practical reasons I organised my time in the field so that I spent a week at a time with each health worker. This was aimed at getting as complete a picture as possible of their duties and, initially, at building rapport with each of the CHOs. In addition, I made sure that, during my fieldwork I had spent at least two complete weeks with each of the CHOs. Beyond this basic structure timings got more fluid as I followed the natural flow of the work, going out with whoever was available, the person who invited me or the one that had something 'interesting' going on that day.

In addition to the structured weeks I also attended as many 'special programmes' as I could, be these annual celebrations, melas (fairs), disability prevention camps or other functions arranged by the organisation, local communities, other NGOs or government bodies. Though my limited attempt at structuring the participant observation helped ensure my exposure to as many different situations as possible, the true test of the validity of sampling in participant observation lies in thematic saturation (Spindler and Spindler, 1992). My presence in the field on a daily basis also enabled me to talk to a wide range of actors on an informal basis, from Medical Officers and nurses at the Urban Health Posts (UHPs) across the city, to anganwadi workers (female community level workers of the Integrated Child Development Scheme) and ayahs (attenders) in the city's slums, political leaders, basti leaders (local slum leaders), government leprosy workers, social-worker students, patients and local community members.

## 2.3 Informal Interviews

To supplement the data collected through participant observation I also conducted informal work-narrative interviews with 7 of the 9 health workers at the project. The interviews were focused around four main topics: background and training, relationship with the community, organisational support, and the effect of recent changes to leprosy policy (see *Appendix 7* for interview guides).

One of the health workers was reluctant to be interviewed. Though he never explicitly declined to be interviewed, repeated requests and evasions made it clear that he was uncomfortable with the prospect. However, instead of an interview, he initiated a lengthy informal 'discussion' at his residence where many of the same topics where covered though the interaction was not recorded. A second health worker was made redundant 4 months into my fieldwork, shortly before I conducted my first series of interviews, and subsequently entered into legal dispute with the organisation, at which point it would have been inappropriate for me to conduct a formal interview.

Two of the interviews with health workers were carried out with the help of a translator as they felt their English was not good enough. The translator used was a research assistant attached to another research project based at the project, but who had limited knowledge of or interactions with the health workers in question. In addition to the interviews carried out with health workers I interviewed most of the other staff at the project level. I also interview line management for the project throughout the organisational structure, up to and including regional and national levels. These management interviews again revolved around 4 main themes; background, impact of recent changes in leprosy policy, role of health workers in the organisation, and future challenges.

In total 16 in-depth interviews were carried out, ranging from 1 – 3 hours in length. All interviews bar one, due to technical malfunction of my recording device, were transcribed verbatim. The transcriptions were then coded and analysed thematically. In addition I conducted a focus group discussion with all the health

workers with the aim of accessing the 'consensus view' of health workers as a group. The focus group discussion centred around what qualities are important in a health worker, how to build rapport with the community and what more the organisation could do to assist them in their work. Both work-narrative interviews and focus group discussions were held at the project offices. I had hoped to conduct them in a different location, the CHOs residence, my residence, a café... etc but all the health workers insisted that we conduct the interviews on project premises, though behind closed doors away from other members of staff or superiors. I was also lucky enough to be invited to attend numerous planning, strategy and update meetings and briefings both at project and regional level.

I had initially planned to administer a semi-structured questionnaire to, or conduct focus group discussions with, people affected by leprosy who were the organisation's clients but soon realised that such an exercise would merely be window dressing on the excellent work carried out by people such as James Staples and, would do little to supplement informal discussions during routine work. I was also keen to maintain the health worker as the main focus of my study.

If I was keen not to divert my attention away from the health workers to the organisation's clients, I was equally eager to keep my focus separate from the organisation's higher management. As it can be exceedingly difficult to maintain good relations with all levels of an organisation as the "organisation's internal complexity means that to have good relations with one set of actors might be detrimental to securing access to another set" (Eyben, 2005:3). Therefore, interviews with the project's direct line management at regional and national level was conducted on a later trip, in February 2008, after the conclusion of my initial fieldwork to try to keep the two, the project and the organisation as a wider entity, separate.

However, I did utilise every opportunity to attend meetings at regional office and head office alongside the ULP project officer. Of these meetings, the quarterly Project Officers' meetings were perhaps the most enlightening for me, as it provided me the opportunity to meet the project officers from other projects and to

compare and contrast their perspectives with what I was experiencing and observing at ULP. This was also a valuable opportunity to access organisational and government documentation on leprosy policy in the past and future as many of the project officers had worked in the field for a number of years and had extensive insights into changes in leprosy policy. These documents, along with project documentation, and policy papers and materials accessed pre- and post-fieldwork was analysed to form an understanding of how leprosy policy and discourse has changed and what these changes have meant in practical terms at field-level.

I was also lucky enough to be able to visit some of the organisations other projects, and some projects run by other similar organisation, during my fieldwork.

### 2.4 Time-Series Analysis – Methodological Mix-up

One of the reasons for structuring my fieldwork so as to ensure that I spent continuous weeks with each of the health workers was my ambition to do a time-allocation studies on how they spent their time (to be analysed in 15 minute segments over a complete week). These data would then be compared to their own work-narrative and stated priorities, as well as the official job descriptions drafted by the organisation.

However, despite my best efforts, careful planning and consultation with the project management, it very rapidly became clear that my fingerprints as a researcher were all over my data, thus, rendering it useless for a structured time-allocation analysis. This is not to say that the exercise was a waste of time, for it shed light on the ways in which my presence as a researcher changed the health workers' routines. In physics, Heisenberg's uncertainty principle stipulates that there are no absolutes or fixed realities, thus through the act of defining a parameter as fixed, in order to measure it, we inadvertently change the nature of that phenomenon. Much the same is true of any research. As researchers we cannot avoid, predict or mitigate our presence as researchers, merely try to observe the impact of our

presence and include an analysis of this impact in our results. So, I continued to collect the time series data despite these limitations.

Then, after 8 months of painstaking collection of time-series data, one of the project supervisors casually mentions that he finds it is interesting that I am doing this particular kind of data collection since they did something very similar themselves a year ago, as a reporting exercise. Would I like to see their results? I took a deep breath and told myself that no data collection is ever wasted work.

### 2.5 The Mighty Pen Stroke, the Photo and the L-word

Finally, a word on the end product of this research process in the form of written text. Clearly, all text is ultimately the result of one researcher's perspective. It is the narrowing down of a multitude of voices and possible perspectives into a defining text. The text is snapshot of reality. What I saw, how I saw it and how I have chosen to represent it to you, the reader, is necessarily a subjective process (Geertz, 1973) but one which lends the analysis strength and validity rather than detracts from it. These aspects are further elaborated in *Appendix 1* but, first, let us look at some of the more technical aspects of the written text.

The text is necessarily affected by the fact that my sample size is rather small and dividing the data into sub categories might render individuals identifiable in the text. Due to these restraints issues such as internal gender dynamics could not be discussed in this text as doing so would constitute a breach of confidentiality. For the same reasons, when discussing senior management I will refer to these merely as senior management distinguishing merely between staff at ULP and staff in the wider organisation. Finally, the primary subjects of this thesis, the health workers, might be referred to using a number of nomen: health workers; Community Health Organisers; non-medical; assistants; leprosy workers; fieldworkers; front-line workers. Depending on the context. These titles should be taken as interchangeable.

With the decline of leprosy in the West and the discovery of an effective cure through multi-drug therapy the very idea of leprosy has been relegated to the history books and religious text in Europe and America. Yet, the word leper is still ubiquitous in our everyday language, used to denote anyone who is considered a social outcast, a pariah, with all the negative social connotations this entails. To illustrate my point: since leprosy as a disease is almost absent from the United Kingdom one would expect to find little mention of it in the daily newspapers, yet, a quick search on the term 'leper' in one of the main British broadsheets found that the term was mentioned no less than 10 times in the last 6 months, and rarely in relation to the disease itself (see *Appendix 2* for discussion and details of search). To avoid negative social connotations this thesis uses variances of the term 'people affected by leprosy'.

Lastly, a word about the unconventional use of photographic materials in this text. They say a picture is worth a thousand words. But whose words do they speak? All photographs are ambiguous and acquire at least some of their meaning from the context into which they are placed. Photographs have traditionally been linked to the written text through explanatory captions or in-text reference. However, due to the dominance of the written discourse in academia the verbal context often serves merely to limit the very ambiguity that gives the photograph a unique means of expression in the first place, "often this ambiguity is not obvious, for as soon as photographs are used with words, they produce together an effect of certainty, even dogmatic assertion" (Berger and Mohr, 1982:91). The caption often destroys the potential of the photograph for providing 'another way of telling' as it forces the viewer to view the photograph as a reader. Thus, in this thesis, I have chosen to intersperse the written body of text with clusters of semi-autonomous photographs. Though the photographs are clearly of the people and places referred to in the text no passage in the text points specifically to any one photograph or sequence of photographs (Chaplin, 1994). By grouping the photographs together the aim is to create a visual domain where the 'reader' must break free of the written text and be momentarily transformed into 'viewer' thus allowing me to communicate some of the feeling of the field, and the subjects of the thesis, in a manner which my mastery of the English language never could. In this way the text and the

photographs become complementary and parallel narratives, inter-connected on a general level, but specifically only by the imagination and 'guesswork' of the reader/viewer (Berger and Mohr, 1997). This hopefully helps to create an interest in the photograph and facilitates a search for meaning which enforces the communicative ability of the photograph. For it is less significant what the image depicts. Rather, the photographs must be seen as an expression of the ambition to provide the reader/viewer with a sense of the field, of the work, of the health workers and of the context so that the colour, the chattering of children and the smell of scorched earth and antiseptics hopefully still linger long into the dry analysis and serve to keep us grounded.

Arguably, the final product of any research is not the text itself but the effective dissemination of the written text produced as an end result of the research process and the analysis of data collected. This is not merely an academic requirement but a moral responsibility. Also, for the organisation which accommodates the researcher, opens its doors and makes its resources available there is an expectation of the production of a result. Despite the fact that anthropological research does not lend itself easily to such summation, as it often means sacrificing depth for simple solutions that are actionable for the organisation (Bate, 1997), I attempted to create a summary of my findings and some basic recommendations which I hoped would be helpful for the organisation. The process also served as an opportunity for the organisation to express its perspective. The report is available to view at http://issuu.com/krisharris/docs/ilo and the feedback provided by the organisation was incorporated in the final version of this thesis.

### 2.6 Me, Myself & I: Ethics, Loyalty and Reflexivity

Data collection is not an exercise in collecting pre-existing objective data but rather the process of collecting data which is the result of the interaction between researcher and research subjects. Thus, it is equally important to understand the researcher as the research subject, it is crucial that we understand how the two relate to each other, what perspectives the researcher brings into the field with him/her and how this affects the research process and the research findings. This

chapter will try to summarize some of the key insights garnered (for further discussion on reflexivity in the research process see *Appendix 1*) primary amongst these insights is the realisation that reflexivity is as much a question of ethics as of methodology.

### *2.6.1 Participant Objectivation*

The silence surrounding the researcher's place in his/her own research was somewhat addressed with the reflexive turn within anthropology in the late 20th Century yet there remains a debate surrounding the delicate balance between the primacy of the researcher, and the primacy of the subjects of research, within the field of anthropology. Many have argued, and I am inclined to agree to some extent, that an overemphasis on reflexivity has somewhat dulled the critical edge of anthropology. That there has been a tendency to become so engrossed in the process of analysing our chosen discipline that we are in danger of reverting to a mode of anthropology which is more similar to psychoanalysis of the researcher, rather than focusing our efforts on the analysis of the social reality of our subjects (Mascia-Lees et al., 1989). Recognising this conflict, Bourdieu's (2003) notion of participant objectivation offers an approach which retains the valuable insights of reflexive analysis, without ever allowing it to fall back into introspection, by shifting the focus from the researcher to the intellectual domain that created that researcher. Rather than asking 'who' we are as researchers, Bourdieu urges us to investigate what intellectual traditions prompted us to ask these particular questions at this particular time.

The key to such an approach lies in the constant and honest assessment of one's motives, transparency in one's methods and a thorough understanding of the power relations inherent in any interaction. Taking a page from Bourdieu's book, it is clear that my fieldwork started the day I decided to apply for funding to do a PhD, several years before I first set foot in India.

I was raised a socialist and schooled in political economy and the social theories of power at a time when anthropology was focusing on subaltern voices, the weapons of the weak and new social movements in a backlash against the identity politics of the 1980s-90s. It is clear that this has had a profound effect on all my subsequent research. The path to my research question can be seen to be the accumulation of my experiences expressed in the desire to harness the practical skills and experiences of ground level health workers and to try to understand how the wider organisational setting enables or hinders the effective utilisation of these insights. Conducting my PhD in a school of public health rather than in an anthropology department was a conscious choice. Having completed a BSc in Anthropology and an MSc in the Control of Infectious Diseases, my fieldwork was prompted by a desire to reconcile these two often opposing approaches and my research tries to identify ways in which public health interventions and perspectives can draw on anthropological theory and modes of seeing. It is clear that this desire influenced both my choice of methodology as well as my theoretical framework.

### *2.6.2 Who Am I to You?*

As important as it is to understand oneself and one's relationship to the field and one's informants, is the question of how my informants saw me and my position relative to them. Organisations fit into the category of subjects that are more powerful than the researcher him/her-self (as opposed to the traditional subjects of anthropology, arguably). To be able to do research, or merely exist within such a context one must be political, one must play the game and avoid being played. Especially in a situation where the organisation is undergoing rapid change and where "champions of change may see such a researcher as a useful political instrument" (Eyben, 2005).

When I first entered the field I entered with the permission of the national leadership of the organisation and I worried that this might compromise my ability to get close to the ground level staff. As it turned out, this was the perfect, and expected, way to enter into the field. It followed a predictable pattern and made my

presence intelligible to the project staff. I was there because senior management had said that I would be arriving and they should accommodate me. This made sense. Yet, it provided me precious little clues as to how the staff saw me and who I was to them. More than anything the staff seemed bemused by my presence. Despite my efforts to introduce myself, my research questions and my methodology there seemed to be an inherent confusion surrounding my presence at the project and a continuing lack of understanding of my research. This was not the quantitative research they were used to, my methodologies and my questions seemed diffuse and unstructured to the health workers. However, after a few weeks of awkward interactions we settled into a social protocol, and the health workers set about teaching me about the clinical aspects of their work and taking me around to meet basti leaders, anganwadi workers and other resource persons. But who was I and where did I fit into their world? Was I seen primarily as a foreigner, a student, a woman, a researcher, a spy, a source of funding, an auditor, an ally, a 'resource person', a problem, a burden, an asset, a friend, a colleague? At different times I am sure I occupied all these roles and not always in predictable ways.

### *2.6.3 Ethics beyond Consent – Elephants and Universities*

I obtained ethical clearance from the appropriate body at LSHTM and from the appropriate local body (see *Appendix 7* for ethical approval and consent sheet). My research was carried out under no monetary dependence, obligation or commitment to the organisation I studied and the fieldwork was carried out in accordance with standard anthropological ethical guidelines (ASA, 2006, SRA, 2003). However, ethical consideration must go beyond this bare minimum of compliance with protocol. The issue of consent is often glossed over or simplified into discussions of the merits of written vs. oral consent. In reality consent is an extremely complex issue. In my research I found that, even if I took great pains to ensure that consent was given by individuals, rather than on the instruction of their superiors, it is actually extraordinarily difficult to break free of this association. My

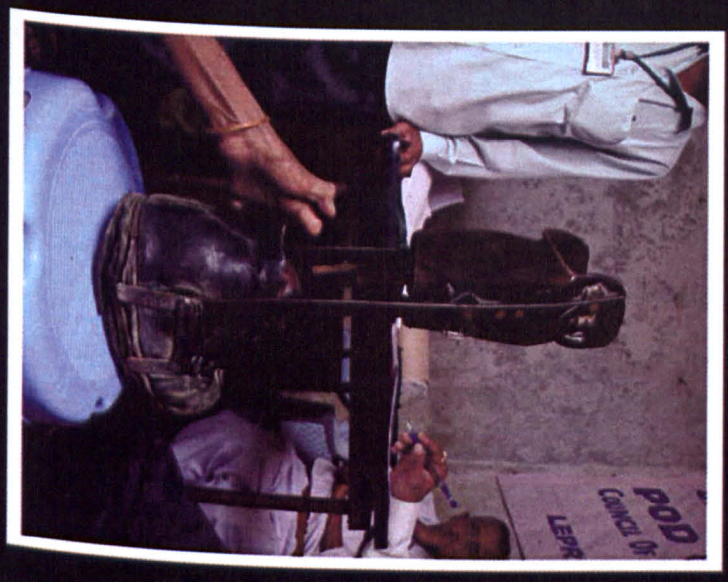
presence in the project was sanctioned by higher management and thus the health workers saw their cooperation largely as a given, not necessarily a choice.

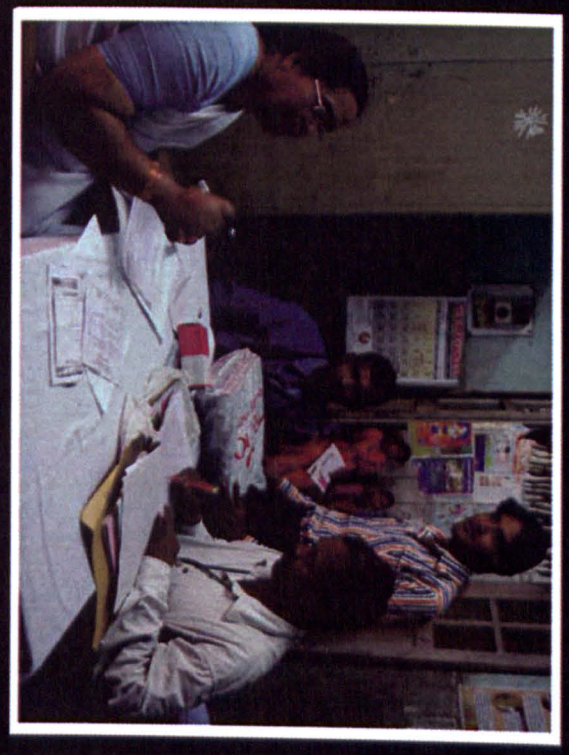
Another issue which influenced my ability to gain 'informed' consent was our diverging ideas about what really constitutes 'research'. The health workers were more familiar with structured, often quantitative, data collection methods and tended to forget that my presence, my 'participant observation', was intended as data collection. Having had all the staff at the project sign consent forms at the start of my project, I used the informal interviews as an opportunity to repeat the process at a stage when the staff where in a better position to actually give 'informed' consent. Since they had at that point experienced me working alongside them and observed my methodology, and we'd had long discussions about the nature of my research and my findings.

Complex as issues of consent are, my ethical dilemma in the field would pose starker challenges. There is a proverbial elephant in the corner of my research, one that was to colour every interaction, every aspect and every day of my fieldwork. When I started my research I was aware of the fact that funding for the project would run out in the end of 2007. However, I failed to appreciate just how profoundly this would affect my research, and ultimately me as a researcher and as a person. As one of the senior managers said one day, *"You have come to watch the organisation fall apart. It makes me very sad"*, it was to make me very sad too. Over time, as I grew closer to the staff at ULP the uncertainty of their situation came to affect me, as well as the research. I came to empathise with their situation, to share their loyalty to their work and, even, to share a very small piece of their social identity. It is the nature of anthropological work that it is slow in the making and even slower in the writing. But as my social relationship with the staff developed, so did my ethical dilemma. I was taking their love and friendship and converting it into research that would ultimately benefit me, yet my research would not come in time to do anything for the project staff.

Even if I could not ensure the health workers' job security in the project or in the organisation, I could do everything in my power to ensure that they were as

'employable' as possible by equipping them with all the transferable skills in my arsenal, and so was ULP university and Professor Kris born. Monday to Friday, from 18:00 to 19:30, everyone available and interested would gather in the project's meeting room for English, computing, anthropology, documentation and 'anything-else-we-could-think-of' classes. To be honest, it was a steep learning curve for both me and the staff. I am not a professional teacher, nor, I admit, did I know a gerund from my elbow before starting this endeavour. These nightly classes also provided me with an ideal forum for learning about Indian culture as well as giving the staff a forum where they could discuss various political, environmental, health related topics under the auspices of verbal English practice. The staff gave of themselves every hour of the day and I felt I needed to reciprocate in some tangible way and, happily, they provided me with the opportunity. Besides, now we all know what a gerund is.





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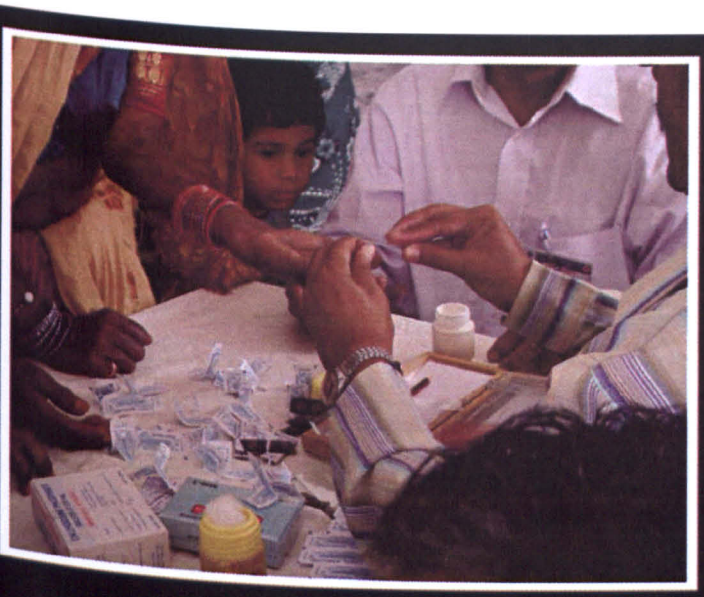

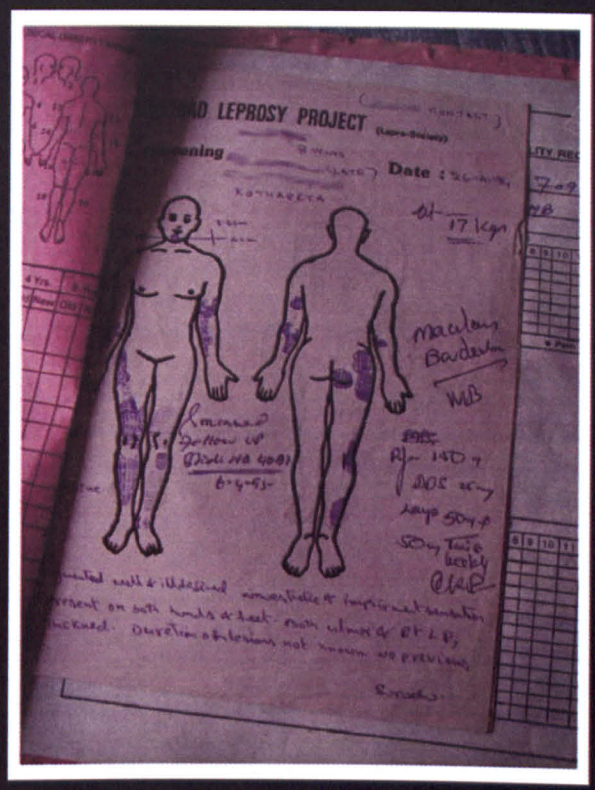
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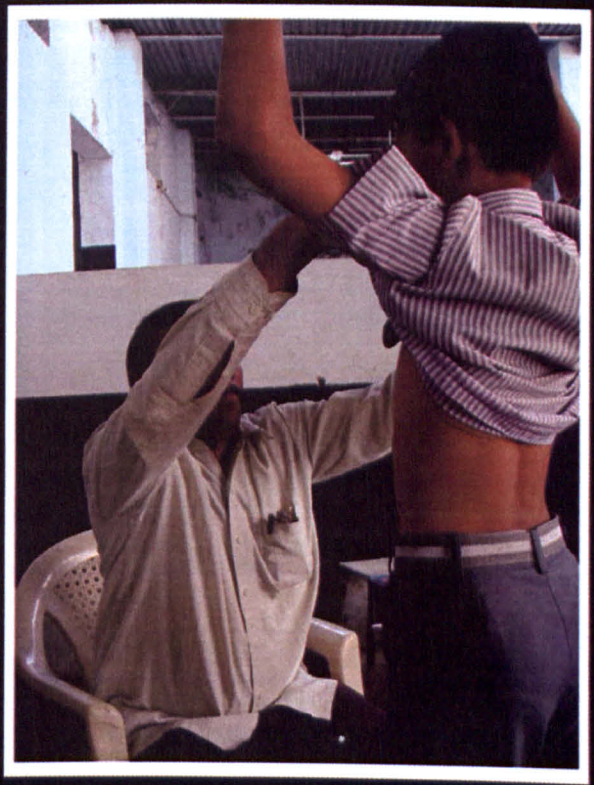

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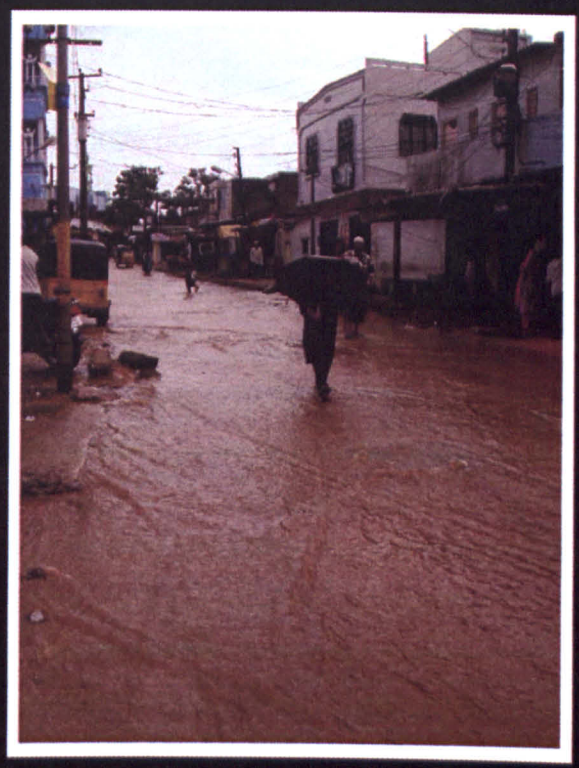

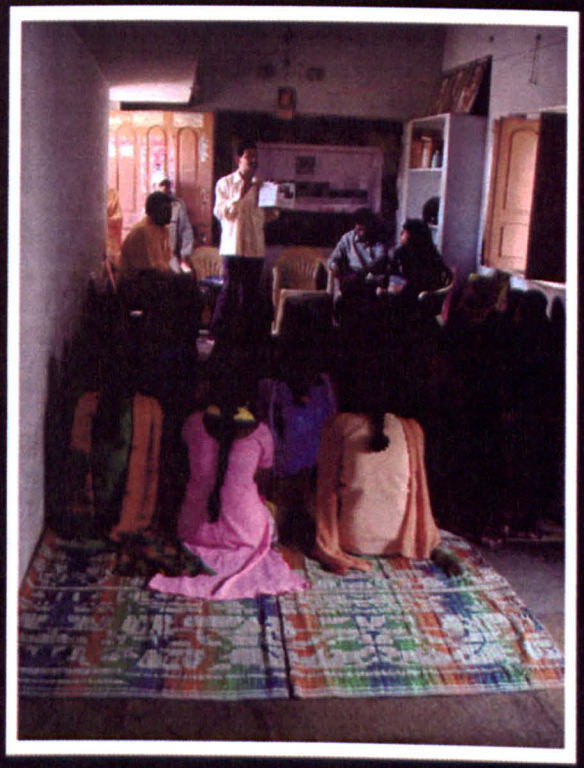

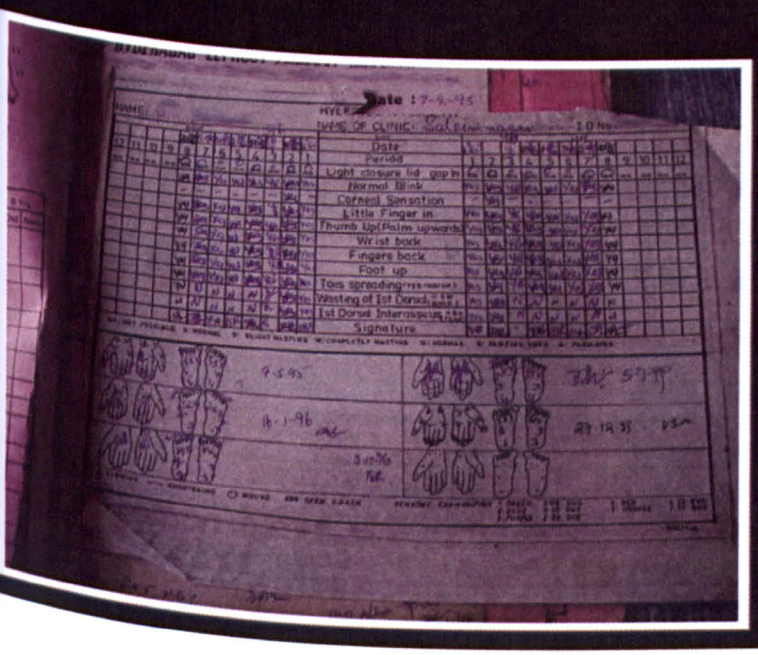
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## 3. Stepping into the Field

A solid theoretical framework and carefully chosen methodological tools are crucial to the successful outcome of the research process but they can only get you so far. At the end of the day the researcher must enter the field and physically engage with the subject of research. Though this is important in all disciplines, perhaps none more so than anthropology. Having a sense of the context within which research is carried out is crucial to the thorough and rich understanding of the research findings. Therefore, I wish to attempt to place the reader in my research landscape, to enable you, the reader, to immerse yourself fully in the narrative of this thesis, to empathise with its subjects and their work. I wish to convey a sense of the context in which I conducted my study, to provide a flavour of the city and its people and to introduce the reader to the organisation I worked with and, crucially, the health workers whose work we will be investigating throughout this thesis.

### 3.1 Leprosy in the Library with the Lead Pipe

The focus of the thesis is on the work and social identity of the field-level health workers, working practices that now extend far beyond leprosy work to include other diseases and community health issues. However, leprosy continues to form a central pillar in the identity of the health workers and, as such, an understanding of the disease became pivotal to understand the health workers. Leprosy, as a disease and as a metaphor (Sontag, 2001 [1978]), is shrouded in myth and prejudice and the image of the 'leper' is one which invokes fear, ostracation and disgust in many even to this day. When I told my friends and family that I was going to India to do research on leprosy the response was almost uniformly: "Does that still exist, I thought that only existed in the Bible?" and "Can you catch it? Will your fingers and toes fall off?" Therefore to understand the disease and to understand a key component in of the health workers' identity I will start off with some basic medical and epidemiological facts about the disease.

Leprosy is a chronic, though not highly infectious, disease caused by acid-fast rod-shaped microbacteria - *Mycobacterium leprae*. Leprosy has an incubation period of approximately five years, though symptoms can take as long as 20 years to appear. Its mode of transmission is not yet fully understood, but it is thought that transmission mainly occurs via droplets excreted from the nose and mouth of infectious patients during close and frequent contact (Lockwood and Britton, 2004). Clinical presentation of disease varies over a spectrum from tuberculoid to lepromatous leprosy, with borderline forms in between, and which form it presents appears to be dictated by the host's immune response which is largely predetermined by genetic factors (Schurr et al., 2004, Bosch, 2004). It is thought that approx 95-98% of the world's population has natural immunity to the disease (Carcianiga and Herselman, 1999). Recommended treatment is multi-drug therapy (MDT) consisting of dapsone, rifampicin and clofazimine which is available free of charge.

The diagnosis of leprosy is based on syndromic management, where the presentation of anaesthetic skin patches, characteristic skin nodules or 'thickened' nerves is used as a diagnostic tool. Paucibacillary (PB) patients presenting with 1-5 skin lesions receive MDT for 6 months, whilst multibacillary (MB) patients presenting with more than 5 skin lesions or thickening of nerves receive treatment for 12 months. The disease mainly affects the skin and nerves and, if left untreated, can lead to progressive and permanent damage to skin, nerves, limbs and eyes. Leprosy is curable and early treatment usually helps prevent disability. Contrary to common misconceptions the fingers and toes of leprosy affected people do not 'fall off' as a result of the disease. Primary disabilities, such as loss of sensory, autonomous or motor nerve function can be a direct result of nerve damage caused by the disease. Damage to motor function is responsible for some of the characteristic disabilities associated with leprosy, such as claw-hands and drop wrist/foot. However, the loss of sensation can be equally as significant as it often leads to secondary disabilities through compounded trauma. As the patient loses sensitivity in their extremities they become more at risk of sustaining injuries such as burns, cuts and other trauma to these parts of their body and it is the compounding of these injuries which leads to the loss of fingers and toes commonly associated with leprosy. Most physical disabilities are today avoided

through early detection and treatment, however the social consequences of the disease still remain severe in many places and the stigma associated with the disease is proving resilient (van Brakel, 2003).

So, now that we know a little about the nature of the disease, the question of prevalence still stands. Since the introduction of MDT as an effective cure in the 1970s, leprosy rates globally have been drastically reduced. Officially, leprosy was eliminated as a public health problem on a global basis by 2001 and in India in 2006. So, my family asks, sensibly: "If we have eliminated the disease that means it is no longer a problem?" If it was only that simple. Elimination is not eradication, but is defined as a prevalence of less than 1 case per 10.000 population. This target has been subject to some controversy but, regardless of disagreement between experts, the fact remains that despite apparent successful elimination there were still 254.525 new cases reported globally in 2007, of which 54% were detected in India. In addition to this, more than 10.8 million people have been directly affected by leprosy (Rafei, 2003), with an estimated 2-3 million of these suffering from permanent physical disabilities as a result (TDR, 2002). This number increases exponentially if we consider the negative ramifications on those indirectly affected by the disease, such as the families and communities surrounding patients. Tremendous strides have been taken towards tackling leprosy as a major public health problem. However, regardless of whether elimination has, or can be, achieved it is clear that people still contract leprosy and suffer the negative consequences, physically, socially, economically and psychologically. In addition there is a large group of persons affected by leprosy who will have to live with the marks of the disease for the remainder of their lives.

This was the world I stepped into as I entered my fieldwork, and to answer my family: "yes, leprosy still exists; no, I am very unlikely to get it; no, my fingers will not fall off" and, most importantly; "yes, leprosy is still an issue that needs, and deserves, to be on the global and national agenda".

### 3.2 Urban Leprosy Project - History, Organogram and Status Quo

By the time I started my fieldwork in October of 2006, the elimination target had already been reached in the city, though leprosy services continued to be provided through the general health services with the aid and continued participation of local NGOs. It was within one of these NGOs that I spent the next year working alongside the health workers as they went about their daily duties. The Urban Leprosy Project (ULP) is one of the Indian Leprosy Organisation's (ILO's) projects in Andhra Pradesh and was established as the organisation's first direct project in 1989, in response to the National Leprosy Elimination Project's (NLEP) call for an increased focus on urban populations (NLEP, 1983). ILO is an independent Indian NGO but one which has strong ties to the British organisation from which it sprung and which still provides 50% of the organisations funding as well as operational and strategic advice and direction.

ULP has gone through numerous changes in terms of coverage area and priority areas. Prior to 1997 the project worked mainly North of the river Musi but absorbed the Old City area when it merged with another leprosy organisation working in this area, taking in its active cases, its backlog, its area and even some of the staff of this organisation. The merger effectively doubled the case load, the population and the coverage area overnight. Today the project covers a population of approx. 2.179.540, primarily in the East and South of the city as well as in the surrounding Ranga Reddy district. The organisation supports the provision of leprosy services through the general health system at 26 Urban Health Posts across the city (see *Figure 6.*).

In addition to its leprosy focused activities the project diversified its activities in 2002 by taking on several microscopy centres under the Revised National Tuberculosis Control Programme (RNTCP). In addition to this the project took up further TB, malaria and HIV activities aimed at strengthening health system responses to these diseases under the funding of the European Commission in 2003, and has since taken up vision care as an additional area of intervention.
The initial phase of the project focused on early detection and treatment through

mass and school surveys. Since cessation of active case finding in 2001 the focus has shifted to an emphasis on prevention of disabilities, strengthening of community structures, IEC, stigma reduction, SER and vulnerable and hard to reach populations (Rao et al., 2000). The leprosy prevalence in the project area has been brought down to 0.4 per 10.000 (see *Figure 3 & 4*). The organisation currently has 13.500 registered leprosy cases and 90 active cases (as of February 2006) in their area (Unpublished project report). When I started my field work in 2006 the EC 5 year project was drawing to a close and, unless alternative funding was found, the project faced closure and mass redundancies in December 2007.

The senior project staff consist of a project officer, medical officer, a physiotherapist, a SERO/Health Education Officer and two Community Health Supervisors. In addition to these, there are 9 Community Health Organisers (CHOs), 2 shoe technicians, 3 drivers, two administrators and a number of auxiliary workers and general service staff (see *Figure 5.*). Each of the health workers has a sub-speciality, an area of activity where they have special responsibility such as eye care or social and economic rehabilitation. The project is based in the South of the city in a building that houses its administrative offices but also an outpatient clinic, an eye care clinic, a TB testing centre and a physiotherapy office alongside a cobbler's workshop for the production of custom made MCR footwear by the two shoe technicians.

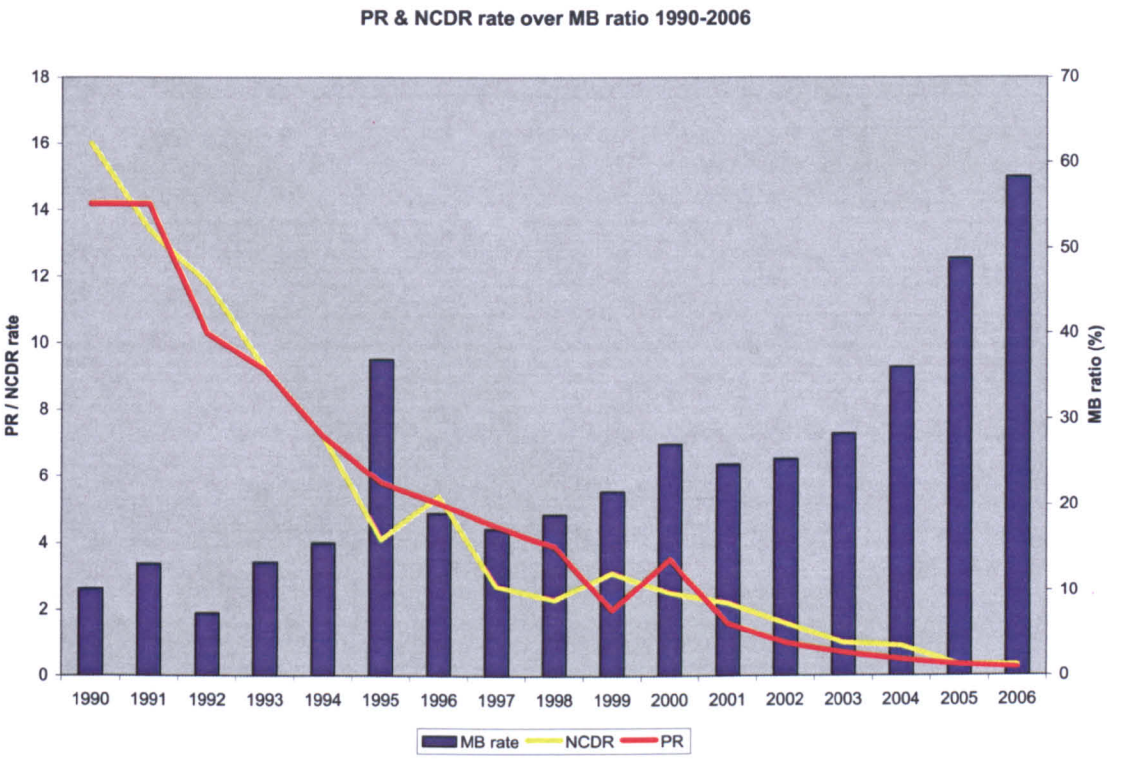



*Figure 3.* ULP prevalence rates, New case detection rates and MB rates 1990-2006

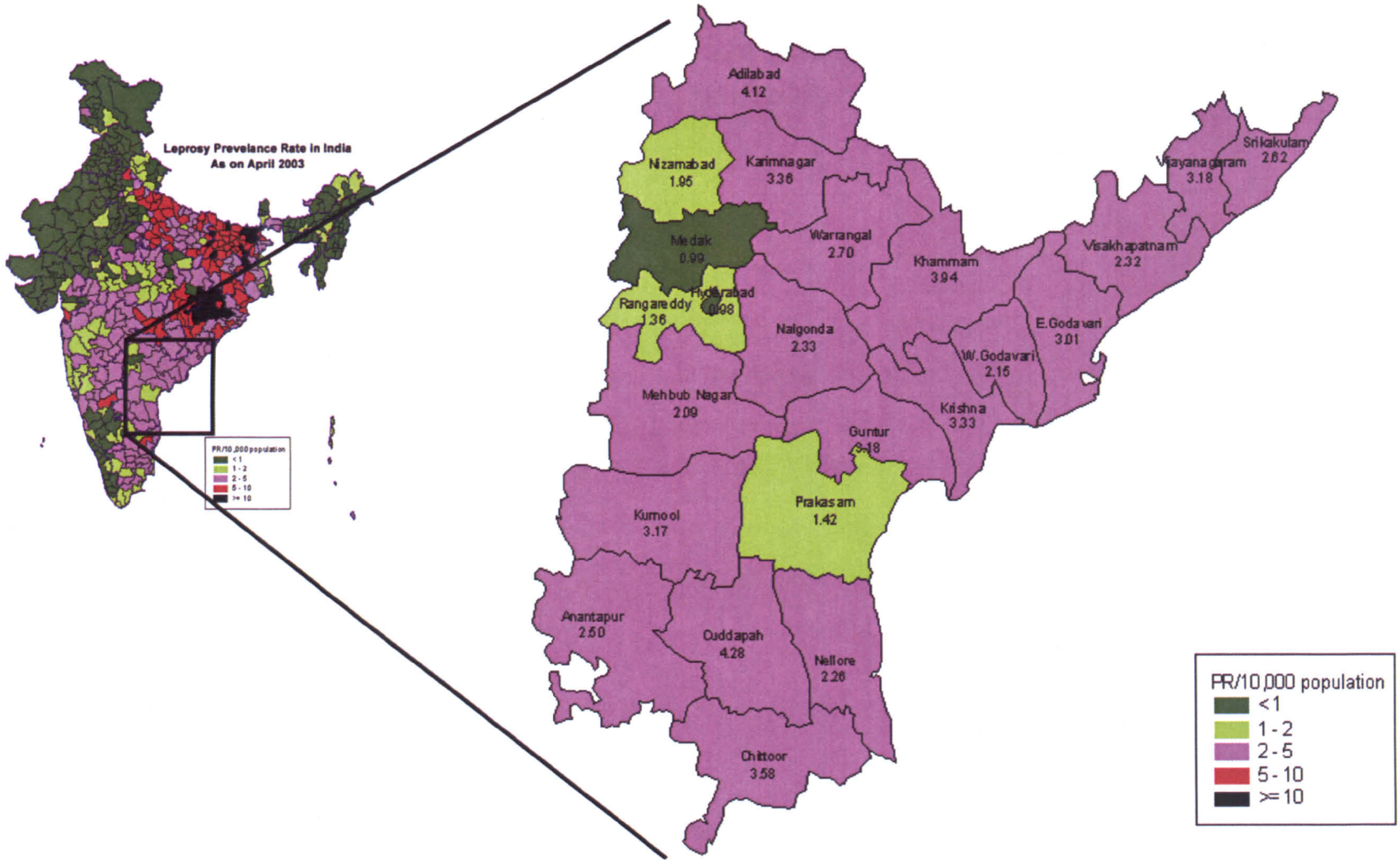



*Figure 4.* Leprosy prevalence rates in Andhra Pradesh as of April 2003 (WHO, 2004)

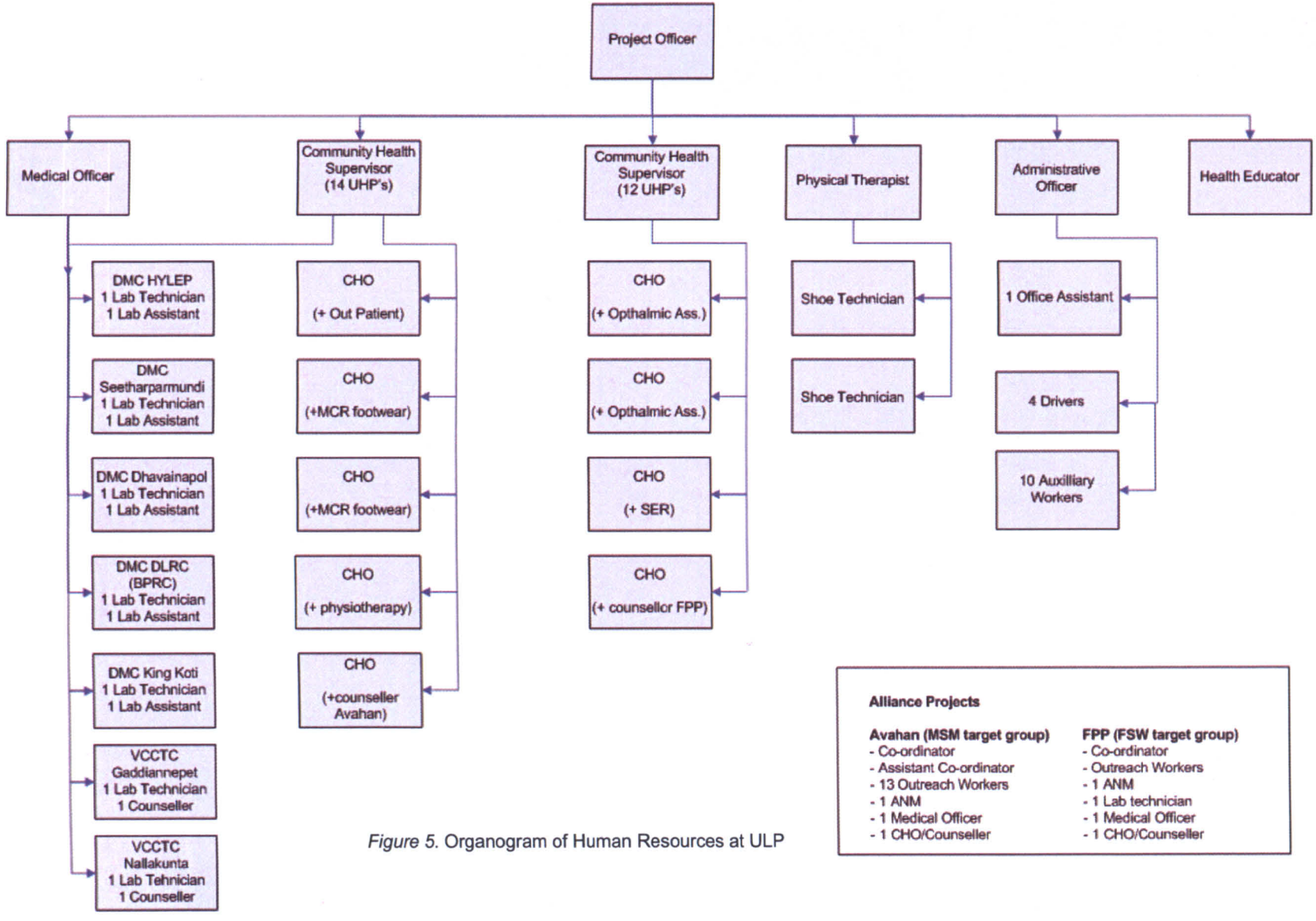



*Figure 5.* Organogram of Human Resources at ULP

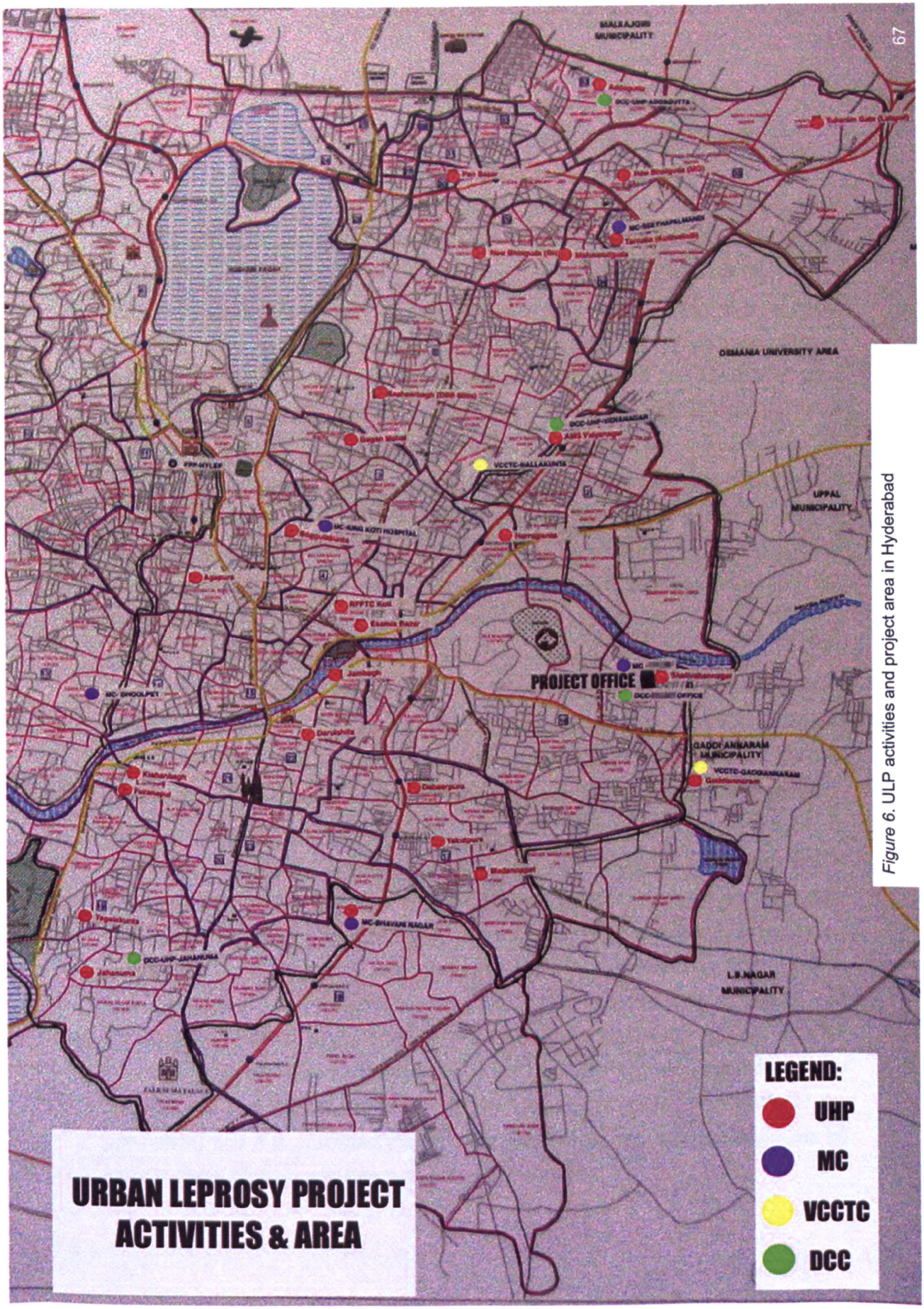



*Figure 6.* ULP activities and project area in Hyderabad

### 3.3 Location, Location, Location

**- The Importance of Understanding Urban Complexity**

The decision to base my fieldwork in an urban context was made partly as a result of my personal preference, but also because I believe there is a desperate need for good social research on leprosy in the urban context. Firstly, the growth of cities and urban agglomerations in the world dictates that this will become one of the most important stages for social interactions. However, we cannot hope to understand this stage without also paying attention to the pressures that have driven this trend and how the emergence of the 'megacities' might affect the wider social and political landscape. Secondly, there is a great paucity in social research into leprosy and leprosy control in an urban context which can be said to differ drastically from its rural counterpart. Lastly, anthropological research in the modern urban context poses a number of new challenges in relation to how we define our target population, how we access this population and how we position ourselves in relation to a global and local context.

The United Nations estimates that, since 2008, more than half the world's population are living in cities (UNFPA, 2007) and that over the next 30 years the majority of future population growth will take place in developing countries (Galar et al., 2005). It is projected that, by 2030, approximately 45% of all urban dwellers in low- and middle income countries will be living in slums, under health or life threatening conditions. Already more than 900 million people worldwide live in slums, almost 1 in every 6 people (UN-HABITAT, 2003).This marks a drastic shift in global demography over the last century, from a situation where the majority of the world's population were rural peasants towards an amassing of the global population into urban centres (Bernstein, 2003). This process of urbanisation can also be seen all over India. In 1901 the total urban population of India was 25 million people (10.84 % of the total population), in the 100 years that followed the urban population has increased by 12 fold and is now 285 million (28% of the population) and it is predicted that by 2020 more than 550 million people will be living in cities (Sivaramakrishnan and Singh, 2002).

The impact of such tremendous growth can be seen in the slums and shanty towns of the world's cities, with India having one of the highest rates of slum dwellers in the world, as the provision of infrastructure facilities fails to keep pace with the urban growth (Galar et al., 2005). Basic amenities such as safe drinking water, sanitation facilities, transportation and housing are unavailable to many in the rapidly growing cities. On the one hand urban growth is associated with economic growth and the economic advancement of India has been led by urban areas with the proportion of GNP made up of industry and service sector steadily increasing, from 62% in 1981 to more than 75% in 2001 (Mohan, 2003). On the other hand, the benefits of this growth are not necessarily evenly distributed.

Urban advances in health as a result of economic growth can constitute a misrepresentations of averages, as poverty and poor health are often concentrated in underprivileged areas and may be masked by city wide averages which include the health of the wealthier citizens. This duality leaves the urban health services to deal with the compounded problem of the non-communicable diseases of the privileged in co-existence with the communicable diseases of the under-privileged (Mutakar, 1995). Spatial concentration of poverty can lead to increased risk of negative health outcomes due to compounding factors, thus, the health of the urban poor may be worse than that of the rural populations, contrary to the indications of averages (Montgomery and Hewett, 2003). As Martelli's GPS study from urban Brazil has shown, leprosy is concentrated in poor urban areas demonstrating both spatial clustering and a clear link to poverty (Martelli et al., 1995). In addition, as Paul Farmer (2003) , Nancy Scheper-Hughes (1993) and others have argued, we need to look beyond the immediate conditions within which disease exists to the wider political economy and structural violence which create these conditions. Globalization has seen to it that cities are no longer connected only to their surrounding areas but are equally connected to cities and regions globally e.g. Bangalore is linked more closely to the US than it is to Hubli-Dharwad.

Urbanisation as a process, and the growth of the urban poor as an indirect result of this process, cannot be fully understood without taking into consideration the external economic factors driving this process. In India the adoption of the

Structural Adjustment Policies (SAPs) in 1991 led to mechanisation of the agriculture in rural areas as the emphasis was shifted from consumer crops to commercial crops. This led to a subsequent decrease in demand for unskilled labour (Bhan, 2001). With less opportunities for employment in rural areas there has been a marked increase in rural-to-urban migration in search of employment and opportunities (Davis, 2004a). Though urban areas afford opportunities for increased income they also drive increased expenditure, as most basic resources must be purchased and there is little space or opportunity for cultivation of foodstuffs. In addition, most employment opportunities fall under the informal sector which often means low pay, low status, no job security, long hours and unsafe working conditions. The income generated from such employment is often insufficient for urban survival, especially for larger families, as a result there is significant fluidity between rural and urban populations with migrants moving between the two as opportunities and needs dictate. Many have argued that Structural Adjustment Policies have pushed subsistence farmers off their land and into urban slums (Dawson, 2004). However, it can equally be argued that SAPs lead to the calculated underinvestment in urban areas, as these were seen to have been over-prioritised in the past, and that funds were rather channelled into industry and technical development, thereby creating an increased demand for skilled labour even within the urban setting (Bhan, 2001). This process compounded the negative effects on the urban poor (including the recent rural-to-urban migrants) and lead to the growth of the informal sector in which most are employed.

This change also has dramatic ramifications for the cultural and political landscape as it can be argued that "SAPs represent not only a change in the country's economic paradigm but also specific changes in processes of production, the sectoral break-up of the economy, the role of the State within the new economy, and the introduction of a new culture of consumerism(...) In the new market-oriented economy, the abdication of the State from its historically central role can possibly have serious consequences." (Bhan 2001:17). Thus, the 'megacity' becomes a political entity largely controlled by corporate interests, whilst the role of the state is weakened leading to decreased investment in social services,

increased investment in high-skilled sector and a furthering of the socio-economic divide between the rich and poor.

### 3.4 Urban Leprosy

This is the context which frames urban leprosy control programmes. It is the context that shapes the lives of leprosy affected persons in the city and the fluid migrant population. However, it is also the context within which NGOs operate, public health initiatives are shaped and the health workers live, work and play. Urban leprosy poses both new challenges and possibilities which differ significantly from the control of the disease in a rural context (Krishnamurthy, 2005). Despite this, the means of control being utilised in the urban context have largely been the same as those utilised in a rural context. Most writing on leprosy control, as well as leprosy control programmes, have focused on rural populations, both as these have traditionally had a higher prevalence and have represented an easier target population. However, we are today faced with an emerging urbanised global context which will necessitate a more concentrated focus on the urban landscape within which urban health interventions take place.

Although the disease and its treatment remain the same in both rural and urban contexts, it is becoming increasingly important that we make an effort to understand the urban context within which people affected by leprosy live, and the possibilities and limitations this poses on their lives and opportunities. The urban context represents a heterogeneous population, comprising of people who speak a myriad of languages, represent numerous religions, have a multitude of health care options open to them, and who live complex and intersecting lives. A systematic literature review of the topic 'urban AND leprosy' carried out covering a large number of databases reveals that the predominant focus of the literature on urban leprosy has been on the epidemiology of the disease and on operational concerns such as case finding and case holding. As my primary interest was in social, epidemiological, operational and policy issues articles on clinical issues, with only incidental mention of urban setting were disregarded. By this method 109 articles

were identified, of which 103 could be accessed and reviewed. The articles were analysed for trends in topic, and 6 categories were identified (for further details on literature review methodology & bibliography see *Appendix 3.*). *Figure 7.* provides a graphic breakdown of the findings:

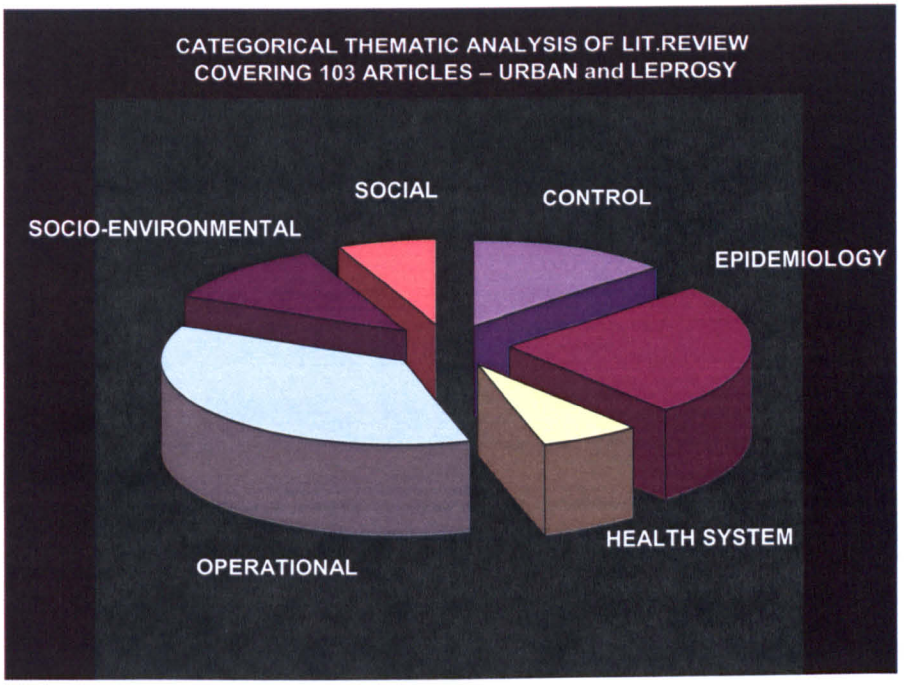



*Figure 7 – Topic analysis of literature review*

Most of the articles designated 'social' category deal with issues surrounding stigma. None of these provide an in-depth look at the social reality of either leprosy affected persons themselves or the institutions/organisations that provide leprosy services in an urban context.

Lastly, a word or two on the anthropological challenges of fieldwork in the city. Fieldwork in a megacity is complex, fraught with both problems and possibilities. As anthropologists, we find ourselves unable to draw a fence around our perimeter and study all 'within', we cannot build a neatly demarcated demographic profile of our study population or construct kinship diagrams of our subjects in any meaningful way. The situation that arises cannot be controlled and cannot be

properly prepared for, as there is rarely pre-warning of significant events. In a rural setting a village might be awash in excitement and preparations for weeks before a 'significant' celebration/meeting/event. In an urban setting, the population is more fluid and more spontaneous/opportunistic. People congregate and dissipate and, as researchers, we cannot be everywhere at once. Often the best study opportunities are happy coincidences that arrive unannounced and fade away as quickly and suddenly as they came. So, we must learn to be opportunists, to go and be as many places as possible hoping against reason that we have chosen the right one this time, or failing that, that we will have better luck next time.

### 3.5 Hyderabad as Mega-City

The location of this study, Hyderabad, is one of these emerging Indian 'megacities' with a population that is expected to exceed 10 million before 2010. Hyderabad is the capital of the state of Andhra Pradesh. At the time of starting my fieldwork, in October of 2006, Hyderabad was the 6$^{th}$ largest city in India with an estimated population exceeding 3.8 million spread over an area of 175 km$^2$ (GoI, 2001) By the time I completed my fieldwork, in September 2007, the city had become, through a process of urban agglomeration, the 5$^{th}$ largest in India covering a staggering 650 km$^2$ with a population estimated to be in excess of 6 million (GHMC, 2007). The twin cities of Hyderabad and Secunderabad, along with the surrounding municipalities, received status as an A-1 city on the 16$^{th}$ of April 2007 when 12 surrounding municipalities where merged into the Municipal Council of Hyderabad (MCH) to form the Greater Hyderabad Municipal Council (GHMC) (GOI, 2007).

The basic contradiction between the prospering urban economy and the growth of urban poverty, which is as evident in Hyderabad as in any other Indian city, has lead to a conflict between the ideal of the city as a high-tech haven for investors and the lived reality of a large proportion of its inhabitants. As a political entity the municipal corporation of Hyderabad remains torn between the vision of the city as a modern metropol, as 'cyberabad', and the sprawling slums without basic

amenities which constitute the lived reality for more than a third of the city's residents. The number of notified slums increased from 106 (population 120.000) in 1962 to 811 slums (population 2.5 million) in 1994. Since then it is estimated that the number of notified slums has grown by at least 150 and that more than 1/3 of the city's population resides in slums or illegal squatter camps (MCH, 2003) and it is expected that this proportion will rise in the future. This two-pronged approach to the city's future can be seen in Hyderabad's City Development Plan (2003) which proposes a dual strategy of pro-poor initiatives to fight poverty and increased coverage of basic facilities, whilst at the same time providing incentives for international business, such as Microsoft, IBM, Motorola etc, to set up operations in the city.

Though the two might seem antipodal they are in fact intimately linked as the city's bid to attract revenue from international business, to reinvent itself as 'cyberabad' and rival the success of Bangalore's service industry, is dependent on the city's capacity for providing a steady supply of skilled, healthy workers for this sector. In this respect the urban poor are both dis-incorporated (Davis, 2004b) and crucial to the functioning of the city. Employed in the informal sector and with few opportunities to access official frameworks the poor are often marginalised from official discourses and decision making processes. Yet, as argued by the 'myth of marginality' literature (Perlman, 2005), the poor and marginalised form networks and perform services which are crucial to the day-to-day functioning of the city. Still, when Davis (2004b) argues for the dis-incorporated status of the urban poor, it resonates well with the situation in Hyderabad which, by linking corporate service industry bids with development of basic facilities in the city, demonstrates how intertwining the future of the urban poor is with that of global corporations. It also effectively illustrates how dis-incorporated the urban poor really are, trapped in a crucial but informal economy which serves to provide essential facilities and effectively serves the function of keeping the city running, despite its inability to provide these facilities to the poor themselves.

### 3.6 To the Sound of the Azaan

Hyderabad is a city defined bureaucratically, as demonstrated by the majestic pen-stroke of redefining the city's boundaries as described above, but it is so much more than a bureaucratic entity. It is also a city defined by its history, its social, ethnic and financial heterogeneity and its vision of the future.

The city was founded by Muhammad Quli Qutb Shah on the banks of the River Musi in 1591 and, for the next 350 years, the Muslim Nizams of Hyderabad ruled over what was India's largest and richest state. In 1948, a full year after India's independence, the Nizams, having initially resisted inclusion in the newly independent India, were forced to relinquish their rule. The princely state of Hyderabad was merged into the newly formed Indian nation and reorganised along language lines with the newly formed state of Andhra Pradesh encompassing the Telugu speaking population (Luther, 2006). To this day, the Muslim heritage of Hyderabad can be seen in its crumbling palaces and its ethic composition, which remains 40% Muslim.

Split in two by the river Musi, Hyderabad's northern part is comparatively prosperous and largely Hindu, whilst the Old City to the south of the river is predominantly Muslim and considerably poorer, with a far less developed infrastructure. Hyderabad is a city of contrasts; economically, the contrasts between the glass and steel shopping centres of Panjagutta and the open sewers of Vattepalli could not be greater. The palatial houses of Mahendra Hills overlook one of Hyderabad's largest slums at Tukaram Gate.

Despite these contrasts, Hyderabadis are always careful to emphasise the importance of unity and solidarity, stressing that they are Hyderabadis first and foremost, anything else is secondary, and they do indeed have reason to be proud of this spectacular city. Hyderabad is a city of alleys, of majestic palaces, of slums, mosques, temples and churches. It is a throng of people, vehicles and livestock. A city where one is just as likely to see camels as holy cows blocking traffic, where the air hangs heavy with the smell of chilli and burning cow dung whilst newly built

high-rises define the skyline to the West. A city where the early morning azaan of a myriad muezzins cascade, compete and interlock with the Sanskrit chanting of yogis and housewives' pujas. It is a city where cockerels crow all night in defiance of dawn, where everything gets covered in a fine red dust and everyone has a favourite Iranian café. It is a city of burqa clad women in the old city, of jeans wearing youngsters in the Banjara Hills and elegant ladies lunching in colonial pomp at the Secunderabad Club. Like most Indian cities Hyderabad defies definition, confounds categorisation and is demarcated precisely by its "cultural and ethnic heterogeneity, transnational flows of labour and capital, and uneven spatial and social development" (Dawson, 2004:18).

The city must be seen as much more than the rich backdrop to the work of the ULP. The city is both where the health workers live and where they work; it is context which frames their lives. The ULP project area constitutes roughly half the city's area, primarily in the South and East of the city, and this is where the health workers carry out their daily fieldwork.

### 3.7 Health Care in the City

Medical services in the modern Indian megacity, including Hyderabad, are varied and multitudinous. Private and public service providers exist on all levels, from tertiary to primary care and allopathic and alternative practitioners (primarily unani and ayurveda), and operate side by side. From 'superspeciality' hospitals and governmental primary health care facilities to neighbourhood family practitioners, the choice is endless, and the cost differentials between services are astronomical. Nationally, an estimated 80% of outpatients and 60% of inpatient care in India is accessed through the private sector (Radwan, 2005) and these percentages are likely to be even higher in urban areas. The array of health services on offer can be bewildering. However, one aspect often overlooked is the porous boundaries between the public and the private sector, with considerable overlap in clientele as well as practitioners. Practitioners often operate 'double practices' where private practitioners have extensive links with public facilities and doctors working in the

public sector often run small family clinics in the evening and, thus, there are considerable cross referrals between these two sectors (Begum et al., 2001, Standing et al., 2008). The porous boundaries also apply to patients as they usually consult several practitioners from several sectors, only one of which is the health care sector, simultaneously, for the same problem, without perceiving this as contradictory. The health workers themselves teach health education to school children in order to root out 'superstitions' and correct 'wrong notions' whilst simultaneously fasting for Sai Baba (a popular Hindu saint/guru) to ensure good health for their families. When a member of staff at the project is faced with a personal health problem they will seek out biomedical, homeopathic or ayurvedic as well as religious solutions in parallel, as these are perceived as complimentary, rather than conflicting, approaches. This approach to health care does not rely on mutually exclusive health systems operating in parallel but, rather, on numerous health and religious systems all operating simultaneously in the same space with patients mixing and matching to suit their particular needs and sensitivities. Health care in India is complex, and following simultaneous avenues of cure is the norm.

Service users will approach any number of providers for treatment, from government hospitals and dispensaries, urban health posts, private clinics/hospitals, charitable hospitals, traditional Indian practitioners, herbalists, alims (Muslim scholars), gurus/swamis/saints, NGOs, Anganwadi workers, super-modern 'Western' hospitals (catering to the rich and 'medical tourism'), to local pharmacists for diagnosis and treatment of 'problems'. These 'problems' may range from the purely bio-medical to more diffuse social, psychological and spiritual concerns. There is no compulsory registration of private hospitals, clinics and nursing homes in the city, so accurate data on available health facilities in the city are not readily available. However, by collating data on property tax and trade licences, Prasad & Ramachandraiah (2006) were able to analyse the spread of health services in the city. Even if this data does not seem to catch the myriad 'family doctors' and 'neighbourhood clinics', it provides an insight into the urban health services landscape. By analysing health facilities over the 7 administrative circles that make up the Municipal Corporation (see *Figure 9.*), they found indications of an unequal spatial distribution of facilities, where the densely

populated, largely middle and low-income zones of the old city have fewer health facilities than the higher-income circles (see *Table 1.*)

Leprosy treatment is predominantly provided through the public sector and NGOs working in partnership with the government. Nevertheless, training sessions with private medical practitioners have been conducted in order to improve correct diagnosis and referral practices. As treatment is available free through government facilities, and there is prevailing stigma even amongst trained medical professionals, few patients are treated for leprosy under private care. However, the individual patient's journey through the health system in search of a diagnosis and appropriate treatment often starts in the private sector where the person seeks out help for 'skin problem', 'nerve pain' or 'weakness'. Patients are often subject to a number of costly diagnostic tests and the condition is often misdiagnosed and incorrectly treated with ointments and pain medication. Often the patients will have been to see numerous private practitioners and 'specialists' before finally being referred through to the government sector or to an NGO provider.

Post-integration of leprosy services into the general services, the primary responsibility for leprosy diagnosis, treatment and case holding lies with the staff at the Urban Health Posts (UHPs), which usually comprises a Medical Officer, a Public Health Nurse, several Auxiliary Nurse Midwives (ANMs) and Ayahs. All the ANMs I met during my study were female; though I was told there were meant to be a male ANM at each UHP I never saw one. UHPs are the urban equivalent of Primary Health Centres (PHCs) and are primarily involved in reproductive and child health, catering to women and children. Their primary focus is on vaccination, family planning activities, post and ante-natal care, child development monitoring and common ailments such as cold, cough, fever, diarrhoea, fungal infections and joint pain. In some of the UHPs I visited in Hyderabad, there were signs outside stating that no men were allowed beyond the main entrance, whilst in others men would be treated for minor ailments. The adult male population must rely on the government hospitals for medical attention.

Officially each UHP covers a population of 50.000, though most of the Medical Officers estimated that the population covered by their UHP was probably closer to 60-80000. There are approximately 60 UHPs in Hyderabad. Leprosy and HIV services are provided by the government, through an assigned Assistant Para-Medical Officer (APMO) under line management of the District Leprosy Officer (DLO), at 34 of these UHP. As an NGO, ULP has taken over responsibility for leprosy, TB, HIV/AIDS and malaria services in 26 of the city's UHPs under the directorship of the DLO (see *Figure 8.*). In this regard, they are essentially carrying out government work on a government mandate without meaningful remuneration from Government departments. When I asked the ULP management what would happen if they were to withdraw from these areas, the answer was always that the government would have to fill their place with APMOs who would carry on the service but that, if the organisation gave up their hold on this area, they would never get it back.

The placement of APMOs in UHPs to cover leprosy services brings into question the extent to which leprosy services have truly been 'integrated' into the general health system or if it is rather a question of an embedded vertical system working out of the same facilities as the general health system, i.e. a question of geographical integration rather than human resources integration. The idea behind integration was always for the primary duties of leprosy control to be carried out by the regular staff at the UHP and that the APMOs and NGO staff would serve primarily to confirm correct diagnosis. However, medical officers and ANMs are already overburdened and overworked. In addition, many of the health workers I spoke with felt that the incentive structure attached to some of the ANMs targets, such as vaccination coverage, meant that these got priority and 'additional' tasks such as leprosy control were pushed to the bottom of the pile.

As my primary exposure was to the 26 UHPs covered by ULP I will confine my comments to what I observed at these facilities, however, my anecdotal evidence and informal conversations with medical officers would tend to indicate that the situation is much the same, if not worse, at the remaining UHPs. The NGO staff frequently expressed concerns about 'ghost worker syndrome' amongst APMOs

and questioned their levels of commitment (Hammer and Chowdhury, 2002). In the 26 UHPs covered by ULP all diagnosis, case holding, paper work and follow-up was conducted by the ULP health workers, sometimes at the referral of the medical officer or ANMs. If a patient was to come in with skin ailments on a Monday they would most likely be told to come back on Friday when the 'leprosy worker' would be here, rather than the medical officer attempting a diagnosis. This varied across the different UHPs, depending on the level of personal interest of the medical officers. However, it was clear that, despite the intensive training of government staff, they would be reluctant to add additional activities to their already overstretched capacities until the supporting NGO staff were withdrawn from the facility. In one instance when, due to change over of ULP staff and lack of active cases in the area, one of the UHPs had remained unvisited for two months. When we arrived one day to pick up the paperwork it was nowhere to be found. Clearly, no one had thought of leprosy since the last ULP health worker left.

Organogram of Leprosy Services in Andhra Pradesh post-integration

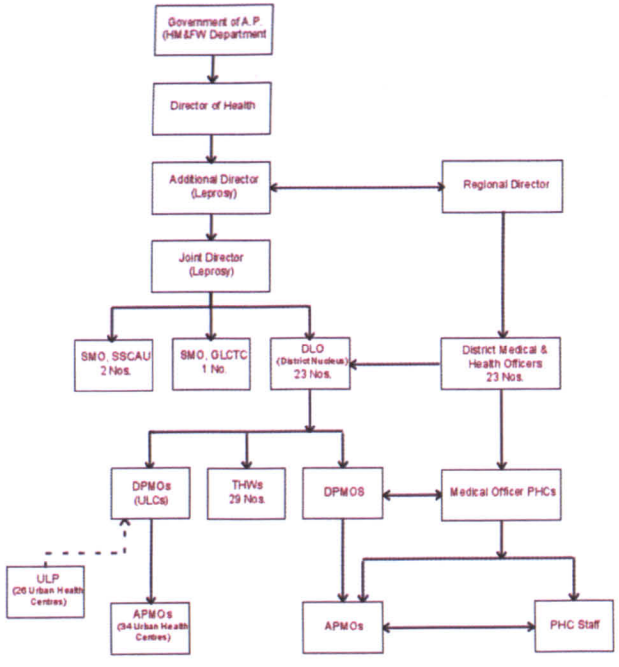



*Figure 8.* Integrated leprosy services

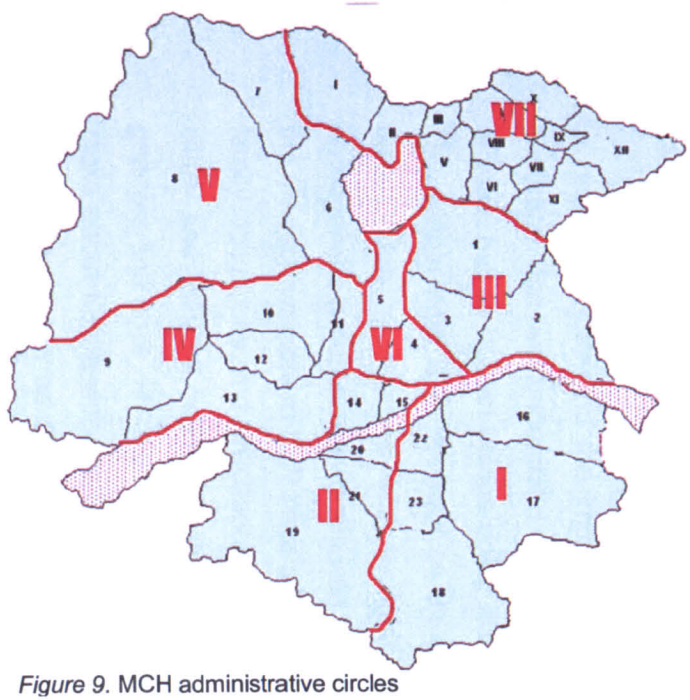



*Figure 9.* MCH administrative circles

**Health Facilities in Municipal Corporation of Hyderabad area: 2006**

| MCH Circle | Area Sq. Km. | Density 2001 | Population 2001 | Growth rate 1991-01 | Private Hospitals/ Nursing Homes | | Disp/UHPs/Hospitals (Govt) | | Total (Pvt + Gov) | | Diagnostic Centres | | Pharmacies, Medical Shops + General | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | Number | Per 10000 | Number | Per 10000 | Number | Per 10000 | Number | Per 10000 | Number | Per 10000 |
| I | 31.02 | 29053 | 901226 | 24.9 | 175 | 1.94 | 90 | 1 | 265 | 2.94 | 23 | 0.26 | 175 | 1.94 |
| II | 14.91 | 32911 | 490703 | 23 | 167 | 3.4 | 48 | 0.98 | 215 | 4.38 | 6 | 0.12 | 167 | 3.4 |
| III | 17.97 | 31816 | 571733 | 23 | 238 | 4.16 | 59 | 1.03 | 297 | 5.19 | 33 | 0.58 | 238 | 4.16 |
| IV | 28.12 | 20205 | 568163 | 22.6 | 255 | 1.49 | 102 | 1.8 | 357 | 6.28 | 28 | 0.49 | 255 | 4.49 |
| V | 45.36 | 12185 | 552697 | 84.4 | 260 | 4.7 | 120 | 2.17 | 380 | 6.88 | 36 | 0.65 | 260 | 4.7 |
| VI | 4.93 | 23997 | 118306 | -1.3 | 107 | 9.04 | 52 | 4.4 | 159 | 13.44 | 11 | 0.93 | 107 | 9.04 |
| VII | 20.26 | 20217 | 409599 | -17.5 | NA | NA | 62 | 1.51 | 62 | 1.51 | 33 | 0.81 | 142 | 3.47 |
| Total | 162.57 | 22221 | 3612427 | 21.9 | 1202 | 3.33 | 533 | 1.48 | 1735 | 4.8 | 170 | 0.47 | 1344 | 3.72 |

**Source: Prasad & Ramachandraiah 2006**

*Table 1.* Health Facilities in MCH 2006

## 4. Health Work and the Health Worker.

In order to understand the impact of health workers and their daily work, it is important that we understand the health workers themselves, not as abstract entities, but as human beings doing a complex job under difficult circumstances. The danger here is to fall back on an analysis of the abstract 'health worker' to discuss the experiences and thoughts of 'health workers' as were they a homogenous group of individuals with the same opinions and background. Rather, the 9 health workers at ULP have an amazingly diverse background, social status, family obligations and philosophies. They belong to a variety of casts, hail from cities and villages, some Hindus, some Christians, some Muslims, different genders and ages, all of which complicate any generalized statements one could make about health workers. However, despite all these differences they have as much in common as that which sets them apart. Perhaps the most important commonality is their training and the longevity of their employment within the field of leprosy, and in ILO specifically, which contributes to the way they understand their duties, their role within the organisation, their agenda and their social responsibility. But, first, let's take a look at exactly what it is the health workers do all day.

### 4.1 All In a Day's Work

The activities of the health workers are varied and it is difficult to describe an 'average' day as every day is different and the challenges they face depends on the problems presented to them by the community. However, there are commonalities and structural similarities. Thus, I will attempt to describe a day in the life of the health workers, the challenges they face and the mechanisms they employ in overcoming these challenges, through a composite ethnographic description drawing on 13 months of participant observation with the health workers in the field with my composite, fictional health worker, Sanjay:

I meet Sanjay by the petrol pump at 9 o'clock and we set out on his motorcycle. It is April and summer. I am already covered in a fine layer of sweat and the red Hyderabad dust clings to me as we speed down back alleys.

The first stop is two Private Medical Practitioners who are working as DOTS providers. One has one active TB case at the moment. The patient has gone back to her village for her brother's wedding and has been given medication in advance to take with her. So now someone needs to go check up on her and make sure she has been taking her medication. The physician administers treatment but, if there is a problem or the patient does not show up for treatment, it falls to the CHO to go and check up on the patient and find out what the problem is. Sanjay makes a note of the patient details. The second PMP is more of a clinic than a private practice. It currently has seven active cases (3 Cat I and 4 Cat III). The doctor here also refers HIV cases to ULP. At the moment, he has two HIV patients, a husband and wife, who wish to receive treatment here rather than in their own area where they risk exposure. Sanjay refers them to the VCCTC at Gadinnaram for counselling and testing.

We leave the doctors clinic and head over to the local anganwadi school for 5 minutes to catch up with the local anganwadi teacher. Sanjay shows me some the flashcards and adult education materials for diarrhoea and sex trafficking. We leave the school behind and head into the slum proper to follow up on some patients and 'to be seen'. Sanjay explains that he does not knock on people's doors; instead he wanders around the community 'making himself available'. If people have something they want to talk about or something they want to ask him, they will come out in the alley and ask him. They all know who he is. Indeed, a few people do come out and ask him about general aches and pains, complaining of 'weakness' and fever. A leprosy patient comes over to complain about swollen cheeks and other reactions to MDT. Sanjay tells him to stop by the Out-Patient (OP) clinic to talk to the medical officer later. Sanjay covertly points out the man sitting on the corner selling heroin out of a clay pot and explains that the community has a big substance abuse problem.

As we wander around there are quite a few kids running around, perhaps attracted by the strange foreigner in their midst, and Sanjay asks the adults hanging around why the children are not in school. The parents argue that there is no use in sending them to school. Government schools are no good and they have no money for private school fees. Sanjay argues that government schools are indeed good, and free, and very close by. He explains that he is educated 'totally in government' and then he points to me and says, *'Madam, also'*. Though I am not sure how relevant that is in the context, it is a nice sentiment and seems to impress the assembled crowd. The conversation continues for another 5 minutes before the crowd gets bored and starts dispersing. Left are two young girls, maybe 7 and 3 years old, who are staring intently at the strange foreigner and listening half-heartedly to the conversation. Sanjay asks them about school and they say that sometimes they go but that there is no use in it, instead they work as domestic workers nearby, helping with dishes and such, for a few rupees a day.

We stop by the hut of the community leader, but she is not there at the moment. As we hang around outside the Basti leader's house a group forms around us. The conversation flutters from schooling to health, to sanitation, and people pipe in as they go about their daily chores. With an assembled audience Sanjay sees the opportunity for some health education and gives a group talk on leprosy, HIV and TB. Sanjay covers the main points of modes of transmission, symptoms and treatment and the crowd is responsive at first but, after a while, the adults again start to disperse. As Sanjay wraps up the talk, there is a little boy skipping around us in circles chanting *'HIV, HIV, HIV, HIV'* at the top of his lungs. After a few circumnavigations he is joined by an even younger boy. Sanjay stops them and asks them: *'what is HIV?'* And the boy giggles. So Sanjay repeats the question, *'No, really, what is HIV?'* The boy stops bouncing, looks at him defiantly and says: *'I am only in 6$^{th}$ class. When I get to 9$^{th}$ class they will teach us, and after that I will tell you'*. Sanjay laughs and the boy skips on past.

We stay outside the Basti leader's house for almost an hour, but after that, people stop taking notice of us and we head off to go follow up on a leprosy patient who lives nearby. The patient in question is the youngest daughter in the family. She is

an old PB case who has completed her 6 month course of treatment, but it looks like the lesions might be spreading and she complains of nerve pain in her elbow. Sanjay palpates the ulnar nerve at the elbow and asks if she completed her treatment. The girl says yes but, when she pulls out the MDT pulse to show us, only half of it has been completed. We take some tea with the girl and her sister in their hut. We sit there, out of the sun, for half an hour or so talking about how things are going at school and what serials they follow. Their parents are not around at the moment, so we leave the girls with a message for them to come and see us at the office.

We walk over to one of the slums lining the Musi river. In the midday sun, the river stinks to high heaven. First stop is the house of an 11 year old boy who is developing lagophthalmos (inability to close eyelid). Sanjay has explained the importance of doing daily exercises to both him and his parents. We are stopping by for a follow up. His grandfather is an old MB case, so the father has some experience dealing with leprosy. Both the boy and the father say he is doing his exercises but he is still exhibiting severe weakness in the eyelids. Time will tell. We say goodbye and head on down along the river to see another patient who has had a lot of problems with drinking, ration cards and domestic violence in the past. As we approach his hut, a woman emerges, looking half-dead, all skin and bones. Sanjay tells me that her husband has a drinking problem and that this has caused a lot of problems in the past. As we approach the hut the husband and three children emerge. Sanjay asks them why they are not in school, and the father answers: *'what use is school? He completes school and then what? Will still be poor and have no options. It is better he get experience.'* Sanjay asks him about how his plantar ulcer is healing and about his drinking, and a heated debate/argument starts up. There is no way I can follow what is being said, but the eldest son seems to be very agitated. At some point the wife returns from the shop with a handful of tambaku paan (betel leaf filled with powdered tobacco and spices) and the conversation trails off. As we leave the huts behind, Sanjay tells me that apparently they both, husband and wife, have a drinking problem. The husband will blame the wife and the wife the husband. The children try to arbitrate and divert the money to food and other items. As he is explaining the complicated domestic

situation to me, someone from the neighbouring hut calls us over. Sanjay tells me she is a former TB patient and we go over to say hello. Again the conversation turns to education, as the girl tells Sanjay that she is planning on training as an ANM at a private college because her brother and sister-in-law want her to. Sanjay argues that being an ANM is not a very secure future. There is a big initial investment for the training, but in return you only get a low salary, contract work and a 'hard life'. Instead, he suggests, she should take some English and computer classes. This seems a strange piece of advice from someone who has chosen to be a health worker.

It is 12:00. We are running late for a scheduled meeting with a Health and Social Development Forum but Sanjay explains that it is important to turn up for scheduled events. Otherwise we will lose the respect of the forum members and, then, the next time we call a meeting, no one will come. So, we jump on the motorbike and drive to the anganwadi school where the meeting is being held, whilst the children are off at lunch. Even though we are late it takes a while for the women to trickle in and the children to disperse. A cat is complaining loudly, prancing around the room and meowing, it seems she wants to be part of the discussion but it turns out she is only looking for her kittens which live under a box in the corner. The group settles down and the meeting can finally start. There are 10 women present, in addition to the anganwadi worker, and we do a quick round of introductions. My stumbling and broken Telugu makes them giggle and serves to break the ice. 4 of the women are also members of the local Mahila Mandali (local women's empowerment group).

Some of the women are complaining about the substance abuse problems in the community and ask Sanjay if he can provide some training or other help for them to address this issue. An old woman raises the issue of old age pensions. Sanjay tries to explain to her about the different rationing schemes (pink card, white card, Anthyodaia, Annapurna) and tells her that she might be better off sticking with the government assisted rations, as she is only entitled to receive one of the schemes at a time. So, for this old lady taking care of her grandchildren this would mean that she would receive 200 INR per month in old age pensions, but that she would lose

her Annapurna card. Sits her down and explains that 1 kg of rice costs between 10-20 INR depending on quality. She nods her head in agreement. However, he explains, with an Annapurna card 1 Kg of rice costs 3.5 INR and entitles her to 35kg per month. If she was to take up the pension and buy the equivalent amount of rice in a private shop it would cost her more, and she would end up with less rice, than with her current ration card. The old lady nods her head but looks sceptical. Either way, time is up and it is time to wrap up the meeting.

As we are about to leave one woman hangs back as she has a problem she does not want to discuss in front of the others. She tells us that she is worried about her husband who has had kidney cancer and is living with only one kidney. We try to reassure and advise her. Walking out, we are stopped by one of the community leaders, who is also a local political leader and a health forum member, who insists we come to her house, where she provides us with some water 'to wash the dust from our mouths', as is the custom, and shows us pictures of her children. She talks about the local community and says: *'We have small rooms but we have big hearts. Don't dismiss us because we have small rooms and no education. We know what it means to be a community and take care of each other. In rural areas they have lots of space but small hearts. Do not care about each other.*' We thank her for her hospitality and water.

It is 13:15 and already lunch time. As we whisk down the back alleys on our way back to the project offices, Sanjay leans back and roars over the engine and general traffic noise: *'Now supervisor will say, why are you late? They do not understand. That you show people respect today and tomorrow they will respect you. And come to awareness raising and take part in forum. Only they will ask, why are you late?'*

Back at the project offices we share our lunch in the health workers' room on the third floor. Some of the health workers live nearby and go home for lunch, the rest tend to gather upstairs for a communal lunch. Having been in out in the baking sun all morning it feels nice to sit down in the relative coolness of the project offices and feel the breeze of the ceiling fan on our necks.

At 14:30 we go downstairs for reception duty. We are on OP reception duty today, which means that we assess all patients that come to the OP and direct them to the appropriate persons, medical officer, physiotherapist, lab technician etc., in the building. A young female patient comes in, accompanied by her mother. The girl is an old MB case who has developed ENL reactions with accompanying nodules, change in pigmentation and other problems. Her reactions are probably the result of hormonal fluctuations associated with adolescence. She is currently being treated with anti-inflammatory drugs and steroids but the reaction is not subsiding properly, rather, it comes and goes in waves. As they go in to see the medical officer, Sanjay explains that it has taken several counselling sessions to explain to her that even though the disease is cured reactions may still occur, that the presence of reactions is not the same as presence of disease. The mother has 4 daughters, all adolescents and of marrying age. Last month, during one of their counselling sessions, the mother finally admitted what the problem was. Potential husbands come to visit the house to meet with the girls but they will not accept this girl due to the change in pigmentation and the presence of nodules. They are choosing her younger sisters instead and this is causing the girl great stress. This stress is driving the reaction and, thus, creating a stress-reaction cycle. Sanjay says: '*who will care for cases like this. If we go, no one knows about this. Primary health centres do not have experience. They do not know. So what will happen to those people? In community people will see them and there will be more beggars and more stigma. People will say treatment is not working and there will be stigma*'.

OP is busy today. There is a queue of 3 people waiting at any given point but this is not unusual on a Monday, as patients come in after the weekend. A few suspected TB cases come in for testing and two patients who need ulcer care. A girl we saw at one of the UHPs on Saturday comes in with her mother to have her diagnosis confirmed, to be charted and to receive treatment and counselling. An auto driver stops by to pick up his next pulse of MDT, takes his initial dose as observed treatment in front of Sanjay at reception. On average 10-15 people attend OP everyday (see *Table 2.* for details of OP activities), and slightly more on

a Monday. By 17:00 things start to calm down and the stream of patients turns into a trickle. We slowly start packing up and finishing up for the day.

We finally head upstairs to finish up the paperwork for the day and to fill in the log book stating where we will be tomorrow. As it is not Sanjay's night to conduct IEC van-shows in the slums he will be joining us for English class. I go downstairs to the conference room to set up for the class and prepare the handouts. By 17:45 I am all set and waiting for my 'students' to join me. From 18:00 to 19:30 we struggle through the complexities of English prepositions together. Sanjay gives me a ride home on the back of his motorcycle. It's time to get some rest and some dinner, before we do it all over again tomorrow.

| ULP Out-Patient statistics May 2007 | |
|---|---|
| No. of persons came for diagnosis of Leprosy | 31 |
| No. of cases confirmed as leprosy | 14 |
| No. of patients recived MDT Intial & follow up | 31 |
| No. of patients attended for physiotherapy intial and followup including general | 155 |
| No. of footwear Issued to Gr I Patients | 14 |
| No. of footwear Issued to Gr II Patients | 53 |
| No. of ulcer patients attended for dressing (intial & Followup) | 37 |
| No. of Patients with complications Reactions & Nurities | 43 |
| No. of Patients for Streiod treatment | 43 |
| No. of Skin smears done | 14 |
| Found Positive | 5 |
| No. of Symptomatic cases for TB diognosis | 23 |
| Found Positive | 5 |
| No. of TB Patients attended for treatment (New & followup) | 49 |
| No. of Fever cases for Malaria diognosis | 4 |
| Found Positive | - |
| No. of urine test for diabetic | 14 |
| found Positive ( diabetic) | 2 |
| No. of persons came for eye check up | 19 |

*Table 2.* Example of the OP activities in a month at ULP

### 4.2 The Health Worker

**- Enti, evasu, eppudu, enduku (what, who, when, why)**

Understanding what exactly it is that health workers do is only part of the challenge. We must also aim to understand who the health workers are, both as a group and as individuals. Out of all the staff at the project, it was the 11 health workers (for this purpose I will include the 2 supervisors as they share the same

history) that were to form the main focus of my thesis. But who are these people who were to become my primary informants, my friends, my colleagues, my guides, my teachers, my students and eventually my ULP family? As a group they are as diverse as they are united. The health workers' narratives are bound together by their experiences and their trajectories, set apart by their social positions and personal histories. The group is made up of men and women, Hindus, Muslims and Christians, they come from a variety of castes, from different parts of the state, some married some not, some with grown children, some with young children, some with second jobs on the side and representing a variety of personal belief systems. Thus, to speak of 'health workers' is to brashly gloss over all these differences. Yet, they have as much in common as a group, as that which sets them apart as individuals.

When I started my fieldwork there were 9 health workers working at the project: Mahesh, Ranjit, Giri, Vibhavasri, Preeta, Manoj, Bhaskar, Aaryan and Sadguna. For a group so rich in diversity their work narratives, current situation, training and social identity are surprisingly similar. To tell the story of 'the health workers' is to tell the story of my above composite fictional health worker Sanjay, to recount the similarities in their work and life narratives, to access that which they share and respect that which sets them apart. All the health workers have more than 10 years experience in this particular project, and many have as much as 20 years of experience in the field of leprosy control. So how did they come to the field of leprosy control and how did they end up working at this urban project?

For most of the health workers the story begins somewhere in a rural area of Andhra Pradesh, growing up in an agricultural setting and attending primary and secondary education in government schools. For some, this educational journey continued to degree level with the help and sacrifice of their family, or outside educational assistance, and for most they were the first persons in their families to attend higher education. By convoluted paths, their journeys led them all here, to work in ULP, but the paths chosen were very different.

The decision to take up leprosy control work, of all possible career paths, and to attend the 6 month paramedical training course was driven by a variety of motivating factors. For some it was motivated by their family association with leprosy while others came to leprosy work through the church, but what united them in their choice was a stated desire to 'do good', to perform social service, and at the same time find a good job in a stable programme which offered good salaries and job security. Most stated that it had been their ambition to get a government job, which was seen to offer higher salaries and more security, in the field of leprosy and some had even applied, unsuccessfully, for such positions before joining ILO. When I probed deeper about the particular choice of leprosy of all things, when they could have chosen to focus on mother and child health, nutritional interventions, eye care or a number of other issues which would have allowed them to 'do good' whilst finding job security, most of the staff referred to a specific incident, or a series of encounters, with people affected by leprosy as a driving influence for their career choice. Some remembered seeing leprosy affected persons around their village, or taking these persons to the local leprosy clinic, some recalled visiting a leprosy hospital whilst still at school and recognising the great need for assistance as well as the worthiness of the work the doctors and nurses where doing there. For other members of staff it was a more specific incident which led them to the field of leprosy, as recounted by one member of staff:

> *"It is nearly 20 years back. I worked somewhere in forest area. In ordinary....other work....not leprosy work. At that time what happened...one patient...he is neighbour. He had leprosy. So what happened... his fingers slowly getting bent. At that time I don't know what is bent (...) So, just I told: 'you go and consult your doctor (...) He went, they didn't take any additional...eh...they didn't start any additional treatment or anything. Just do exercises. Not exercises exactly. Just massage (...) like this all the paramedical workers, supervisors and physiotherapists and medical officers: everybody told only massage, massage. After 15* [days] *to one month his fingers become flexion. (...) I have interest in leprosy also. I have discrimination....this is leprosy, this is not...Because we can do some service (...) So they asked. Do you like to join this...in our parent hospital? Ok, because I am working in a private. That is not good amount also, I am not getting. So why don't we go there. I got. Then I went there. Because diseases also I saw. There is no treatment for this bending fingers? They are not doing or they don't know or there is no treatment for this flexion deformity? I want that answer. So...due to this things...so better I go there. I*

*can do some work, this is necessary there. Then I went to (...) training so that I got all this information. Because there is a treatment, there is a steroid treatment is there and exercises are there, splints are there. So many treatments are there. [...] But they didn't (...). Because of they don't know. And the negligence become like this. For example we have....we dealt so many cases a year. Like that cases. So many cases. 95% recovered. Like this, same 20 years back. 20 to 25 years back that one. What I saw, that patient, the same cases we are getting now also."*

Another issue which was brought up repeatedly by the health workers was that leprosy was the 'big disease' at the time, that it was not like now, that leprosy was a very serious public health concern and a priority for the state. Much in the same way as ambitious health workers, or students of public health for that matter, might feel steered towards HIV/AIDS as a career choice in the current climate.

### 4.3 "When I first started working here I had no moustache"

Some of the health workers have spent their entire working life in the field of leprosy control whilst others had other roles, such as carpenters, salesmen, nuns or teachers, before coming to the field of leprosy control but these previous careers where seldom referred to by the health workers in question. Rather, they would refer to the amount of time they have spent working in the field of leprosy control as their 'experience'. Even though I waited for several months into my fieldwork to conduct my 'work-narrative interviews' with the health workers, at which point I had already gotten to know them fairly well as a group and as individuals, it often came as a surprise to me when I asked them to describe their background and they would start off by describing how they came to the field of leprosy control via another career. In the months we had been worked together these 'other' jobs had never been mentioned though we often spoke about their past, their families and their education. Even if, as was the case for many of them, these other careers had merely lasted for a few years I would have expected that during our numerous visits to schools and other health education programmes when we discussed the Indian education system at length that it would have come up at some point that, 'by the way, I myself worked as a teacher for a few years'. But somehow, by the

health workers, this was never seen as relevant. What we did discuss, at length, was their various experiences working for different organisations and under different leprosy policy schemes.

Even though most of the health workers have been working in ULP for more than 10 years most have worked for other organisations or in other locations prior to joining ULP. Only a few started their career in this particular project, and for those it was almost as if they were 'raised' by the organisation. As one health workers in particular remembers it: *"When I first started working here I had no moustache. Only 16. When they saw me they said, are you working here? But you are only small?"* The moustache is the perennial symbol of Indian manhood so, in other words, he was saying: when I started working here, I was nothing but a boy. He went on to recount how he had started working for the organisation as an auxiliary worker on 20 INR per day helping with the survey in the mornings and occasionally helping out in the OP. He had worked like this for 2 years whilst waiting for a vacancy to open up in the organisation. At the same time he was attending training in radio/TV repair as he felt this might be a growing field in the future. After 2 years as an auxiliary worker, and having accrued debt, he was ready to switch careers when some health worker positions opened up. Still, he felt he might be able to make more money and have better prospects in the repair business. It was not until a senior person within the organisation contacted him directly and said, 'go and take the test, this is what you should be doing with your life' that he felt decided that this was indeed the right choice for him. The story of the subsequent 10 years of his life was a story of training, opportunities and support from senior persons within the organisation. But, it was also, a story of personal problems and wrong turns. However, the recounting of these problems would always be followed by another story which emphasised the role of his fellow health workers and the role of the organisation (or rather, certain persons within the organisation) in pulling him back from such problems and helping him to grow as a person and to become a man. Not only did he not have a moustache, thus being physically a boy, but he also described how he lacked direction, confidence and clarity and, thus, was not mentally a man. Through the organisation, and the support of his 'ULP family' he

described a process of 'growing up', learning to deal with stress and finding balance, literally being raised in the organisation and by his colleagues.

Alhough this is not the experience of most of the health workers, who either joined the organisation at a more advanced age or who perhaps had other pressures in their personal life. Yet, the importance of the support of their co-workers, the sharing of 'ULP family bonds', attending weddings and lending support at difficult times is something which is echoed by the other health workers. Clearly the shared experiences, loyalties and not least shared time has had a profound impact on the work narrative of all the staff at the project, as is evident in their tendency to refer to themselves as a 'family'. Yet, like most families they have their own feuds, rifts and internal problems. The image painted above has been one-sidedly positive, emphasising the bonds that bind them together at the expense of the divisive factors.

### 4.4 Unity and Diversity

What separates the health workers is as important as what brings them together – gender, age, religion, background, caste, connections and wealth all play a part in how they see each other and their roles in the organisation. Three issues emerged during my conversations with the health workers as the primary divisive factors; a) networks, b) caste, c) seniority - and the effect these have on human resources decisions within the organisation. These are clearly issues which are very difficult to document or to validate the accuracy of as some of the feelings expressed by the health workers relate to situations that happened years before I entered the field. However, for my purposes, the accuracy of the allegations is less important than the fact that many of the health workers felt that these were very real and prevailing problems in the organisation.

Firstly, the networks. As mentioned above ULP merged with another organisation in 1997 in a process which saw them take over not only the territory and cases from said organisation, but also some of the staff. Some of the staff at ULP

mentioned that they felt there was a divide between the original staff of ULP and the staff who came over from this organisation, even now 10 years later. As they had known each other longer and worked together for a greater number of years they were more likely to promote and support those who shared their history. These feelings ran in both directions. It was not merely a question of ULP staff giving preferential treatment to their original ULP colleagues, but as staff from the absorbed organisation climbed the ILO hierarchy similar accusations of preferential promotions were levied against them.

Secondly, and more seriously, there were serious concerns over caste loyalties and the extension of preferential treatment along caste lines when it came to promotions, redundancies, training and other benefits. As the staff of the project represents the three major Indian religions, one might have expected to find less impact of caste as a divisive issue but, as all non-Hindus are effectively regarded as "backward castes" (by society in general) this issues has the power to affect everyone. Whenever a specific instance of caste loyalty was discussed the conversation usually ended with someone shrugging their shoulders and muttering *'Rao with Rao and Reddy with Reddy'* (Rao and Reddy being surnames indicative of caste affiliation). Though it is impossible to say just how big of a problem this really is in the organisation on the basis of anecdotal and outdated information it was, however, something which would come up in conversation whenever something the health workers experienced as 'unfair' happened.

Lastly, the issue of seniority, and I am using the term here as it was applied by the health workers themselves, indicating a mixture of years of service and technical skill. Amongst the junior staff the feeling was very strong that they ought to be ranked on the basis of their seniority, in terms of years with the organisation, and that promotions ought to follow these lines. The health workers argued that, in order for someone to be a supervisor they should know more and have more experience than the staff they supervised. However, due to the before mentioned factors, the feeling was that the existing hierarchy did not reflect the skills or seniority of the workers but rather their networks and caste loyalties. As expressed by one health worker:

*"In previous days, in...few years back. Supervisor is...he is senior than me. He is supervisor, ok. Because, with that person's experience he used to give advice to the field staff. And also he used to work along with us also, supervisor. Like that in previous years. Now a days, like what happened. Supervisor is not senior than us. He just came to supervisor...as supervisor with the support of somebody. For example Mr. ___Reddy. Reddy is one of the castes. Reddy is those who have money, there they have Reddy name. Is official caste. (...)Only with the recommendation of Mr .___ Reddy* [another Reddy higher up in hierarchy and also connected through previous workplace] (...) *He is not....eh... He is not understand the situation. He is just a Reddy – I told you, no. Reddy is...eh...I am ____, he is Reddy. Like that his equal person he will give respect. (...) any Reddy. As Reddy he will give the respect. Christians, backward caste, in that he will not give any respect to the...those. That culture is there. The disease. "*

Each to their own, and each to the cause. The solidarity amongst the health workers is incredible, yet this allegation of caste loyalties would come up again and again. Whether they constitute instances of true discrimination or merely the aftermath of internal political battles, such internal conflicts cannot simply be written off as backbiting, as the internal conflicts between staff are as much a part of the everyday existence of the organisation as their solidarity.

### 4.5 'We are family' – Loyalty to the Organisation

In the presence of such divisive factors, feelings and resentments one might expect these to have an effect on the morale and loyalty of the staff or, at the very least, on their willingness to follow the instructions of their supervisors. However, these resentments seem to be generic and do not affect health worker's willingness to carry out the instructions of line-management. Although they state that hierarchy should be determined by skill and seniority, and these might be their basis for giving respect to individuals in the hierarchical structure, this does not have a wider bearing on their willingness to recognise the validity of the hierarchical structure per se.

Loyalty and obedience seem to be understood by the health workers as a given, as something which is offered to those in more senior positions, regardless of their

respect for the individual currently occupying that position. In a focus group discussion I had with the health workers, 3 out of 7 listed obedience to superiors as one of the 5 most important qualities in a good health worker. However, loyalty is not purely operational; the concept of loyalty permeates through the social identity of health workers. It is not merely bound up with the ability and willingness to follow directions from line-management but is equally related to their willingness to take on the messages, goals and outlook of the organisation wholesale. Loyalty then becomes a question of total commitment and dedication to a cause, at the expense of all other things. One of the Christian health workers explained to me one day that the central message of the Bible was to obey one's superior:

> *"In that way I am doing....I am reading bible every day. Because always our colleagues say why you are bending down so many time, 'Madam, Madam, Sir, Sir. Right away'. I follow only bible....eh... it is my boss. That is why I am.....morning....in bible says: 'your boss is good or bad. Always obey your boss'. That is why I follow. People don't know bible, that is why always says: 'eh, why are you bending, bending?' why bending, bending, bending?' like this. But I know only this way....".*

A little surprised by his assertion, I said that it was my understanding that the central message of the Bible was one of forgiveness and love for your fellow man and that, surely, obedience must be secondary to moral conviction, so that we only follow our 'bosses' if we believe what they are doing is 'right'. "Yes", he said and then he was quiet for a long time. It was raining heavily and we had taken shelter to wait for a bus, the sound of the rain drumming on the corrugate iron awning above us. Finally he finished the sentence, "...but it does not matter if he is right or wrong, only we must follow". Hierarchy and submission are common themes in Indian discourse, to know one's place and to fill that place. Here, in meeting with religion, these ideas had formed an unlikely, if not unusual, alliance. During my fieldwork, the Biblical story most frequently referred to, among Hyderabad's Christians and Muslims alike, was the story of Abraham/Ibrahim's sacrifice, and not only around the time Eid ul-Adha, or Bakrid as it is known locally.

There is a tremendous feeling among the health workers of having given their all to the organisation, of having become one with the organisation, of being family. This is not just with respect to the project, but the organisation as a whole. In fact, the

two are often seen as interchangeable. In a way, the insistence on the importance of seniority must be understood in relation to this loyalty, as it can be seen as a measure of the level of sacrifice and dedication of each individual. The staff also feels that their dedication to the organisation has come at an opportunity cost, as the promise of a bright future with ILO stopped them from looking for other opportunities within the government or in other NGOs:

> *"we can get more opportunity...we don't know. In our knowledge, in our qualification, in our degrees (...) We can see other organisations, other government....government Ok. Government we cannot approach and we cannot get....we approached but we cannot get job. But other NGOs, other things...any time we are not seen. Why? Because we have ILO. Good NGO. We are...our job satisfaction is there. We are doing service to people. We are getting salary also, but we are serving people...."*

Now that funding is running out, the health workers feel that this promise of bright future has been betrayed and that they ought to be rewarded for their loyalty and its opportunity cost. In the very least they feel that redundancies should follow the lines of seniority. For obvious reasons this is not practicable, as the organisation must look to retain the staff that will build the strongest team for the future, and not merely consider their years of service. Part of the loyalty that the staff feel is to the organisation and the 'cause', part is to their colleagues and to their 'family', but there is also undeniable loyalty to their clients and to serving people affected by leprosy. In the eyes of the health workers, changes to the value structure of their 'family' represents a double betrayal because it constitutes a divergence from the values they have dedicated their services and commitment to over the last 20 years. Thus, when the organisation and its values change, it is felt as a personal betrayal of the moral universe they have shared. When my friend acts in ways I cannot condone, I feel disappointed but when my brother does, I feel betrayed, for he is me and I am him, we are family.

The health workers' all consuming passion for their work, the fear of not reaching the goal of leprosy eradication and losing everything they have been working toward, ties in with this fear of losing this moral attachment with the ULP/ILO "family". At the beginning of my fieldwork period, there were rumours circulating in the organisation about a project officer at one of the organisation's other projects

being fired for inappropriate behaviour. There were murmurings of incompetence and bribery but I was never privy to the details of the situation. However, the issue of bribery for positions kept coming up in conversations and could be understood, not just as a discussion of bribery, but as an expression of the moral decay, in terms of a departure from the value base into which the staff have been indoctrinated, of the organisation, as experienced by the field-level staff. Bribery is obviously a huge problem in the Indian sub-continent but, to the best of my knowledge, this has never been an issue in the organisation. One of the CHOs, however, was of a different opinion:

> *"ILO name losing, madam. If we go in another NGO organisation ILO name becoming to reducing. Because while preparing the jobs previously no one takes any bribe to do the routine employment. Now some new persons, new water...protein... came in ILO. Higher authority places and while recruiting they are taking some bribes. For some recruitments. Even they do not have proper knowledge to work that area. Even like that people becoming a employee in this ILO. Same time the bribe – religion, caste and relationship are occurring things. Even these...all these things occur in the organisation - automatically the organisations quality is becoming to reduced (...) We have come here, we have to leave from here. Up to now we have think only: We can work under this tree, we can live this tree, we can live under this green tree. It is a very holistic, is a very selfishless and it is a very hopeful organisation. To work this hopeful tree, this hopeful green tree. We can live well life and we can give well service to the needy people. When we entered...when we keep the life in that day... but the present situation is not like that"*

The narrative speaks of bribery, but there is very little specific information about any particular instances of bribery. When I sat in the tiny sweltering room and listened to this health worker talk about instances of bribery, it was not money grabbing officials I saw in my mind's eye, but the slow wilting of a green and vibrant tree. Clearly the health worker was concerned about bribery but underneath lay grief over the loss of a shared moral universe.

### 4.6 Assimilate, Integrate, Conform

**- The Role of Training and Peers in Identity Creation**

The health workers all have basic paramedical training, in the form of 6 month courses at various institutes across India. They also have more than a decade's experience of working in the field of leprosy control. The perspectives and working practices of the organisation have always followed official policy extremely closely, aiming to put into practice the guidelines of the Indian government and the WHO. Taken together, the organisation's outlook, the official guidelines of the government and the WHO, as well as the day to day reinforcement from fellow health workers, supervisors and other staff, serves to recreate and maintain the axioms of the health workers' training as sacrosanct. Every meeting is started with a recital of the organisation's mission statements with hand on heart. As one member of staff put it, "leprosy is our bread and in our blood". The health workers are fond of pointing out just how pervasive their preoccupation with leprosy is, how it permeates every part of their lives and how they 'see' leprosy everywhere, in their personal lives and in their professional activities, to the extent that their work persona has become inseparable from their personal lives. While discussing how he felt about the change in work emphasis from active case finding to promotion of voluntary reporting, I laughed in recognition as the ULP member of staff recounted this story:

*"ULP Staff: This policy change is good in other diseases, except leprosy. Leprosy also we can do, but very little. When he will suffer any leg, then he will think: oh, I have to go. I have to rush doctor'. Even previously also we...eh....went to survey. At that time one big common family is there...eh...52 members in one family.*

*Interviewer: 52 members?*

*ULP Staff: Big house. But they will eating, cooking....own workplace. At that time we done the survey. But in that 2 – 3 is there, 2-3-4-5 doctors are there, some business people are there. So many brothers, fathers...like that. At that time we detect one case in that house. One school boy in 8th class or 10th class....8th.....but so many doctors are there. How can we...eh...tell this is leprosy. As the paramedical people we don't tell at that particular point. At that particular place. We told the...head of the family: 'Sir, this lesion is also here. You can come our hospital. Once...'. 'What is this?', he said. We said: 'we think leprosy, Sir. But not compulsory. We don't know. But you came to our hospital'. 'no, why you are saying leprosy. We have so much of...so many people in our*

*house, doctors. We are seeing daily. No, that is wrong', he said like that. But he went to...he taken his boy to one of the skin specialists. They will refer to us. Skin specialist, what he done, he refer to ULP/ILO but the doctor don't know we are from ULP/ILO. He came and he came and around, around. And he: OK, this is leprosy, this is ULP'. He entered the office, we are there. 'Ah, you people here?' 'Yes, Sir, sorry, sorry. You are thinking wrong way'. From that day he is referring so many cases. Same house...4-5 doctors are there, no? they are sending the cases from that day. Nearby office only that doctor who is there. Sometimes happened like that.*

*Interviewer: Yeah. Yeah. Ehm...Manoj [one of the health workers] told me one time he went to Apollo hospital with his brother, and one technician or porter or something in hospital had lesion on his face. Manoj said: are you taking treatment? He said: treatment for what? So Manoj said, Ok come to ULP.' And then he came and had leprosy. But working in Apollo Hospital every day, sees 300-400 doctors nobody says, nobody did.*

*ULP Staff: Yeah! Our eyes sees!*

*Interviewer: Exactly. We only see patients and other people, family maybe not...*

*ULP Staff: Yeah. Sometimes we have to go to some picture, movies. Colleagues like that...with family. Somebody.....'oh, see. Patch, patch' . our spouse will go: 'No! here also he can see lesions, he can see picture. We buy ticket, like that. But you are seeing lesions! Skin lesions!' [laughs] Habit is like that. Even...he told, one of the doctors, even picture also. Heroine dancing we have to see only lesions! [laughs]"*

'Our eyes sees'! But it is not just that the health worker's investment in their field is so complete, it also that the nature of this investment is so homogenous among the staff, and this goes beyond the field-level staff. There is a great uniformity of opinion in the field of leprosy control, throughout the organisation but also in government and internationally. Leprosy is one of the few diseases where we are still unclear on the precise nature and mode of transmission (Webber, 1996). Despite this uncertainty, and no doubt partly as a result of the buoyancy brought by MDT and the success of the elimination campaign, there is a belief in the leprosy control community that we have the answer to the problem, and that leprosy control is simply a matter of applying this strategy effectively enough. This is not only the attitude of the field-level staff, but can be found, to some extent, in the international leprosy community as well. For example, the discussions and presentations by professionals from all over the world at the 17th international leprosy conference in Hyderabad followed similar lines and utilised the same wording of rehabilitation and elimination, regardless of the presenter's country of

origin. Even in the recounting of the experiences of leprosy affected persons, there seemed to be a certain element of standardised discourse, as if the real life experiences of people affected by leprosy have been translated through the standardised discourse of leprosy policy so as to be presented to the professional community in a predictable and acceptable manner.

Something similar can be seen among the health workers when they seek confirmation of a diagnosis, or help from their colleagues in handling a particularly complicated case, or in the handling of delicate family situations – the peer exchange serves a function not only of supporting colleagues but also in reaffirming their mutual discourse and shared training. The language of the health workers is the language of training manuals and international policy documents. Interestingly enough, there is no *one* training manual or collected set of guidelines at hand for the health workers to follow. They share paramedical training, government guidelines (NLEP, RNTCP, NACO etc.) and organisational strategies. They have all attended various training sessions on infectious diseases and community health and they have WHO/ILEP and other training material available at the project offices. However, without a doubt, the biggest source of information on various diseases and procedural issues is each other, and secondly, their supervisors or the project's medical officer.

Asking your colleagues for advice carries no risk, whereas asking your superior is an admission that you do not know the answer to a question to which you perhaps ought to know the answer. Thus, the field of knowledge is maintained within the group, and their field of knowledge becomes homogenized and standardised due to their constant conferring. When I first entered the field, I knew little of the technical aspects of diagnosis and treatment and, sensing my ignorance on this subject and having identified an uncomplicated field of interaction for us, each of the health workers set about teaching me how to distinguish tinea and vitiligo from leprosy and how to palpate to assess nerve involvement (something I never really mastered the finesse of). However, what was interesting about this process is the remarkable standardisation in their lessons. Without using a manual or relying on a reference work, all the health workers taught me the same techniques, and taught

them to me almost verbatim. Though there might be minor disagreements about whether a nerve involvement was a 2 or a 3, there was a distinct and shared field of knowledge to which they all subscribed. This is perhaps expected in terms of medical procedures and treatment protocols, but the shared field of knowledge went beyond this to include the social aspects of their work, and it also extended beyond the group of fieldworkers to the wider organisation.

### 4.7 Walk the Line: Party Line and 'Wrong Notions'

This shared field of knowledge is expressed in the health workers actions in the field, as they go about their daily duties. Though a certain degree of devotion to their belief system is necessary in order for the health workers to be able to carry out their duties effectively, such devotion can also serve to block potential input from the community with regards to, for example, how they see their situation and what potential strategies they might utilise to address their problems. This could have a devastating impact on the opportunities for bottom-up communication from the field. Though health workers adapt their approach to suit the community this is not merely informed by what the community wants or does, but is equally about the individual health worker's personal belief system and what they think the community needs and *ought* to want.

Fulfilling community requests often forces health workers to go beyond the official remit of their job description. As part of this, they must be careful to balance their dedication to organisational targets with the needs and desires of local communities – which again must be balanced against what they see as reasonable 'social service' and what they think is good for the client. The health workers must maintain a delicate balance between client and organisation, as well as personal and professional. The personality differences amongst the health workers play as important a role here as religion, personal beliefs, cast prejudices, political affiliations and value judgements, as these all play a role in shaping what the health workers see as the 'right' thing to do. However, vast as these differences are, what the health workers do share is the discourse of leprosy control and the

organisational doctrine to guide their work, and this commonality far outweighs any personal differences. Though they may have different takes on how one should live a 'good life' and these differences colour individual advice given in the course of their work, their shared belief in a common goal and the belief that the guidelines they follow, if applied correctly, will lead them to achieve those goals, bind them together and form a shared world view. They have believed in, and worked according to, a particular set of ideas for 20 years.

This shared set of ideas can be seen in terms of how the health workers conduct health education programmes, where the health workers stress the importance of weeding out 'wrong notions' in people and teaching them the 'right thing'. These programmes will often follow a scripted formula where the health worker invites the audience, be it a school class or a health forum, to tell them about leprosy, TB, HIV or malaria. After the person finishes their recounting of causes, symptoms and treatment the health worker then set about 'correcting wrong notions' and telling them the correct information. This exercise is carried out by the health workers in different forums on an almost daily basis, and usually follows the same, or variations on the same, script. Now, of course, having worked in the field for 20 years, a certain degree of devotion to their belief system is necessary in order for the health workers to be able to carry out their duties effectively. The use of the terms 'wrong notions' and the general indoctrination – which is also part of establishing social identity and belonging, in the forming of a shared habitus and in rationalising their approach to work. However, it can also be a hindrance to effective communication. At one point I challenged the project's health educator about the appropriateness of this approach:

From my field diary, entry morning of the 2nd of August 2007

> "Community Capacity Building Programme in Mallapur, Nehru Nagar. 2 social work students come with us. 17 women and lots of children turn up. Community hall is musty and smells of sour milk. Get the women themselves to talk about leprosy and TB – peer education – to avoid just passive reception. Have been trained many times before. Do quite well. Afterwards [health worker and health educator] address the 'wrong notions' [or as I would say correct anything that is not 'correct' in terms of ILO discourse. No attempt to understand why there is confusion – or indeed if there might be a

way to draw on these notions to achieve positive results (personal note)]. Before the meeting I was discussing superstitions and the need to correct them with [the health educator]. And he said *'If people are taking superstitious cure we need to correct this. This is wrong. We need to correct their notions.'*

I argued that it is not that simple. Western medicine is also a system of belief. All are systems of belief, belief not superstition [superstition is only negative brand wielded by those who don't believe in that particular system. (...)That showing proper respect for other people's beliefs and advocating both systems at once might be more appropriate in some settings and might even yield results. [He] responded *'you have to have total belief in MDT. Without total belief how can you give clear message. Total belief, and saying is incorrect, is only way. Should not take superstitious cure. How can we work without belief? For 20 years we have been doing."* I argued that the world is not black and white but many shades of grey and [he] countered with *'black is black and white is white'* Blind faith in and devotion to the programme and message they have been provided with and are providing. It was probably absolutely necessary in the early days of the programme, and part of what inspired such loyalty and dedication – total belief in what you are doing not just as a job but as an article of faith. (...)

I tell [him] that perhaps it would be interesting to find out what people think about cultural features, i.e. superstition, and use this understanding for health education. [He] just shrugs and says *'you are coming from anthropology'* then he and [and the health worker] proceed to give a talk with 'right notions'."

Clearly the health workers are a product of the organisation's discourse. In fact, they would not want to question this discourse. Only when I got them talking about how the organisation and their work had changed were they willing to question the organisation's position through juxtaposing what they saw as the 'correct' mentality of the organisation with what it was currently changing into. It is this notion of 'total belief' which best exemplifies the devotion that the ULP staff feels to the discourse within which they have been providing services for 20 years. As the health educator argues, *'without belief, how can we work?'* The field guidelines and procedural manuals are no longer merely procedural standards, they have become tenets of faith which cannot be questioned for they form the basis of the staff's worldview and structures their approach to life as well as work. This brings to mind the argument made by Pigg that *"It makes no difference that training manuals frequently include statements about the need to respect and value local ideas and to learn about local customs. It makes no difference that many development*

*programs are planned with "cultural appropriateness" and "sustainability" in mind. In practice, it is extraordinarily difficult actually to implement these values. Without a constant reinforcement of the program's philosophy, the original intent for collaboration recedes in favour of a more familiar mode of imparting information . . . and teaching them the right way."* (Pigg, 1993:51-52). Health workers are a product of a discourse within which they exist and into which they have been socialized. In addition to this, the discourse, the habitus, is reinforced through social interactions and discussion on a daily basis. But what exactly is this discourse in which the health workers are embedded? In order to understand the impact it has had on the lives of the health workers, we must take a closer look at leprosy policy and the changes it has undergone in recent years.

## 5. Mapping the Dance Floor. Policy, Process and People

Leprosy has long been a disease apart, physically segregated into vertical programmes within the health sector and socially compartmentalised through fear and stigma. The history of leprosy policy is long and well charted by others, so, I will merely provide the briefest of outlines. Despite being set apart from other health issues, leprosy policy has been subject to the wider political and economic changes that have dominated the last 50 years of international relations. The discursive shifts we find within leprosy policy take on new meanings when seen in relation to broader trends in international discourse. By looking at leprosy policy in relation to these influences we can identify distinct discursive trends within leprosy policy, all with different drivers, perspectives and impacts. After looking at these, I wish to examine how recent changes in international policy have impacted on health workers, their social identity and their understanding of their role as well as the challenge this poses for the immediate future. International discourse cannot be understood as purely hegemonic but must been seen as the products of a dialectical process of local and global influences. If local understandings do not match international discourse this can make future interventions hard to implement efficiently. But, first, let us take a brief look at the history of leprosy policy.

### 5.1 Leprosy through the Ages In Policy and Practice

Leprosy is perhaps one of the oldest, most infamous and feared diseases. Leprosy is feared not for its mortality rate (as it is rarely fatal) but rather for the physical and social consequences of the disease (Hastings, 1986). Mention of the disease in historical text goes back as far as ancient Egypt, China and India – e.g. leprosy was mentioned as early as 2000 BCE in the *Atharava Veda* (Jacob and Franco-Paredes, 2008, Gould, 2005). Perhaps the most commonly known references to leprosy come from the Bible, and the portrayal of leprosy in the Bible has had devastating consequences for those suffering from the disease. However, it is now thought that what is referred to as leprosy in the Bible has little to do with the

disease as we know it today. The use of the term leprosy in the bible probably arises from a mistranslation of the Hebrew (Hastings, 1986). This mistranslation, as well as the later and possibly conscious manipulation of the definition of leprosy as a strategy for social exclusion (Douglas, 1991), have had dire consequences for the subsequent treatment of people affected by leprosy all over the world, by providing a basis for moral judgement of those affected by the disease.

In India leprosy has been a public health problem for centuries but the first concerted efforts to address the problem in a structured manner came during the British colonial period. A conjunction of factors led up to the colonial effort to control leprosy in its territories. Firstly, accounts, from returning missionaries, which were often exaggerated, started trickling back to the British public. Secondly, Armauer Hansen's discovery of the *M.leprae* bacteria in 1873 and the death of Father Damien in Hawaii in 1889 proved the disease was contagious rather than hereditary, a fact which caused great concern in Britain and fuelled the fear that the disease would spread to the 'metropole' (Edmond, 2006). Lastly, the first official Indian leprosy census in 1872 found a prevalence rate of 54 per 10,000. Even if this claim was dismissed in a subsequent report, from the Leprosy Commission in 1891, which concluded that "the amount of contagion which exists is so small that it may be disregarded" (NLF, 1892), mounting pressure from within India as well as from the British public led to the enactment of the Leprosy Act of 1898. This Leprosy Act stayed in place until 1983, when it was repealed as a result of the discovery of MDT which was effectively a cure for the disease. The Leprosy Act brought on the age of segregation of leprosy affected persons into 'leper asylums' and, on the Indian subcontinent, segregation within these asylums along gender lines to prevent reproduction. The double strategy of segregation, to limit both contagion and hereditary spread through reproduction, displays lingering confusion over causation within the medical establishment. As the British colonial state lacked the resources to enforce a forced segregation policy, segregation into leprosaria was nominally voluntary for individuals capable of managing their own situation and only compulsory for 'vagrants' and those caught begging. Absconders from the leprosaria faced punitive repercussions. In fact, living conditions for many

leprosy affected persons were so precarious that the voluntarily submission to segregation was often the only choice available in a highly stigmatised world.

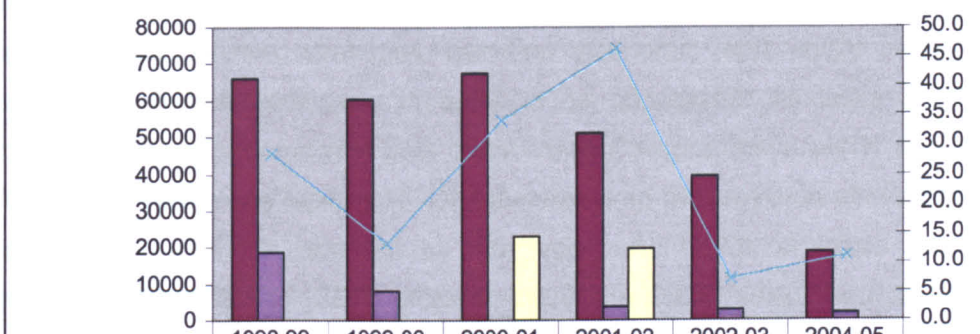
The Leprosy Act also resulted in the establishment of a range of charitable and religious institutions aimed at providing care for leprosy affected persons to supplement the shortfall in government care facilities. This involvement of non-governmental organisations continues to the present day, as leprosy programmes still rely heavily on the involvement of NGOs to provide ground level care in the name of the government. The organisation in which I conducted my fieldwork is one such NGO.

In the newly independent Indian state leprosy was recognised as a public health problem through the establishment of the National Leprosy Control Programme (NLCP) in 1955. The aim of the NLCP was to provide care and treatment, in the form of dapsone monotherapy, for leprosy affected persons. With the discovery of an effective cure in MDT the onus of leprosy policy changed from care to cure and, in 1983, as a result of the then prime minister Indira Gandhi's commitment to eliminating leprosy as a public health problem by 2000 (Staples, 2007), the institution changed its name to the National Leprosy Elimination Programme (NLEP). This pledge of eliminating leprosy as a public health problem by 2000 was echoed by the 44$^{th}$ World Health Assembly in 1991, where elimination was defined as a prevalence rate below 1 per 10,000 population. At this low level, it is assumed the disease will die out naturally, though there is, without going into details on this rather complicated issue at this point, considerable controversy surrounding this assumption (Meima et al., 2004b).

Globally leprosy was officially eliminated as a public health problem on May 16$^{th}$ 2001, though 12 endemic countries, including India, had yet to reach their elimination target (WHO, 2003b, WHO, 2003a). As 70% of the disease burden at this time was to be found in India, true international elimination could not be said to have been reached until the situation in the endemic countries had been redressed. The WHO responded by issuing its 'Final Push Strategy' in 2003. This aimed to bring down the prevalence in endemic countries to less than 1 per 10,000

by the year 2005 (WHO, 2003a). On the 31st of January 2006 the government of India proudly announced that it had reached the goal of elimination of leprosy at a national level, having a national prevalence rate of 0.95 per 10.000, and projected that leprosy would be totally eliminated in the next 20-25 years (TheHindu, 2006). Even so, the distribution of leprosy is not homogenous across the country and 6 states (Bihar, Chhattisgarh, Jharkhand, Orissa, Uttar Pradesh and West Bengal), as well as numerous regions and high prevalence pockets, still have prevalence rates well above 1 per 10,000 (Sahni, 2006).

Since the instigation of the National Leprosy Elimination Programme in 1983, the primary goal of leprosy control has been elimination. The primary strategy for reaching this goal had been survey, education and treatment (SET). In 2001, NLEP issued its second phase guidelines (NLEP II) in association with the World Bank. The main emphasis of this strategy was to decentralise leprosy services to state and district levels, to disband the vertical control structure and to integrate leprosy services into the general health system, with the aim of making leprosy services sustainable and to contribute to the destigmatisation of the disease, by reversing the image of leprosy as a disease apart. This strategy made leprosy services the responsibility of medical officers and nursing staff throughout the general health structure and made MDT available at all sub-centres, PHCs, government hospitals and dispensaries (GoI, 2008). Extensive training by, and involvement of, specialised services and NGOs in this process has helped to transfer the expertise of this staff into the general health care system. Simultaneously, the emphasis of leprosy policy shifted from systematic active case detection to an emphasis on voluntary reporting through health education and awareness raising. Between 1998 and 2004, four national Modified Leprosy Elimination Campaigns (MLECs) were conducted in the form of targeted surveys. In the state of Andhra Pradesh, 5 MLECs and 2 Rapid Enquiry Surveys (RESs) were conducted between 1998 and 2005 (NLEP, 2007b), no RES or MLEC was conducted in 2003-04 (see *Figure 10.* below):




| | 1998-99 | 1999-00 | 2000-01 | 2001-02 | 2002-03 | 2004-05 |
|---|---|---|---|---|---|---|
| Total Cases | 65746 | 60388 | 67230 | 51175 | 39115 | 18751 |
| MLEC | 18742 | 7919 | 0 | 3797 | 2740 | 2062 |
| RES | 0 | 0 | 22851 | 19828 | 0 | 0 |
| % | 28.5 | 13.1 | 34.0 | 46.2 | 7.0 | 11.0 |

*Figure 10.* MLEC and RES findings from ULP 1998 - 2005

With the integration of leprosy services into the general health system, all active case detection for leprosy has been discontinued, both in the general population and in specific target populations. Case detection now depends on the voluntary reporting of symptomatic patients, awareness raising and Information, Education and Communication (IEC) campaigns in the general population. It remains to be seen just how successful the integration process has been as a whole.

With the attainment of the elimination goal, the focus of leprosy policy has shifted towards the social and economic rehabilitation of current and former patients. Most recently, the Indian Government launched the Disability Prevention and Medical Rehabilitation (DPMR) strategy aimed at introducing routine disability prevention and reaction management protocols into the general health services, as well as clearing the back-log of persons with grade 2 disabilities through reconstructive surgery at designated tertiary hospitals. Further, the strategy aims to establish secondary referral centres that can provide specialist care to more complicated cases and expert services for disability care and management. The DPMR strategy focuses primarily on the bio-medical aspects of rehabilitation through the means of

reconstructive surgery and prevention of disabilities through pharmacological and physiotherapy interventions. However, leprosy rehabilitation strategies must adopt more comprehensive strategies targeting economic and social rehabilitation alongside physical measures in order to be successful. As there is still little capacity for such comprehensive rehabilitation programmes within the general health services, many leprosy NGOs have taken up the provision of such services, effectively, to fill the gap left by integration. As NGOs embrace social and economic rehabilitation (SER) projects, there is a risk of setting leprosy apart yet again, by providing services exclusively to those affected by leprosy through an expected channel. As Waxler argues; "(...) we suspect that the organizations most committed to treating and curing may have, inadvertently, had a part in perpetuating the stigma of leprosy, through a complex and circular relation between the expectations that some societies have for people with leprosy and the organizational constraints and requirements of the leprosy organizations' own survival" (Waxler, 1981:185). Yet, social and economic rehabilitation is now becoming part of mainstream leprosy policy, with official guidelines drawn up by ILEP (Nichols et al., 1999) and promoted by the WHO's Global Leprosy Elimination Strategy for 2006-2010 (WHO, 2005). In addition to a focus on rehabilitation services, leprosy organisations have also been branching out into other health issues such as HIV, TB and community health.

### 5.2 Discourse, Development, Definitions and Drivers

From segregation to SER, the history of leprosy policy history is long and varied. Leprosy policy has generally been implemented through separate, vertical agencies and been kept outside of the general health system. However, even with this degree of separation, it is clear that the programmes have not remained unaffected by wider economic, social and political trends. What are these broad international trends, how do they coincide with national Indian policy and how have these influenced the aims and means of leprosy policy?

In order to answer these questions, we need to separate wider international and national agendas from the policy formulation process. One way of achieving this is to interpret changes in leprosy policy over time, through insights gleamed from the anthropological analysis of development discourse. Utilising such a framework enables us to juxtapose international trends and national influences in order to illustrate the extent to which they play a part in the formation of policy landscapes, even in sub-disciplines as specific as leprosy policy. Ralph Grillo's perspective, which divides development into three distinct discourses, argues that each of these discourses has a distinctive mechanism, driver and impetus:

| | Mechanism | Driver | Impetus |
|---|---|---|---|
| I | State engendered order | UN agencies and bilateral aid agencies | An elaborated, authoritative, interventionist ideology |
| II | Market engendered spontaneous order | World Bank and the IMF | Cost effectiveness rationale and structural adjustment programmes |
| III | Discourse of public sphere | NGOs, research institutes and charities | Optimistic, reason informed pursuit of formal and substantive democracy |

*Table 3.* Three stages of development discourse. Adapted from (Sutton, 1999)

Recognising that this perspective is necessarily simplistic and overly generalising, it still has the potential to offer insights into how policy is shaped by wider discourses, where discourse is defined as "appropriate and legitimate ways of practicing development as well as speaking and thinking about it" (Grillo, 1997:12). Utilising Grillo's general framework (summarised in *Table 3.*) allows us to look beyond the specifics of leprosy policy and to investigate this policy through the lens of international and national trends, thereby demonstrating how these wider trends play a crucial role in shaping policy by determining what are legitimate ways of thinking about policy. So, let's take a look at what insights we can gleam from looking at leprosy policy through this novel lens:

Due to the particular history of leprosy policy, I believe it is necessary to include a Pre-World-War 2 perspective, which precedes Grillo's timeframe and engages with leprosy policy as manifest in India under the colonial administration, taking into consideration both the colonial agenda and local perspectives. For, as Jane

Buckingham argues, leprosy control under British colonial rule cannot merely be seen as an expression of hegemonic colonial power but must be understood as a process of conflict and compromise between internal Indian pressures and colonial interests. "The blurring of the lines between the leprosy sufferer as prisoner or patient in the Madras Leper Hospital reflected the complexity and incoherent expression of British power. Rather, it was a consequence of the dual pressures from both government and medical officers to provide medical care and shelter for leprosy sufferers and to clear beggars off the streets of Madras." (Buckingham 2002:59). In much the same way, it is clear that national leprosy policy in India has been heavily directed by international policy but, equally, that it is subject to specific national interests and pressures. Due to India's particular history, I believe this added category is necessary in order to distinguish effectively between the impact and role of the colonising state power as state driven actor from that of the nationalised state power.

Grillo's 'state engendered order' can be seen to influence leprosy policy from Independence to the late 1980s/early 1990s. During this time, leprosy policy followed a traditional state driven vertical programme format with a strong focus on the control of the disease through the identification, treatment and segregation of cases. At this time, India was pursuing Nehru's dream of a socialist democracy with strong state controls, heavy investment in infrastructure and industry and a planned economy (Khilnani, 1997). Leprosy was on the nationalist and social agenda at the dawn of the new nation, leprosy sufferers were treated as wards of the state and the focus was very much on care and containment of those affected.

There is a concurrence between the shift towards 'market engendered spontaneous order' discourse within development, the liberalisation of the Indian economy and drastic changes in leprosy policy. At the same time as we see the emergence of an international development discourse focused on market engendered spontaneous order we also get the liberalisation of the Indian economy through the adoption of one of the World Bank's Structural Adjustment Programmes (SAPs) in 1991. This change in global development policy had ramifications for international health policies which can be seen to have shifted

towards an emphasis on the dismantling of vertical state driven programmes and a move towards private-public partnerships and cost-effectiveness driven implementation strategies. Even if the impact of SAPs could be said to be less extreme in India than in some other contexts, as economic reforms were less radical and the state retained significant power over the economy. Around the same time, leprosy policy saw a shift from vertical state driven programmes towards decentralised horizontal programmes, and the inclusion of the private sector. The shift from control to elimination in leprosy policy entailed a shift in the perception of leprosy affected persons as they went from being wards of the state to being wards of the medical establishment and the pharmacology industry. With MDT, leprosy affected persons went from being a group to be cared for to being a group to be cured, they became a problem to solve through the proper administration of treatment.

Grillo's final stage, the 'discourse of public sphere', where the agenda is driven by NGOs, is currently in its very early stages of infancy in India. This is partly due to the prevailing dominance of the State and its reluctance to allow international aid agencies to operate freely in India. The Indian government understood early on what many others are only just realizing, that development is a matter of perception, dictated by so-called developed countries (Escobar, 1995). Thus, the Indian state engages critically with international aid in recognition of the fact that to accept aid is to consent to being defined as a developing country, something which could be more damaging, due to its impact on foreign investment and revenue flow, than to forego such financial assistance. Still, NGOs such as ILO play an important role in the provision of leprosy services, acting in the capacity of a state agency within the newly integrated services, often by taking over expert referral services that are not available in the general health system.

Leprosy policy discourse has shifted to a focus on empowerment, participation and rights. Even within the field of health policy, economic and community development is taking on new importance. It is no longer the role of the state or the biomedical community to take care of people affected by leprosy, this responsibility has been shifted back to communities and the onus now is on integrating people affected by

leprosy and building community capacity. However, stigma and prejudice against people affected by leprosy, not only within communities but in civil society and the general health system, places people affected by leprosy at a disadvantage in this respect. This shift towards public sphere discourse has increased the power embedded in civil society organisations. This could potentially lead to a reduced focus on people affected by leprosy in general as they have to compete with all other 'causes' and, after 200 years of vertical programming, they are spectacularly badly equipped for the fight.

In addition, the emphasis on 'elimination' has lead to the erosion of leprosy as a social issue. Thus, people affected by leprosy could stand to lose their identity as individuals and communities affected by leprosy, the very thing that could provide a basis for them to compete for influence and access to resources from the state through civil society (Staples, 2005). Even organisations that previously worked exclusively within leprosy are now branching out and reorganising their activities around a more varied agenda. So, people affected by leprosy risk dropping off the radar completely and becoming marginalised as resources, attention and political will are diverted to other diseases. Or as Gould has argued: "Leprosy patients had struggled for so long for freedom; now, in the era of multi-drug therapy and the 'horizontal' – as opposed to 'vertical' – model of health care, they have achieved it, but at a cost. The danger they now face is neglect" (Gould, 2005)

Looking at leprosy policy through the lens of international development raises the question of whether there can truly be a post-colonial leprosy policy, when policy can be shown to be so intimately linked to an internationally defined agenda. This is a difficult question. It is tempting to give primacy to international and national agendas, which obviously have a crucial impact, but we must remember that these must interact with, and be implemented through, local, independent agendas and influences which have as much impact on policy as international trends. Not all agendas are set at international level, as the following example of the influence of the Indian state's modernist ambitions shows. The current DPMR strategy has surgical reconstruction of Grade II disabilities as one of its primary aims. Part of the reason, arguably, for why the focus is on Grade II disabilities, apart from their

severity, is their unsightliness and, hence, the proliferation and conscious manipulation of such disabilities amongst beggars. The DPMR strategy's focus on clearing the backlog of disabled leprosy patients through reconstructive surgery must be understood, at least in part, in relation to the Indian government's desire to be seen, and taken seriously, as a modern state. It is incredibly difficult to maintain this vision, if next to your gleaming new IT hub, there is an intersection full of beggars, bearing the marks of leprosy and invoking images of medieval Europe in the minds of visitors. Thus, the policy is as much a question of national image as of public health priority (Staples, 2007).

### 5.3 No Discourse Is an Island

By drawing on Grillo's analysis of development discourse we can identify ways in which public health discourse, and leprosy policy specifically, has been influenced by wider global trends. Policy is in constant change and the current point in time is no exception. In addition, discourse trends are not mutually exclusive, when one major trend is replaced by another dominant discourse this does not mean that the previous discourse disappears from the policy arena. Clearly, international discourse has an influence on the way leprosy policy takes shape on the ground, however, this process must not be seen as merely hegemonic. There has been a dangerous trend in the past to overemphasis the hegemonic nature of international discourses and to focus on dominant 1st world discourses imposing their will on the subordinate 3rd world scenarios (Olivier de Sardan, 2005). The influence of international discourse is always subject to polysemic local political and social influences on this process (Friedman, 2006).

Friedman argues that we must see the relationship between local and global influences, not as hegemonic, but as dialectic (2006). Such an approach carries with it the advantage of considering the influence of multi-vocality and local agency on the policy formulation process. He suggests, that by drawing on the insights of the Comaroffs, who argue that discourse must be seen as the result of two distinct dialectical relationships in a dialectical relationship to each other, i.e. that discourse

is created through the local interplay between social structure and human agency on the one hand, and domination and subjection in a global policy encounter on the other hand (Friedman, 2006), we can build an understanding of how people, health workers in this case, are "determined, yet determining, in their own history; as human beings who, in their everyday production of goods and meanings, acquiesce yet protest, reproduce yet seek to transform their predicament" (Comaroff, 1985:1).

By recognising the existence of myriad competing development discourses, as well as the competing interests of different actors in the process, it helps us explore the complex ways in which local actors challenge, co-opt and reform discourse through the complex interplay between structure and agency at a local level (Everett, 1997). Moving away from seeing the subject of development, or public health policy, as a passive recipient of aid or services, this perspective recognises that "the so-called beneficiaries of development, the so-called local communities, the so-called objects or targets of development, become active subjects in the making of the development encounter" (Friedman, 2006:207). This encounter, between local agents and an overarching discourse, can only be understood through in-depth ethnographic fieldwork and long term participant observation at grassroots level or even at individual level (Arce and Long, 1993). International discourse is not homogenous and, thus, policy interactions cannot be seen as the product of a reified, top-down discourse. They must be understood as the product of a dynamic interplay between conscious living subjects, with considerable agency, who actively contribute to, and are part of creating, the discourse 'interface' (Long, 1992) and direct the impact of this discourse on ground level.

### 5.4 Dominant Discourses...

Over the last 50 years the emphasis of dominant leprosy discourse has shifted, in response to pharmacological advances and wider discourses, from seeing leprosy primarily as a disease, to conceptualising it as a health issue, to perspectives which see leprosy as an expression of development. Having established that

leprosy policy is intimately connected to international and national discourses, let's look in some more detail at exactly what these discursive shifts have entailed for leprosy policy.

Practical considerations for service provision aside, changes in policy imply a fundamental change in the way leprosy is viewed within the public health framework, with a shift in discourse from care, to control, to empowerment. The impact of such a shift goes far beyond treatment protocols and working conditions, and affected the way leprosy as a disease is perceived and the way that persons affected by leprosy are viewed, not as patients but partners in their own care. As outlined in the diagram below (see *Figure 11.*) these discursive shift are a continuous process.

At the time of the founding of the organisation in 1989, the focus was very much on prompt treatment and control. Let's call this *Phase I.* In this discourse, leprosy is seen primarily as a bio-medical problem to be treated through bio-medical means. A cure, in the form of MDT, has just become available and the priority is on identifying and treating as many cases as possible to limit the spread of the disease and, ultimately, to eliminate leprosy as a public health problem. The focus is on service provision in the form of pharmaceutical treatment, ulcer care and physical therapy to prevent disabilities. The service structure is extremely vertical and the leprosy workers work in relative independence from other parts of the health system, with a singular focus and priority. The services provided are unidirectional, service is provided by organisations and institutions to persons affected by leprosy with little or no involvement of the leprosy affected persons themselves in the process. One of the health workers described the process of ulcer care in the early days in these words:

> *"Previously...what in ulcer dressing.....we will do ulcer dressing. He will sleep like this* [showing head hanging back and making snoring sounds]. *He will give foot like this* [sticking foot out], *we will do ulcer dressing, he will....sleep. He leg is ours. (...) Now we changed. Self care. What we are doing, you see.(...) You see, you can do. Twice or trice or trice. Then afterwards he will take care. Previously we are not like this [laughs]. Not thinking. We are not thinking. (...)Just little bit of conversation we have to use. We can change our ways, like this. Our duty, what we can do, we have*

*to do ulcer dressing. Patient where he have to see? He reading, he sleeping, no problem. What our duty? We have to clean ulcer. But now a day's changed. What changed? The patient also see, patient also participate in this, patient also think himself: why it came ulcer?"*

Such passive receiving of services by people affected by leprosy also meant that the power balance in the relationship was heavily skewed in favour of the professional health workers. The health workers understood themselves as in possession of the 'answers' and as tasked with the job of applying these 'answers', these 'correct practices' as effectively as possible. As the emphasis was on direct service provision and active case detection the organisational structure was 'bottom heavy', in that it must rely on a large core of field-level operatives and health workers to provide services with merely a handful of supervising staff to coordinate these efforts. In the minds of the health workers I worked with, life was simple and their tasks clearly delineated.

However, as leprosy prevalence fell, a new approach was needed. Let's call this *Phase II*. At this point NLEP introduced the NLEP II strategy, detailing the decentralisation and integration of leprosy services. NGOs faced dwindling funding for leprosy work and started diversifying their activities to include other infectious diseases and health problems. International leprosy policy was starting to recognise that persons affected by leprosy faced a number of challenges that extend beyond bio-medical complications and the need to include social and economic rehabilitation strategies into leprosy services was recognised and embraced. At this point, leprosy was no longer seen merely as a disease, but had become a health issue. Integration of services into the general health system stressed the need for sustainability of leprosy services post-elimination and the role of the field-level health workers now becomes primarily one of facilitation, training and support of general health service staff, at least in theory. The dismantling of the vertical service system meant that the work of health workers was no longer independent of other health services but necessitated close cooperation with other service providers, both public and private. As activities diversified, the work of health workers was no longer simply about leprosy but, rather, a multifaceted approach targeting issues relating to community health and other infectious

diseases such as HIV/AIDS, TB and malaria. Interestingly, the shift in focus and diversification of services was prompted and reinforced internally in ULP by the specific requirements and needs of an external donor, the European Commission (EC), who is of course intricately connected to the shifting trends in international development discourse. The focus on sustainability also affected the kind of services provided. It was no longer enough merely to provide ulcer care but, as described above, the emphasis was now on teaching persons affected by leprosy how to care for their ulcers themselves. Active case finding was discontinued and the task of health workers shifted to health education and community awareness to promote voluntary reporting of cases. This entailed a shift in the power dynamic between provider and service user, and a shift in the position of leprosy affected persons within the organisation. As service provision developed into a more collaborative and inclusive process, the participation of persons affected by leprosy, and other clients, became more important to achieving a successful outcome. It was no longer enough to provide passive ulcer care to the sleeping service user. Instead, ulcer care developed into a collaborative process where the client would be asked to reflect on how they got this ulcer in the first place, how they could avoid such situations in the future and how they could care for their own ulcers at home. The 'answers' were no longer universal or simple, nor were they the sole property of the health workers but must be created through interactions with the individual service user.

Though there were now fewer leprosy affected persons to care for, the nature of the services provided required a higher time investment per case, so, field-level health workers were still in high demand. However, the diversification of activities within the organisation meant that there was a growing demand for supervisors and administrators of other projects, thus, the middle and senior management of the organisation necessarily grew to fill this gap and the organisation's human resource structure became less 'bottom-heavy', and the role of field-level staff less crucial to the organisation's operations overall.

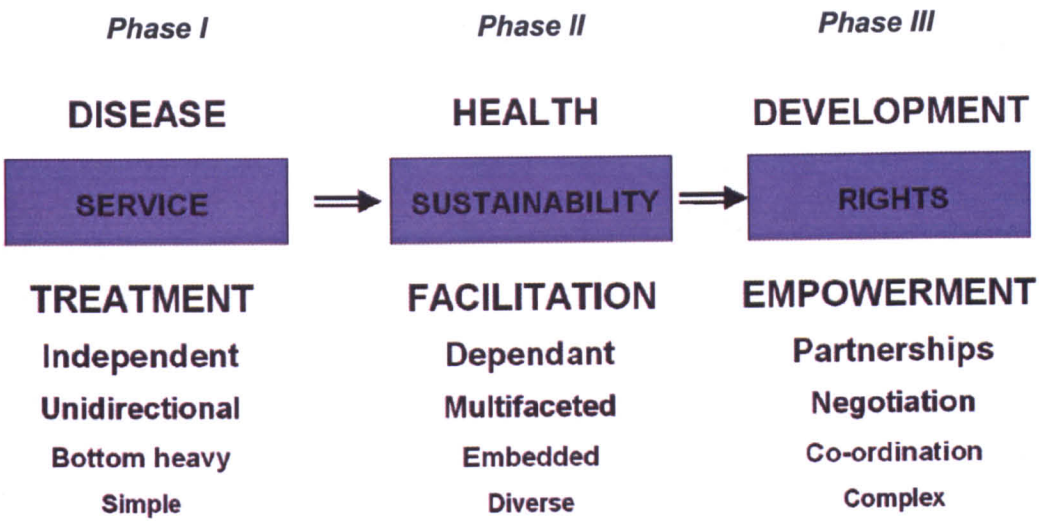



*Figure 11.* Trends in international leprosy policy

Lastly, the exposure to other discourses and other types of projects, especially HIV/AIDS related work, changed the way that traditional leprosy organisations think about interventions and the role of service users in these interventions. Let's call this *Phase III*. Though this is an emergent discourse within leprosy organisations, one that is by no means present in all organisations and certainly not yet present in national policy, it is nevertheless proving to have a profound impact on organisations working in today's policy climate. HIV/AIDS interventions, as a result of the strong and long-standing involvement of civil society and patient lobby groups, have a very different nature and tone than other disease policies. It is a policy that stresses the importance of involving service users in their own care, one that stresses the need for empowerment and the human rights of clients, and one that potentially transforms the role of leprosy organisations from service provider to enabler. The debate is no longer of disease or health, but of development, of either the individual or on a national scale. Indeed, the organisation I worked with describes itself as a health and development NGO.

This new policy framework calls for complex interventions provided in partnership, and driven by, the service users themselves. It is a framework where the professional providers attempt to consciously relinquish power and take on the role

of coordinator rather than provider, and as such the role of health workers in the professional employ of the organisation is less relevant. The human resources needed in this type of framework are project coordinators and administration staff to manage, supervise and support implementation, as it is carried out by the clients and target populations themselves. Thus, the organisation's staffing structure becomes 'top-heavy' and health workers must be dismissed or, if they have the requisite skills, absorbed into these new roles. For an organisation like ILO, with very close links to funding organisations in the UK or elsewhere, the emphasis on 'development' in their internal discourse is revealing. It is questionable just how relevant this emphasis on development is in the context of an NGO dealing primarily with tangible health and poverty related issues in the field. Though their activities clearly have a development impact down the line, this is hardly the framework that staff would choose to describe their activities. It is, however, a fundamental component of international policy discourse which is highly useful for policy discussions and fundraising activities and has, thus, taken on new meaning in Indian NGOs. Locally, development is a nice side effect of the practical interventions planned, for the attached international organisation it can be seen to be the underlying agenda. This confusion risks confounding interventions, where development becomes the means and the goal, the method and the outcome, of the process.

These three *phases* must not be understood as mutually exclusive, or even as distinct, stages in a linear development. Indeed, they all co-exist in the field activities of leprosy organisations and in the intentions of leprosy policy. Successful leprosy policy strategies must encompass the capacities of all three. Just because the human rights and empowerment of clients has entered the agenda, this does not mean that the issue of care can be ignored. Future strategies will need to balance these priorities without creating a hierarchical relationship between them. For organisations and health systems the danger is that discourse is not communicated effectively throughout their structure, thereby potentially creating a schism between different types of interventions or different operational levels, thus inadvertently crippling the system's ability to effectively plan and implement service delivery with a unified vision and intended outcomes. Any successful strategy must

represent a balanced mix between all these different aspects; it is merely a question of timely and appropriate emphasis. These organisational issues will be discussed in detail in later chapters.

For leprosy services to move into the future, new policies must aim to retain the expertise of the past whilst embracing the partnerships and priorities of the future. Leprosy organisations must be ready and able to implement a range of different projects; some of them with a clear service provision focus and others with more of an enabler focus, without becoming fragmented within themselves. An organisation's ability to survive over time will depend on its ability to adapt to changing environments and new conditions. However, the organisation's ability to effectively respond to these depends on its ability to create a unified vision of its goals. As I will attempt to demonstrate below, this united vision is intimately connected with the influence of international discourse, despite an undeniably local flavour.

### 5.5 ... and Emotive Narratives

Discourses are lofty ideals, broad trends and general directions. But how does discourse become a narrative with emotive power to drive and motivate the work of organisations and ground level workers?

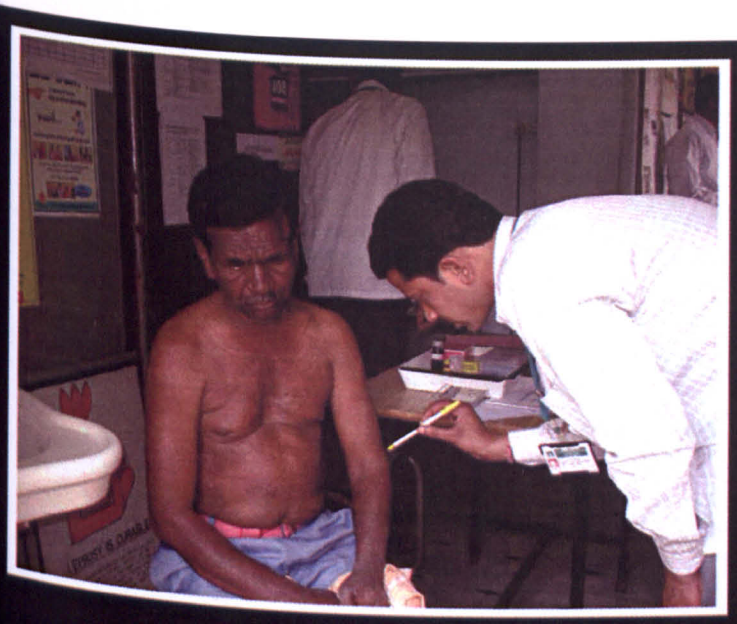
To understand the impact of narratives we must understand how discourses and narratives differ, in that "discourses relate to modes of thought, values and fundamental approaches to issues, whereas narratives define an approach to a specific development problem" (Sutton, 1999:14). Narratives are stories, simplifications of complex and fragmented issues into coherent and structured narratives with a clearly defined problem, a course of action and a desired outcome. Famous examples of development narratives which hold tremendous power, in the minds of practitioners and the general public alike, are those surrounding the 'tragedy of the commons' and the 'doomsday scenario', each distilling vastly complex issues into causative narratives.

The development of policy, and the prediction of outcomes as a result of this policy, is "a genuinely uncertain activity, and one of the principal ways practitioners, bureaucrats and policy makers articulate and make sense of this uncertainty is to tell stories or scenarios that simplify the ambiguity" (Roe, 1991). Leprosy elimination can be seen as one such narrative. The epidemiological variables of leprosy are so complex that even epidemiologists struggle to understand exactly how they work. So, a somewhat 'arbitrary' threshold was selected and an 'elimination' target set. Anchored on an axiomatic belief in the power of MDT, a narrative was hastily spun, a narrative that painted a future free of leprosy and served to motivate leprosy field workers for 20 years. However, listening to the discussions at the 17th International Leprosy Conference, it is becoming increasingly apparent that this narrative might have outlived its usefulness. It is becoming clear that we do not have all the answer when it comes to leprosy. As a matter of fact, most of the evidence suggests that the strategy which has been applied for the last 20 years is now outmoded. To free leprosy policy from its history and move forward into a new era of leprosy care, it will be necessary to free leprosy policy from the constraints of this narrative and to construct a new and more creative approach to leprosy policy and interventions. However, this might be easier said than done.

Narratives exist for a reason. We create them because they are, as the anthropologist Claude Lévi-Strauss would have phrased it, "*good to think with*" (Levi-Strauss, 1968). They have the power to transform abstract discourses into tangible solutions, and have the power to motivate, rally and inspire those who work within the field. It is these narratives which become key components in the social identity of health workers, and can help us understand why it is that health workers are so invested in the structure they work within. Narratives easily become tenets of faith, and these tenets of faith denote a shared moral universe. For the health workers, embedded as they are in this discourse through their work-narrative, the 'discourse-narrative' comes to take on an important role in defining and reinforcing their *habitus* on the ground. It defines the older health workers as a group and sets them apart from recent arrivals, who they feel do not 'understand' leprosy work or have the 'right' attitude. It also sets them apart from higher

management who have already successfully updated their narratives in accordance with more recent shifts in leprosy discourse. Discourse sets the tone for policy but, on the ground, something more pragmatic is needed. So discourse is transformed into narrative to provide an emotive 'hook' on the basis of which a 'right' answer can be determined and uncontroversial, ethically justified, actions taken. This narrative becomes an intimate part of an organisation's and a workforce's own narrative. It is not merely a question of how they connect with leprosy policy but, equally, a question of how they ascribe meaning to their social identity and work-narrative. Clearly, these are incredibly powerful structures, both at international and hyper-local level and, by investigating these linkages, it becomes clear that not only are discourses instrumental in shaping policy, they are also key to the construction of the organisational culture of leprosy organisations and the self-image of those who work in the field.

Having drummed up religious fervour around a narrative for over 20 years, it can prove difficult, though not impossible, to change the mindset of leprosy organisations and the field-level staff. The leprosy narrative has changed before, with the introduction of MDT, and it can be changed again. However, in order to achieve this, we must first fully understand the narrative's components, the structural arc and the pivotal role of each of the main characters involved. For, in order to achieve a successful transition from the current leprosy policy environment into a new and appropriate narrative for the future of leprosy care and control, the effective components and insights of the existing narrative must be transferred and carried over into the replacement narrative. As will be discussed later, the health workers currently continue to justify their actions in terms of a nostalgic narrative which is firmly anchored in the elimination narrative into which they were trained or indoctrinated. However, this narrative no longer speaks the 'right' language or thinks the 'right' way in relation to the dominant discourse of the organisation and, as such, the narrative has become a counterproductive driver for creative action at field-level.



NOT GIVES LEPROSY COMPLETELY
NOT AVAILABLE FREELY AT ALL
DON'T HOSPITALS OPEN ALL DAYS.
DISTRICT LEPROSY SOCIETY,
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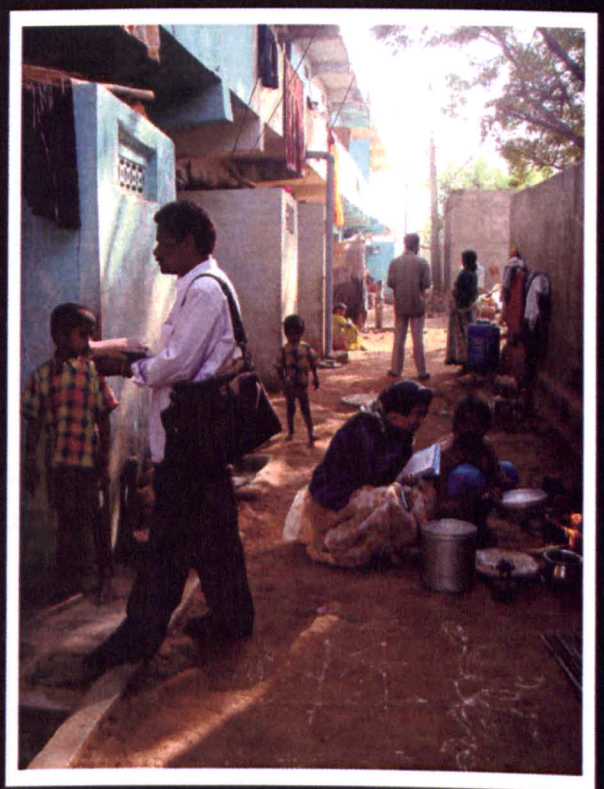

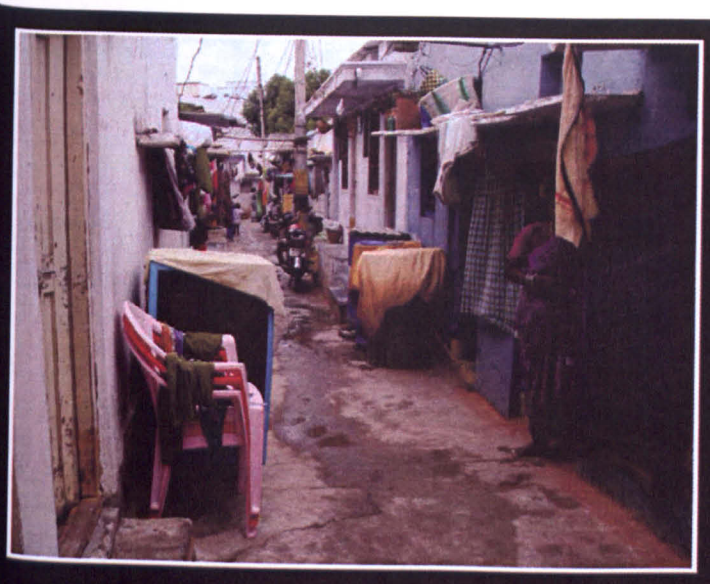

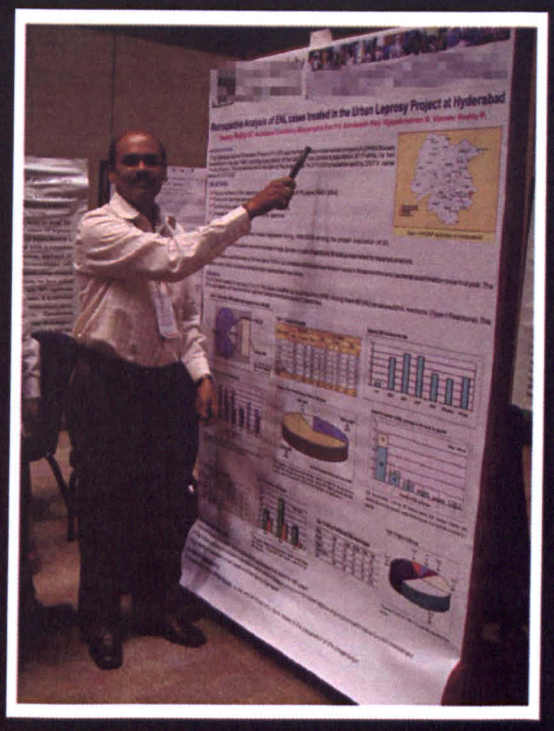
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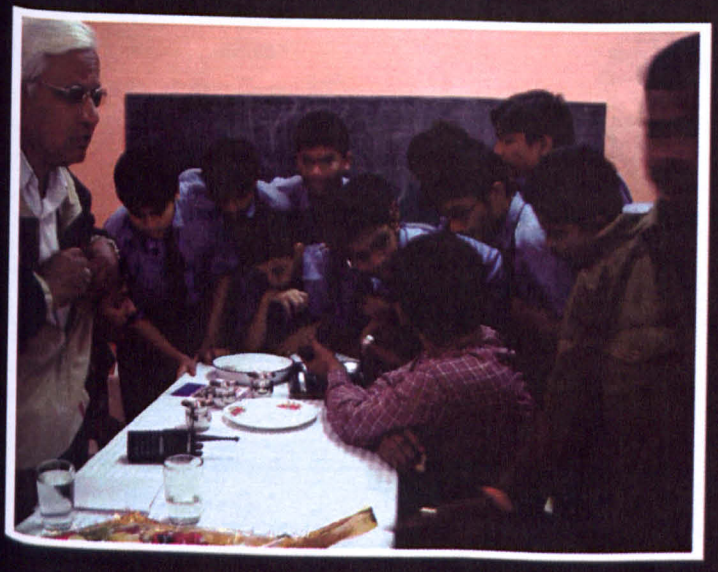

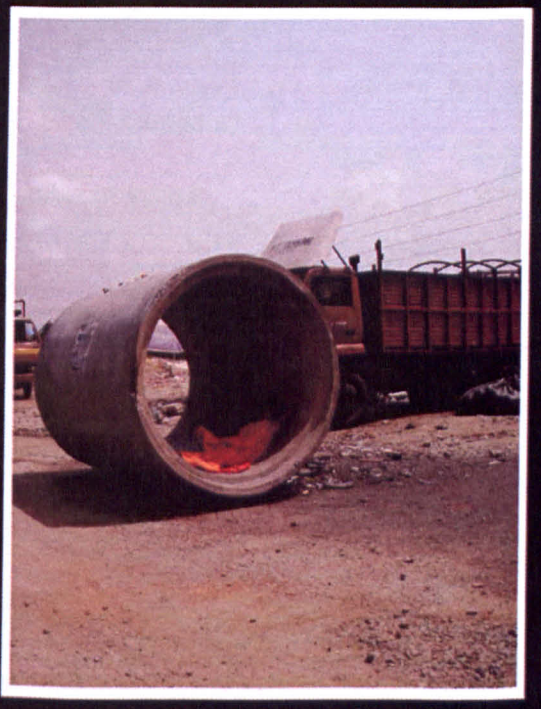

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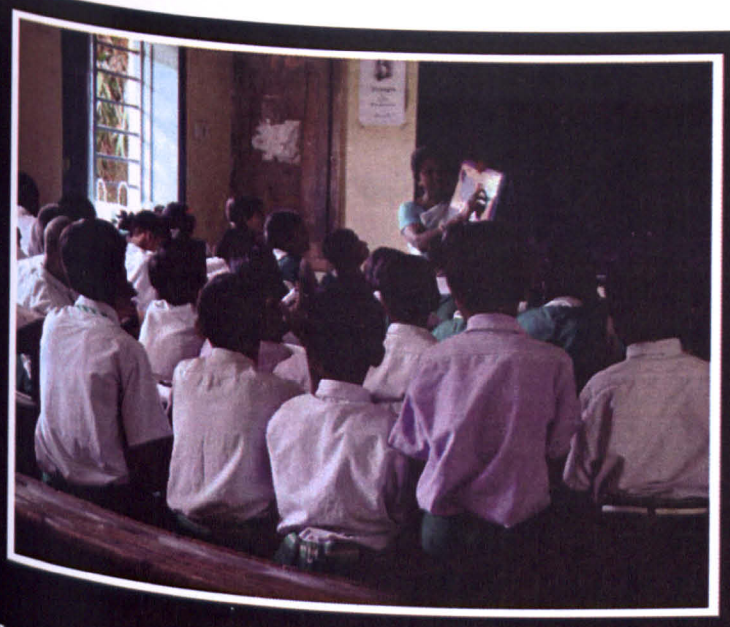

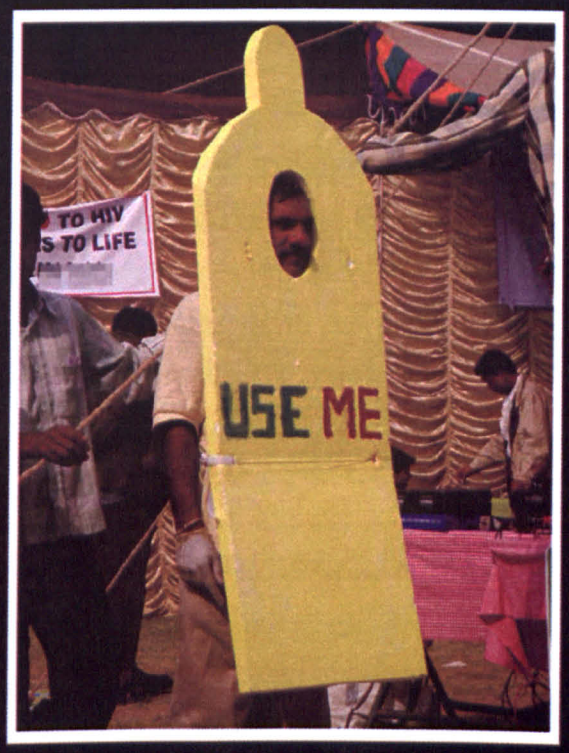
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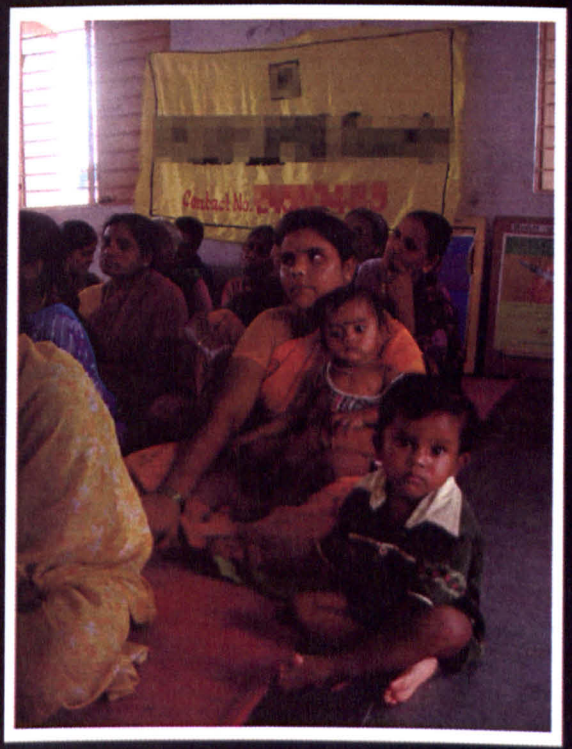
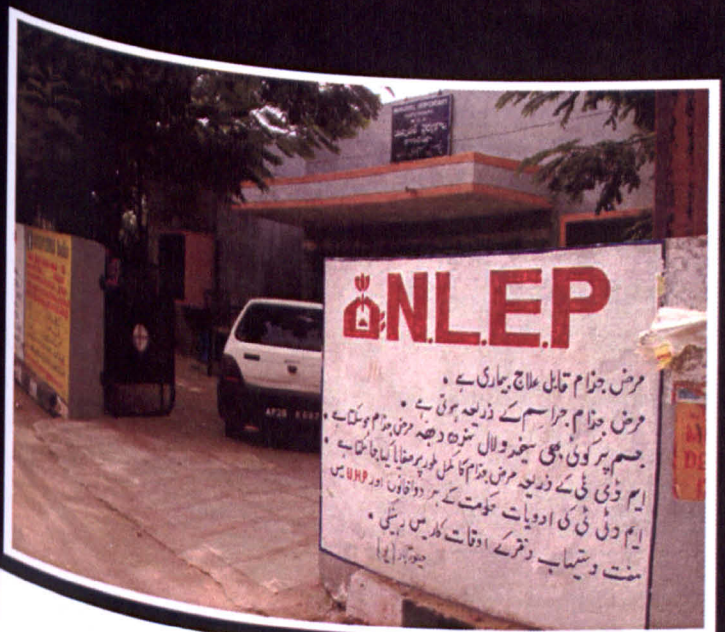



N.L.E.P
مرض جذام قابل علاج بیماری ہے ۔
مرض جذام جراثیم کے ذریعہ ہوتی ہے ۔
جسم پر کوئی بھی سفید و لال سنن دھبہ مرض جذام ہوسکتا ہے ۔
ایم ڈی ٹی کے ذریعہ مرض جذام کا مکمل طور پر علاج کیا جاسکتا ہے ۔
ایم ڈی ٹی کی ادویات حکومت کے ہر دواخانوں اور UHP میں
مفت دستیاب دفتر کے اوقات کار میں رہیگی ۔

# 6. Social Identity and Restructuring - Health Worker Role in a Changing Policy Landscape

There is a strong sense of change amongst the health workers. A sense of that which their world was in the past, a world they very much still feel part of, and that which it is about to become, a becoming which most do not approve of though some do recognise the need for. Change is all around, in the air, in working practices, in social identity, in organisational values. As discussed in the previous chapter, recent changes in leprosy policy have had immediate impacts on the social meaning of leprosy, the contextualisation of the disease and those affected by it. In addition, the changes affect leprosy organisations and their modes of operation and identity as they restructure their services.

Eric Silla's analysis of leprosy in Mali has demonstrated the extent to which wider social and policy change affect the lives of people affected by leprosy, both directly and indirectly (Silla, 1998). In addition, these changes also affect leprosy organisations (Porter et al., 2002) and the people who work for them. However, little attention has been paid to the role of the staff and how policy change has affected their lives and their sense of social identity. Beyond the obvious impact on procedures and routines, these changes have had an impact on how health workers perceive their role in relation to local communities (Yallop et al., 2002) and to the larger organisation.

## 6.1 The Times They Are A-Changin'

For the health workers, the change in policy that followed the fall in leprosy prevalence involved a profound change in their daily working routines, and even a change in their designation. Between 1989 and 2002, ULP's main priority area to carry out was leprosy work as agents of NLEP. For the health workers, then with the designation Non-Medical Assistants (NMAs), this meant a focus on survey, education and treatment (SET), where the onus was on maximum coverage of the

population and their days were primarily spent conducting door-to-door surveys throughout their project area.

As the health workers themselves describe it, their day would usually start around 5 in the morning when they would head out on bicycles, often meeting up along the way, to whatever area they were covering that particular day. As the project area was vast, this would often involve a 20 kilometre bike ride. They would then meet up at a designated spot at 6 o'clock. Survey work was carried out in a group, with one person announcing their arrival and their intentions with the aid of a megaphone and the rest, working in pairs of one male and one female NMA, going from door to door to examine each member of each household, charting any suspected cases and providing information about leprosy to the group of onlookers who would invariably gather to see what all the commotion was about. As the prevalence rate was still relatively high in the city, and the charting of an actual case took considerably longer than the mere collection of household data, the team would not work to a specific target but, would cover as many households as possible before 12 o'clock, usually around 200.

At the time, there were 16 NMA and 4 supervisors working in 16 sectors. With a high prevalence rate and a large back-log of cases each, NMA would be responsible for as many as 100 active cases at any given time. Treatment was provided at Drug Delivery Points (DDP) around the city at a specific day of the month. In total there were 16 DDPs, one for each sector. Even though these DDPs are now defunct one can still see their tell-tale murals on the walls of community centres and other buildings around the city. It was each individual NMAs responsibility to 'motivate' their patients to come to the DDP at the specified time and day to collect their treatment. In the days before mobile phones, this usually meant going to each individual patient's home the day before, or on the morning of, the designated day to remind them that they had to come and pick up their medication. With all the patients gathered in one spot to receive treatment, the medical officer and supervisor would drive over in the project's jeep with medication and other supplies. If someone neglected to show up, the NMA would have to go to their house the next day to enquire about the reason for their

absence, to reprimand them and to provide treatment. Since each NMA was holding such a high number of cases, the health workers told me they would usually partner up with an NMA from a neighbouring sector, in order to be able to cover all their patients in a day, and then repay the favour to the neighbouring NMA when it came to their DDP day.

In addition to monthly drug delivery, it would also be the NMAs responsibility to ensure that medication was taken by patients. As MDT is supplied in one month 'pulses', the NMAs would conduct spot checks in the form of pill counting when they visited people's houses and, if in doubt about the adherence of a particular patient, they would conduct urine tests to confirm the presence or absence of the drugs in their system. The NMAs were also responsible for ulcer care and prevention of disability (PoD) activities. The majority of these activities would be carried out in the Out Patient (OP) clinic conducted in the afternoon at the main project offices. After completing the day's surveying activities at 12 o'clock the NMAs would have a break in the middle of the day with OP duties commencing at 2:30. Officially the OP opening hours were from 2:30 to 5 o'clock but, according to the recollections of the NMAs, this was rarely the case and they usually found themselves working in the office until 6 or 7 o'clock at night. In addition, ULP covered such a large area, it was not always possible for patients to come to the OP clinic, and thus ulcer care and PoD activities often had to be carried out in individual patients' houses.

In 2002 ULP took on a project funded by the European Commission which aimed to help achieve leprosy elimination through the continued support of government interventions. However, in addition to fulfilling government guidelines, the intentions of the 5-year EC-funded project go beyond disease specific approaches and aim to strengthen the general health system through a dual strategy. Firstly, by increasing health system uptake through intensive IEC campaigns and instigation of health forums in slum areas. Secondly, by strengthening health system responsiveness to service users through training programmes and technical support to general health staff and private medical practitioners (PMPs) in situ. As part of this, the health workers continue to support the 26 UHPs in their project

area. This also diversified the organisation's remit to include a focus on HIV/AIDS, eye care, malaria and other allied diseases.

With changes in international and national leprosy policy, health workers' working practices have changed drastically over the last decade. ILO works in close co-operation with the Indian government and most of their activities are aimed at supporting existing national initiatives, though they also run independent projects. As a result, most of the daily activities of the health workers are structured according to NLEP, the Revised National Tuberculosis Control Programme's (RNTCP) and the National Aids Control Organisation's (NACO) National Aids Control Programme's (NACP) national guidelines. These frameworks proscribe strict protocols for the disease specific strategies which frame the everyday working practices of the health workers, with respect to direct handling of records and case handling of patients. As these protocols change, so does the working practices of the ULP health workers.

As part of the integration of leprosy services into the general health services, all active case finding activities ceased in 2003, thereby removing the primary activity of the health workers' past work, the survey, from their daily schedule. Rather than working in groups to identify active leprosy cases all over the city, the health workers were now responsible for supporting the totality of leprosy services in their designated areas, as well as providing health information on tuberculosis, HIV/AIDS and malaria to the community. The number of health workers shrunk from 16 to 9, with each health worker now responsible for 2-5 UHPs, or a population somewhere between 100,000 and 300,000, spread over a large geographical area. When I asked one of the managers in the organisation what they thought were the greatest challenges facing the health workers today, aside from the lack of funding, this is the answer he/she gave:

"*ULP Staff:* *Biggest challenge is coping with the work itself, because here...when we taken them in the beginning of the project we have taken for them: 'you do this job'. So many slums you look after. But a certain stage comes when there are so many, so much of work also. Now the person who was looking after 2 or 3 UHPs is looking after 5 or 6 UHPs. Work-wise also. So there is a dual type of pressure, not only physical and*

*mental. And they are coping with it. No one says 'no, I won't do it' or 'I can't do it'. Maybe because they know...(...) Difficult. That the situation is so... that those who can't do they can go. That feeling comes. So, for them I feel bad. In a sense not only we are mentally torturing them but are pushing them to the wall. Like 'you do it, or you don't do it'. But I am doing it...it never happened in... maybe it is because NGO culture is like that? Or the people themselves are like that? Or ULP staff are like that. Never, never I have heard them say 'I can't do this. I won't do this. This is too much for me'. No one has said till now. That is the greatest thing which...I think most of them are like that. They put in a lot of time...eh...they don't say, even at 6 o'clock we say now some report has to go...they will sit. Whether it is NMA or supervisor or anyone, they will sit and complete the job. So, that way they are very willing workers... or it could be willing workers or... Now situation and even before also! When everything was in sync. Except a few people are there, one or two you can count on fingers, the others you can ask to sit after duty also. Anytime. They will sit.*

*Interviewer:* *Organisation is like home. Of course now it is also, like you said, a question of proving*

*ULP Staff:* *Proving themselves. Who works hard and...*

*Interviewer:* *It becomes a competition...?*

*ULP Staff:* *Mmh. It is a very sad thing. It is not that...they have nothing to prove actually if you ask me. They have already proved themselves but still...it is so difference working in an NGO organisation and working in the government. Government they have nothing to prove. Everybody get the salary and go."*

The project timings were changed to reflect the new working reality and health workers were now expected to work 'normal office hours' from 9 to 5:30. From 9:00 to 13:00 they work individually in the field carrying out a variety of activities in their designated areas, ranging from home visits, community awareness programmes and setting up health forums, to health education in schools and weekly clinics at their UHPs. The nature of this work will be discussed at length in the next chapter.

From 14:30 to 17:00 the health workers work in the OP covering 4 positions on a rotational basis; reception, body charting, ulcer care, and PoD duties. The two health workers who work as counsellors in HIV projects do not participate in OP duties. The health workers assigned to reception duty receive patients as they arrive at the project offices, evaluate their problem and refer them on to more specialized services within the building. The health workers assigned to body

charting duty are responsible for the evaluation of suspected leprosy cases by visual body surveying, sensitivity tests of any suspicious patches and palpation of nerves to check for possible nerve involvement. In the case of a positive diagnosis for leprosy, the health worker will carry out detailed body charting, drawing any patches of hypo- or hyper pigmentation, as well as anaesthetic patches, on a body chart for future reference. Due to the intimate nature of body charting there must be a male and female health worker available to carry out these duties at all times. The health worker in charge of PoD will carry out three monthly follow-up assessments, provide coaching for rehabilitation exercises and refer any problematic cases on to the physiotherapist for specific treatment. For ulcer care duties the health workers clean, treat and bandage ulcers as well as engage the patients in counselling regarding self-care practices and engaging the person affected by leprosy in identifying the origin of the ulcer. Each health worker performs these duties on a weekly rotational schedule.

During weeks when they have no designated OP duty, or during downtimes in their OP activities, the health workers withdraw to their office on the third floor to complete their paperwork and monthly reporting duties. In addition, the health workers will see any patient from their area that turns up with concerns or problems, for counselling, for help with social and economic rehabilitation or other less specific problems.

In addition to these duties, one night a week, from 17:00 to 21:00, each health worker is responsible for carrying out IEC van shows in the slums and encroachments of their area. The IEC van is a modernised van with a mounted LCD projector and a screen, on which the health workers show films about leprosy, HIV and TB, interspersed with popular film clips and Telugu songs to gain and retain the interest of the audience.

## 6.2 From 'Dr. Patches' to 'Jack of all trades'

Changes in policy and epidemiology have driven the changes in working practices described above. However, these practical changes to the everyday working reality of the health workers also resulted in a fundamental change in their relationship with local communities. As described above, diversification of working practices at the start of the EC project coincided with the NLEP push to integrate leprosy into the general health services and, thus, entailed a total restructuring of the health worker's working practices, as well as a change in designation from NMAs to Community Health Organisers (CHOs).

As their activities diversified it also entailed a change in the way that the community perceived them; as they were no longer merely doing leprosy services, they went from being 'Dr. Patches' to being seen as multi-purpose health workers. Of course, this change did not happen overnight and some community members refer to them as leprosy workers to this day. With such strong presence in the community and such a specific focus on leprosy, the NMAs became known in their area as the 'matchalu doctor' ('Patches doctors'). As part of the previous order of things, a visit from one of the NMAs would be seen by the community as confirmation that someone in that household had leprosy and, with the disease still highly stigmatised, this meant that the NMAs would need to be cautious about how they approached individuals in their own homes. However, after 5 years of diversified activities, this association is slowly fading and the health workers are increasingly seen as 'resource persons'. This change has had a profound effect on their patterns of interaction with the community; I will discuss this in depth in Chapter 7.

The changing nature of the health worker's presence and work in the community has led to a redefinition of their relationship with the community, as they have gone from being leprosy workers to being 'total health workers', from 'Dr. Patches' to 'Jack of all trades'. As a result of this change in perception, and of their physical presence in the community, the health workers are approached by the community to fix any problem and to answer any question. Some of the health workers felt that

the breakaway from a strongly recognised national programme like NLEP, which is instantly recognisable to everyone in the community, entailed a loss of 'official authority'. However, on the other hand the move away from being 'only' leprosy workers increased their remit and, therefore, their standing within the community. Diversification of activities may have changed how the community see health workers but, in turn, it also impacted on how they see themselves. New training and new tasks was seen as an increase in status as exemplified by the fact that their change in designation was often referred to by the health workers as a promotion. Though they may have improved their standing with local communities they simultaneously feel that their standing within their own organisation has been greatly reduced.

### 6.3 From Pillars to Millstones

### - Health Workers and their Organisation.

These changes affected not only the health workers relationship with the community but, also, how they understand themselves and their role within the organisation. The changing role of field-level health workers, or specifically 'leprosy workers', in the organisation can be seen concretely in the human resources staffing structure but can also be deduced from organisational discourse. From the point of view of the health workers, this entailed a loss of status, for them and for their work.

The health workers strong association with leprosy and leprosy discourse means that their perceived role within the organisation is very much tied in with that of leprosy activities. Even though the health workers have willingly taken up new challenges, learnt new skills and adapted to new working practices, they are still seen, and primarily see themselves, as leprosy workers. For the health workers themselves, this is a designation of honour, connoting past achievements rather than limiting future possibilities. However, they feel that newly appointed senior staff, with little experience of the field or of leprosy work, are *"thinking leprosy worker is leprosy worker. He has to die with that designation."* Thereby, their

association with leprosy becomes not a badge of past achievement but a limiting factor for future deployment.

The reduction in leprosy prevalence and the diversification of ILO's activities has naturally led to less investment in leprosy services throughout the organisation. As funding for, and interest in leprosy activities fall, the health workers feel that this is disproportionately affecting 'leprosy staff'. *"Now in ILO those who are working...those who are doing working in leprosy field they are suffering now"* and this is, in turn, making their future uncertain. Though the rhetoric of ILO still places leprosy at the core of its activities this statement fits poorly with the reality of the actual work carried out, as funds are now coming in primarily for HIV, TB and community health projects. For the health workers this means that their work no longer forms the cornerstone of the organisation's activities.

In addition to falling funding there has, as will be discussed in Chapter 9, been a restructuring of the organisation's human resources; in the early years there were 25 odd staff at ULP and merely a handful at Head Office. Now that the operations have expanded and the organisation has taken up new projects, in Andhra Pradesh and around the country, the staff in Head Office have ballooned and two regional offices have been set up to support the new projects. This change in human resources has also entailed a change in the organisation's pay structure. ILO has traditionally had a relatively horizontal pay structure and staff salaries have been strongly linked to staff seniority, with pay increases awarded incrementally according to the number of years of service. This means, as most of the staff at ULP have been with the organisation for more than 10 years, that the health workers are relatively 'expensive' and have come to be seen as an unsustainable in their current capacity.

As the organisation's activities are diversified, there is a feeling among some of the staff that the focus on leprosy, and dedication to leprosy services, is being withdrawn just as they have the finishing line in sight. There is a deep-seated fear that, without sustained effort, we might see a resurgence of leprosy in the future and that 20 years of hard work will be wasted. As expressed by one CHO:

*"I have spent my life to reduce, will eradicate the leprosy program. If we may not success in future – tomorrow like you researcher or even my junior or my daughter-in-law may ask: You worked in leprosy service to eradicate leprosy and you got two or three awards. What is the use? Now still some people are suffering with leprosy. So, they may ask. At that time I have to feel shame. "*

Most of the workers do not believe that the official numbers actually reflect what is truly going on in the city but, rather, are a reflection of what officials want to show to the world. As one CHO put it, rather harshly, *"I say, as one health worker, that the Indian government is deceiving the WHO. They want to be able to say that in my time this or that target, goal was met."* Hailing from so many years of active case finding it is natural that the health workers would be sceptical to the reliance on voluntary reporting, especially, they argue, for a disease which is determined by an absence of pain (assuming that pain is a primary motivator for seeking medical attention). They worry that 20 years of work will slip through their fingers and that negligence at this final stage in the programme will leave them not only without a future but, also, robbed of a past with a purpose.

There are indeed some worrying epidemiological indicators (see *Appendix 3*), but of more immediate concern is the effect this belief is having on morale on the ground and the extent to which the health workers see this as an expression of their own situation. In many ways, the role of the health workers was always to work towards their own extinction in the sense that, by eliminating leprosy they would also eliminate their jobs. The health workers frequently refer to how the organisation and its senior staff have told them that they are the 'pillars of the organisation', that their work is crucial for its success and that they, as fieldworkers, are the most important persons in the organisational structure. They feel that no one sees them in this light anymore. In their eyes, they have gone from being the 'pillars of the organisation', the heart and soul of its operation, to being seen as backward, old fashioned and redundant in the current policy landscape. They feel they have come to be seen as a millstone around the organisation's neck, too expensive, too reactionary and too dated for the future, through no fault of their own.

### 6.4 Stigma of Leprosy Work – New Men for a New World.

For years, there have been warnings of leprosy affected people being marginalised within leprosy organisations as these continue to incorporate work within new fields. However, so far, few have addressed the marginalisation of leprosy workers within these same organisations. This marginalisation is encountered primarily in two ways; when trying to access work outside the organisation and when their potential is evaluated within the organisation. The stigma against leprosy workers outside of leprosy organisation is not a new phenomenon and has been reported by many over the years (Yellapukar, 1987). However, the presence of stigma against leprosy staff within leprosy organisations themselves is rather a new phenomenon.

In addition to this stigma the leprosy workers now feel that they face an additional challenge brought on by ILO working so extensively in other fields. As they attempt to access employment in other organisations they have to contend not only with a prejudice against their past in leprosy work, but also the implication that their own organisation does not recognise their potential. Sitting in the office one afternoon I discussed this issue with one of the health workers:

> "Manoj talks about problems regarding finding a new job after ULP closes down. The monthly review meeting has just finished, and again they have been reminded that they might not have a job after December. Manoj says that one of his colleagues approached another NGO to find work but they said: *'Why have they put you out [meaning let you go]? ILO has so much money and so many projects. Why have they put you out? Because of some mistake you make, or some past mistake? Because of problem?'* Manoj says, *'they will say like that. If ILO has so many projects, why they have put you out?'* He argues that, *'if ILO close tomorrow, then OK. We have good reputation and good contacts. But ILO will not close, only us put out. How can we find work like this?'* Just then someone breaks (knocks over) one of the big water bottles and water rushes across the floor and creates a mini flood. I jump halfway out of my seat. Manoj quietly points to the spill and says *'ILO is becoming like that – broken"*

Essentially, his argument is that, if a leprosy organisation fails to see the capacities and potential of leprosy staff, how can other organisations be expected to? There has been great encouragement for field-level staff to develop their skills and

capacities in recent years, a challenge which has been taken up enthusiastically by most of the staff as they have pursued post-graduate degrees in sociology or psychology and diplomas in counselling, HIV or other related fields. However, despite this self-development, there is a lack of appreciation of their skills and capacities within the organisation. This is based, not on actual lack of capacity, but on the stigma attached to leprosy work and in a lack of understanding of the work and qualifications of field-level staff within the organisation.

In addition to this, the health workers feel that their experience from leprosy work is not seen as transferable by other organisations. So, when they apply for positions in organisation focusing on other diseases, they find that in the eyes of other organisations, their years of experience working with leprosy do not count. For, just as leprosy is still seen as a disease apart, so is their 'leprosy work' seen as separate. So, when their own organisation hires new people to work in their HIV projects and bypasses them they are made to feel that even within their own organisation leprosy and leprosy work is seen as separate, as different and is systematically undervalued. At the same time, the organisation keeps emphasising how leprosy work must remain at the core of the organisation and its identity. However, the organisation's actions speak of different priorities to the leprosy field staff. In the eyes of the health workers they are like foxes:

> *"People in ILO becoming like foxes. When EC people first came here they promised us increments and rewards. According to skills and our performance, after that they mingled with ILO peoples and they also became like foxes – showing one thing in front and another behind. So, now nothing happened. They have squeezed us. They have squeezed more than our capacity and more than our time. I am not angry but this happened. Now new people are coming (...) all of ILO is not bad, but some small part is bad and this will spread and spoil the whole milk, whole organisation, like cancer."*

The health workers dedication to leprosy discourse has left them inalienably associated with this discourse in the eyes of the organisation. As such, the very dedication that has served the organisation so well in the past, and that enabled the organisation to reach the leprosy elimination target, has now come to be seen as a hindrance to the future development of the organisation and its involvement in

new fields of intervention. Leprosy workers are frequently seen as backward and stuck in the ways of the past, unable to acquire new skills and attitudes appropriate for working in other fields or settings.

If organisations are to move beyond this conservative view, beyond the stigma that is presently attached to leprosy workers, and to be able to draw on the years of experience and invaluable insights that these health workers embody, they must find a way to understand how the experience the health workers embody can be relevant for new challenges. Even when these skills have been demonstrably acquired by 'leprosy workers', there seems to be a reluctance to consider their qualification when it comes to filling other positions within the organisation. This situation is probably not unique to ILO and discussions with senior management in the organisation and discussion with representatives from other organisations at the 17th International Leprosy Congress in February 2008 seems to indicate that this is an issue which permeates leprosy organisations around the world.

### 6.5 No Room in the House We Built...

Despite 10 years of service and extensive expertise, the health workers feel they have become the victims of the stigma of leprosy work, even within ILO. As a result, the health workers feel their skills and experiences are disregarded as 'leprosy work' and that there is a lack of appreciation by senior managers of what their work entails, due to manager's lack of field experience. As a result their capacities are systematically undervalued as new staff members are recruited to fill new positions, which older staff nevertheless feel they have the skills and capacities to perform. Scarcity of reporting on qualitative work further contributes to the invisibility of the actual work carried out at ground level and compounds this stigma.

This lack of insight means that perceptions of leprosy work are often based on prejudices which see the health workers' experience as pertinent only to leprosy work, and thus, not necessarily transferable to other public health fields. It could be

argued, that, in the face of such lack of insight there might be a natural reluctance to assign 'leprosy workers' to new fields; to giving up control and to place ones trust in the capacities of what are essentially unproven entities. However, the health workers argue, they are not unproven entities. Over the past 20 years the organisation has faced numerous challenges, in the form of external challenges, such as the communal riots in 1991, or new directions or challenges that the organisation has chosen to take on, such as tackling the leprosy problem in the Old City. The health workers emphasise that they have always faced up to these challenges, at great personal expense and risk, and have only ever brought glory to the organisation. In the word of one member of staff, they have always approached all their work for ILO as a challenge, so why should now be any different and why would the organisation turn to outsiders?

*"ULP Staff: But the change is we have so much of experience, field experience. Like that. Since 17 -18 years we are doing so much of work(...) But now a days they are coming some people, with no experience also they are getting good appraise. (...) Good...eh...recognition. But we are not like that. You are NMA, yes. There only. You stop there only. In between some...so many people, without any background, without any certificate without any experience. They are coming.....*

*Interviewer: From the outside?*

*ULP Staff: Yes. That is not good (...) There is no recognition for old staff (...) Not me. All staff. Their view...I know their view. What they are thinking. So many.... previously what did you work. 6 morning to evening night 9, up to 9. Such good work we done. That is why ILO recognised and they are giving so many projects. Previously there will be...eh... in Old City, very critical problem will be there. First they taken complicated part in the Old City. So many leprosy patients is there but nobody come forward to do work in Old City. Even government also. The prevalence is going, going up. At that time ILO will taken as a challenge. But they proved...eh...the programmes, the communications networking, leaders, doctors. First we came here...eh... we done one month evaluation programmes. Big, big programmes. We called to Basti leaders and we have to give some food, some lecture....eh....very good networking. That is why we grown up and they given projects in Orissa also* [another state in which ILO now works]. *We think, any time ILO, taken any work as a challenge. There is very big, huge number of patients. In concern time, there is communal direction previously, one....eh...in '91 near about 2000 people killed. [referring to the communal riots] At that time also we had to go to patient house. (...) Dangerous time also we went to patient house and in police escort and given treatment. Even 15 days, one week the patient not taken treatment is OK. But our work is....and you go and do this. At that time, while*

*walking also we have to see around. Anybody will come and stab? At that time also we done work."*

The perceived shift in health workers status within the organisation, from pillars to millstones, and the prevailing stigma towards leprosy work, has led the health workers to question their social identity. Their aim, as encoded in the organisation's mission statement, is to instil hope and dignity to those suffering from leprosy and related diseases. Now they ask, how can we instil hope and dignity in others when we ourselves have none? Though the health workers cast themselves as victims of circumstance, they are in fact an integral part of creating the very reality they object to, as they remain deeply committed to a hierarchical mindset.

This uncertainty surrounding social identity creates a feeling of insecurity on the ground. Dignity, hope, motivation and a sense of duty/calling are hard to maintain in an atmosphere where people feel that the project is unravelling around them. The issue of job security is on everyone's lips, and the lack of it is causing demoralisation among the ground level staff.

As a result of the organisation's success in leprosy elimination work and the reputation it built for itself through these efforts, it gained access to projects in other fields such as tuberculosis, malaria and HIV. Opportunities within these fields were largely given to new recruits. As funding for leprosy projects dwindles there is a feeling among staff in the more leprosy focused projects that there is no room for them in 'the house that they built'. The success of the leprosy interventions came off the back of their hard work yet now, that there is less leprosy work, they are facing redundancy at the same time as others benefit from their hard work by being given opportunities in new projects. The fieldworkers feel that promises of job security and reward for hard work in combating leprosy have been betrayed.

ULP was ILO's first direct project in India. All funding is provided on a project to project basis and ULP is merely one of many though, as the first, it has a special place in the heart of many in the organisation. So, when the funding runs out in December 2007, the project may be closed whilst the organisation as a whole

remains. For the staff at ULP, this is hard to accept as they see their association as primarily with the organisation, rather than the project per se. They consider themselves 'ILO family members' not 'ULP staff', as expressed by one of the health workers during our focus group discussion:

*"CHO: ...we are ILO family members!*

*Facilitator: Yes, but ILO is different. As in...projects. Projects are funded. You get funding for a project, not for organisation. So organisation, if it gets funding to run [a HIV] project it cannot just take that money and say...*

*CHO: This is not [a HIV project]. This is 'mother project' for ILO.*

*Facilitator: Yes. But if ILO does not have any funding....*

*CHO: In that, madam, we work not for ULP. We work for ILO, in total! We all have written project reports and planning and everything. Even we are co-operating and supporting some new initiative projects also."*

The field workers face severe cuts in jobs and, judging by the experience of those who have been let go so far, there is little room for re-absorption into the organisations other projects. The health workers feel that *"once funds is completed all staff has to go. Whether it is the director and sweeper...till now all has to go, close the organisation."* However, the organisation continues to expand into new fields and, in the health workers opinion, the immediate negative impact is felt primarily, and disproportionately, by leprosy staff.

### 6.6 The Room to Roam – The World of Health Workers

It is not just that the health workers do not feel that there is no room for them in the organisation's future, they also occupy marginal space within the physical structures of the project offices. The corporeal significance of the health workers position in the field, and their nostalgic reaffirmation of their connection with communities and patients, serves to establish them at the forefront of the health provision frontier. It also serves to place them at a privileged position in order to gain access to the perceived worlds and desires of their clients, to achieve the rapport necessary to provide the level of service they deem necessary in order to achieve 'social service' alongside the concrete services encoded in targets and

evaluations. However, this attachment to the physical space of clients, rather than the power structures in the organisation, also places them at a remove from access to higher positions of influence.

The marginalisation that the CHOs feel within the organisational hierarchy, and their attachment to client interactions, can also be seen subtly expressed in the physical layout of the project offices where the health workers primarily occupy the same areas as clients. In the three story building the health workers occupy the top and bottom floors (see *Figure 12.*). At ground level, providing services to clients in the form of outpatient treatment, and in their assigned room on the second floor, filling in paper work or seeing clients. On the ground floor, they perform a form of service triage, essentially functioning as gate keepers, assessing patients at the reception desk and then passing them on to more specialised care, provided by more senior or specialised staff deeper within the building. As the project has recently moved offices, I have no direct knowledge of how the physical dynamics of the project offices were prior to the move. However, they are unlikely to have changed significantly over the last few years and can probably be seen more as an expression of the Indian reverence for hierarchy than as an expression of the relative position of leprosy workers as a result of recent policy changes. However, it is interesting to note that, in the HIV projects attached to ULP, there is no such spatial demarcations, rather, the offices are expressly planned to avoid this kind of us/them dynamic. This is probably related to the involvement of members of the key population as outreach workers.

The second floor is very much the domain of the health workers. For their day to day activities the health workers share a cramped office lined with the records of the project's 13.000+ cases. During the entirety of my fieldwork, I only ever saw the Project Officer enter this arena on two separate occasions, both on very specific errands. In addition, the physiotherapist, medical officer or other senior staff rarely entered this space. The only others to share the third floor with the health workers are external to the project as two rooms are 'leased' out to associated projects. The second floor also officially houses the supervisors' office and the health educator's office. However, these offices are rarely occupied by the assigned

persons. Instead, the offices are used by the health workers to ensure privacy when charting new cases, conducting follow up examinations or counselling sessions.

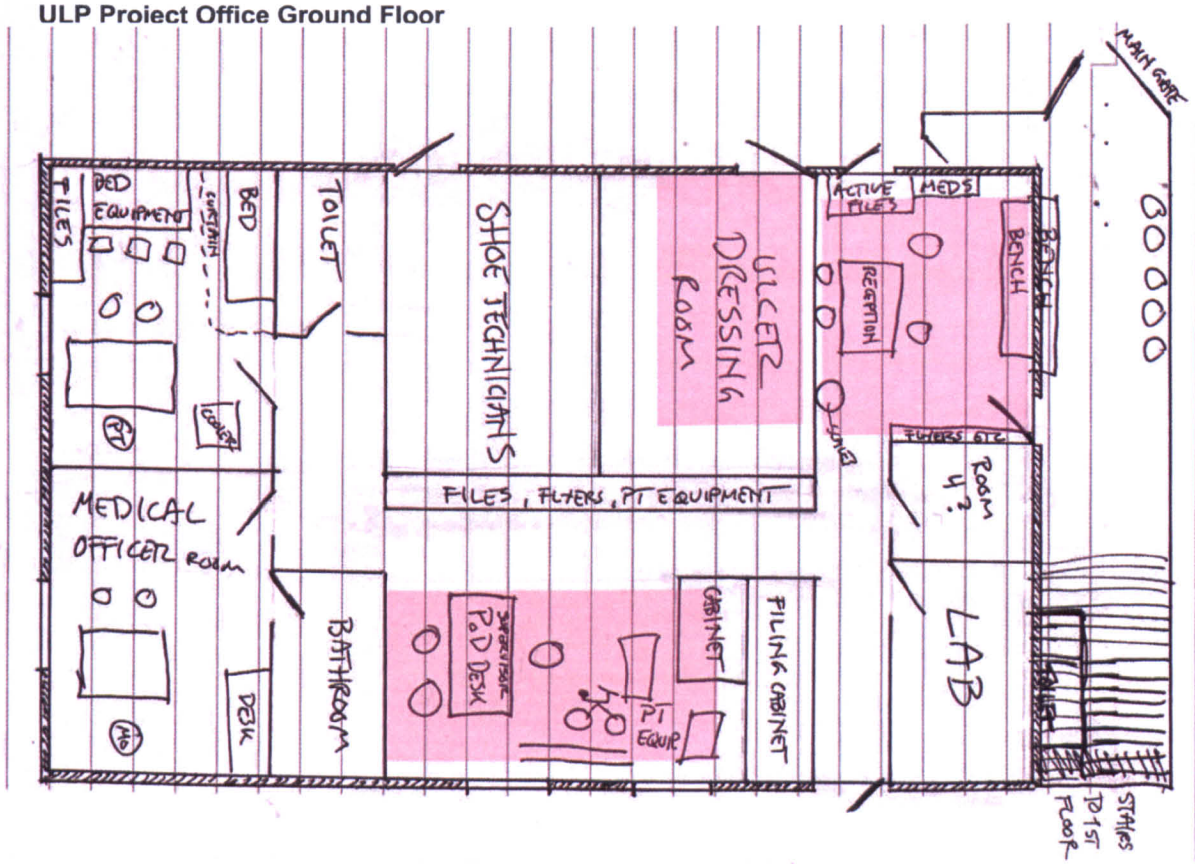
As the supervisor's role has become more and more administrative, and administration has become increasingly computerised, it is rare to see the supervisors outside of the 'computer room' on the first floor, a room which is off limits to health workers without the supervision of senior staff. This is officially due to data protection, as the two computers housed here contain all the projects' data including sensitive and privileged information about salaries and staff assessments. As computer literacy is relatively low among the health workers, there is also a natural reluctance towards unsupervised access to what is seen as a 'fragile' information system. All reporting is done on paper and later transferred to computer by the project supervisors. This can at times be a frustratingly laborious process, with manual calculations absorbing unnecessary time out of the health worker's schedule. This divide also effectively demarcates access and authority.

In general the first floor of the building is totally given over to senior staff, management and administration, with the exception of the bi-weekly eye clinic and the 'conference room' which serves as the projects public arena and meeting room. This floor also houses the Project Officer's office which is the only air-conditioned space in the building, which could be interpreted as an overt expression of hierarchy. Health workers 'visit' the first floor to see the project officer, administration officer, pick up water or consult with supervisors in the computer room. However, it is clear that it is a visit. This is not the health workers domain. Their 'space'/'place' is with the clients and the files.

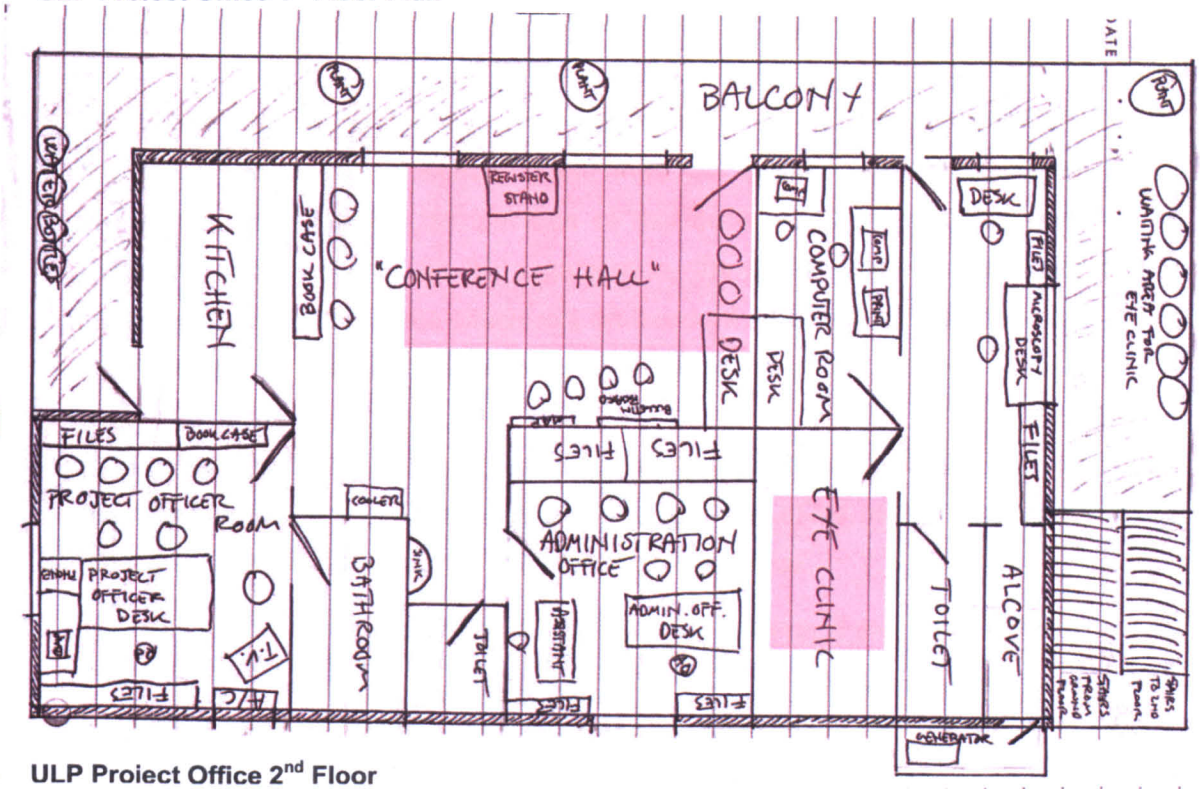
This symbolic spatial remove from the decision making processes is utilised by the health workers in the creation of their social identity, an identity which, rather than oppose their 'place' in the hierarchy, attaches great importance to their physical connection to the 'field', to service provision, and the 'reality' as experienced in the field. It is also expressed in their criticism of supervisors with statements such as: *"they never come to the field, what do they know', 'they used to come to the field*

*with us, but now they are always in the office with the fan. What do they know of what we do?"* The emphasising of their corporeal proximity to clients and communities serves the dual purpose of giving credence to their claims of special insight, as well as underlining their separation from the power structures of the project. However, this marginal position in the physical space of the project, is reflected in their marginal position in the decision making process.

**ULP Project Office Ground Floor**



**ULP Project Office 1st Floor Plan**




**ULP Project Office 2nd Floor**

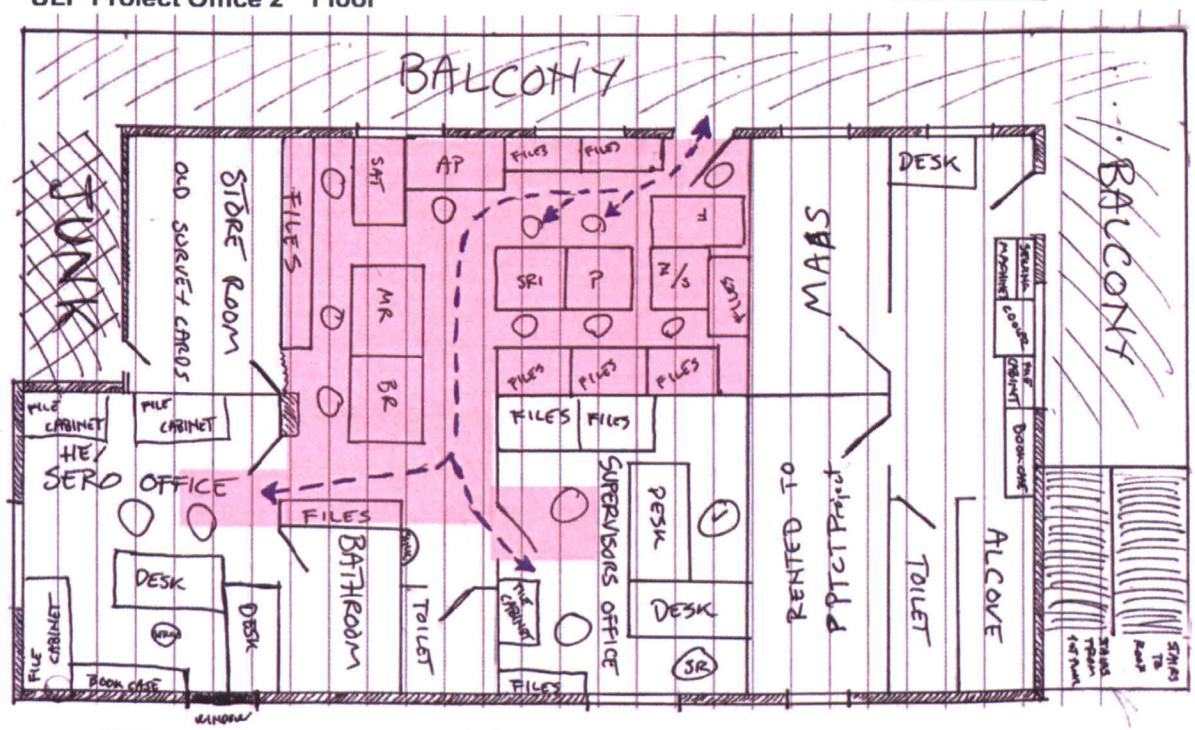



*Figure 12.* Structural lay-out of the ULP project offices. (in the drawings the pink areas indicate the primary areas occupied by CHOs in the ULP project offices. On the 2nd floor plan arrows indicate the movements of clients as they come in to speak to a specific CHO or for body charting in one of the secluded offices.)

## 6.7 Social Identity and Nostalgia. 'We were warriors...'

ULP's lack of future funding was an inescapable part of the everyday reality of the health workers, as they worried about their job security and how they would provide for their families. In the face of this social reality, and in the face of increasing marginality within the organisation, the health workers responded by creating nostalgic narratives which rely on frequent reference to their sacrifices in the past, as a means of re-emphasising their importance in the present.

Late at night, after 'ULP university' classes, after all others had gone home and only the insects were left buzzing around the light, two of the health workers pulled me aside to tell me of what they felt was a grave betrayal:

> *"(...) then they have said to us, you are like soldiers. If you work hard we can be like soldiers and eradicate leprosy. Like this Dr,____ has said to us, then he was medical officer, now he is [higher up in the organisation]. Work hard in good organisation and you will have good future. We worked hard, madam. Not like now. Then we get up at 5 in the morning and cycle 20 km to motivate patients to come to drug distribution point. Then supervisor and medical officer would come in jeep and distribute medicine. Often without breakfast or lunch we would work – 12-13 hours a day. Like that. When Sadguna [pointing to the other CHO there with him] left in the morning his children sleeping, when he come home in the evening children sleeping. Like that. But we do social service. Now, no more leprosy work. But it is not eradicated. We were like soldiers fighting leprosy. What about the promise – have good future. One person made that promise. But where we are now? It is not for us, but for our families. We work for strong organisation, they feel proud. Everyone so happy for us. How can we tell them? I have not told my brother or my father. If I did, his heart may stop."*

As part of their embeddedness in the discourse the health workers and the organisation created a narrative where the health workers were brave 'warriors' fighting a 'war' on leprosy. And as soldiers will, they endured hardship, toil and sacrifice for their duty, for the greater good, for 'social service'. These basic elements are recreated in their nostalgic narratives. Though the narratives vary from person to person, the elements remain the same throughout the group: sacrifice through long hours and loss of family life, physical hardship through field work in extremely difficult conditions, cycling long distances in the mid-day sun and forgoing food (Hyderabadis do not forgo food lightly), loss of opportunity through

their loyalty to the organisation and unwillingness to look for alternate employment. These are 'war stories'; of fearing for their lives when they visited slums with open sewers and drunken rowdies late at night for IEC programmes. They are, as above, stories of working through the communal riots of 91' without regard for personal safety. They are soldier's tales of a war they fear is all but forgotten by those that surround them.

The list goes on, but the elements themselves are not the significant issue here. These nostalgic narratives can be seen as a self-interested 'selective remembrance of the past' constructed to support a particular version of events in order to influence the politics of the present (Amin, 1995). We shape our present understanding in reflexive ways.

By building a 'thick description' of the situation; by looking at to whom, in what manner and when this discourse is expressed we can build an understanding of what purpose this narrative is intended to serve for the health workers (Geertz, 1973). Interestingly, the narrative is largely kept internal to the project, shared primarily between the health workers and their supervisors (who worked as health workers in the past). It is after working hours, or in quiet moments, that these narratives of shared suffering are expressed rather than in the meeting with outsiders or in opposition to senior management. As the health workers feel they have little power to influence their situation outside of their group or their place in the social hierarchy, this nostalgic social identity can be seen to serve primarily to maintain their status, and their position, in each other's eyes, as it is not consciously projected outside of their social circle. The expression of such nostalgic narratives provides social cohesion within the group and, as such, creates a platform from which they could attempt to redress their diminishing influence and importance within the organisation and wider structures.

Much has changed, in terms of working conditions and how the health workers are perceived within the organisation and these are changes they cannot control. So, the fieldworkers talk of the past as a way to stay connected to the ideals they share, a dedication to 'social service' and an embeddedness in the leprosy

discourse of the past. The tales they tell each other are familiar to all. They are 'do you remember that time...' stories that serve to bind the group together through shared history, communal sweat and bloodshed, and thereby, forging a powerful habitus (Bourdieu, 1986a) amongst the co-workers, a bond which reaches beyond the idea of organisational culture as habitus.

### 6.8 Alternative Discourse as Technology of Self

Recent changes in policy and practice are acutely felt by the health workers, and it has affected how they work and it has led them to feel marginalised within the organisation. The health workers' response to these changes is telling. As their relative influence on the creation of meaning within the organisational structure diminishes they fight to retain their dignity and sense of self-worth through the construction and maintenance of nostalgic narratives that emphasises their past glories and the sacrifices they have made for the organisation.

Their construction of a nostalgic discourse can be seen as what Foucault would call 'technologies of the self'; as practices whereby subjects construct themselves within and through existing power structures and thus, actively promote a particular perception of themselves in the eyes of others but also in their own eyes. These 'technologies of the self' must not be understood merely as acts of resistance to marginalisation. They are proactive efforts at maintain a fading discourse, a discourse to which the health worker's social identity is intimately tied, and which is now losing its importance in the organisation and the wider leprosy policy field.

The health workers may complain that they have little access to influence decision making processes but the problem runs much deeper than that and the situation cannot be fully appreciated if we caricature the situation as oppressed workers being dominated by their superiors within the organisation. The health workers are more than carriers of organisational culture; they are an integral part of its formation, as well as its primary expression to services users. The health workers

are very much part of the habitus of the organisation, as they are part of maintaining the very hegemonic structures that serves to marginalise them.

As was argued in a previous chapter, the health workers are loyal not only to the organisation but, importantly, also to their shared discourse, the belief system they have shared over the last 20 years. The sanctions against 'bringing themselves forward', to emphasise oneself or one's achievements are severe. Though these technologies of self could provide a platform from which the health workers could emphasise their role and fight to redress their loss of status, it is not being utilised in this manner. Rather, it serves primarily to maintain this, now outdated, discourse internally within the group and, as such, contributes to social cohesion and informs their working practices. To utilise these technologies as a platform to further their interests would mean opposing the wider structures within which the health workers exist. Rather than force such a confrontation, the health workers maintain a discourse within which they still retain status and importance, even if only in their own eyes.

It is debateable how effective this 'technology of the self' is as a strategy in the new policy and funding climate, where the discussion is not one of 'family' but one of cost-effectiveness and return on investment. Though this discourse serves to cement solidarity between the health workers, their loyalty to the organisation and their dedication to their work, it might also be contributing to the stigma against 'leprosy workers' and serve to further alienate them as a group, as it reinforces their association with past working practices and value systems which are not necessarily in tune with the current working climate. The organisational culture has moved on, changed in the face of epidemiological realities and policy shifts, yet the health workers have been left behind, thus weakening their connection to the organisational habitus and their future prospects.

As argued in the previous chapter, leprosy discourse has been largely homogenous, unilateral and insular for decades, if not centuries. By looking at field-level discourses and working practices, by looking within the structures rather than merely at them, we find that the expressions of these policies are not as

monotone as one might expect. Subordinate discourses are allowed to flourish in implementation, as long as they are seen to achieve the intended outcome of the reigning policy, and the outcomes achieved are accredited to the dominant discourse. By looking at the multitude of expressions that is implementation, we can gain a better understanding of public health policy as it is experienced on the ground. There are no written records of these field-level discourses, no channels of expression, no platform for sharing these ideas. However, there is an oral history of sorts, in the nostalgic work narratives of the ground level workers.

In order to effectively change their role in the organisation and improve their current situation, the health workers would benefit from embracing the new agenda of the prevailing discourse and constructing a social identity which emphasised their embeddedness in the future rather than in the past. However, as the organisation is largely failing to communicate the changed organisational culture down throughout the organisation's ranks, the health workers are at a loss as to what exactly this new day requires, and find that the past is all they have on their side.

## 7. Judicious Agency. That Thing that They Do.

As argued in the previous chapters, health workers are products of the wider framework and discourse within which they work. However, it would be erroneous to depict them merely imprisoned by this structure, as they can be seen to exercise considerable agency within it. If we wish to understand the work of CHOs we must look beyond what they do and aim to understand how they do that thing that they do. The everyday work of health workers in the field goes well beyond that which is defined by their targets or the organisation's goals. By understanding their innovative actions in the field as acts of agency, we can start to build a deeper understanding of their social identity and how they relate to both the community and the organisation. Leprosy work for the ULP health workers is, as an expression of 'social service', equally about the creation of meaning as the attainment of targets and, as such, it must be understood as a means by which they create themselves and their social identity.

> *" We have to understood, have to understood their persons and their needs, everything. If we go and we did provide that treatment. If we say you have disease they can't accept. Because leprosy having some of stigma and... misunderstanding and discrimination. In that situation we have to convince, we have to educate... and we have to becoming a confidence health provider. Then only they can accept.(...) We have to respect their language, first. (...)When we... enter their language and slang they will respect us. When they respect them...when we respect others, automatically others respect us.*
>
> *(...) Because we respect them. First we listen. Listen, listen, listen. Patient.(...) We have to learn, from them. And we have to give the suggestion from them. Not ourselves. Solution is there. In psychotherapy, there is a problem there is a solution. (...)When we enter the community we are giving all of us all things. But they have a little bit of potentiality in them (...) We have to encourage them. Already you know skills, potentiality, knowledge and everything (...) From higher...highest level to low level when we have mutual rapport and good rapport we can success.(...) If you have good rapport, by the good from the room you can connect the network. Automatically, what other services are there like this people from the government aspect you can get all things. (...) Actually we should aware about all things what we have rights to get in our society from the government. (...) National fight everyone knows. You are doing, you are fighting for a main cause. Everyone knows. Same time, why not you go and develop the network – this related department, this related department, this related department, this related department* [see *Figure 13.* below for health workers diagram of 'network' as he sees it]

*(...) Leprosy we have to work multiple level. (...) About implementation of the activities. As a health worker, when I go into the community people are asking... affected and non-affected people. For their needs. Can you assist us, can you prescripted us. Social aspect, education aspect. And communal problems and economic aspect and vocational aspect. Many needs are there asking us. Because they having a little bit of confidence on us (...)Someone is making the guidelines and planning, we are following that. But... routine activities. The field worker is getting different, different, different, different list from the community.*

*Figure 13.* The mind of a health worker - The health provision network as illustrated by the Health Worker during the talk.

For me this narrative demarcates the main areas of health workers' daily activities, as it discusses how to connect with local communities by approaching them at their own level, in their own language and stresses the importance of remembering that it is often the local communities, rather than outsiders, however good they are, who hold the solutions to their own problems. By giving support where it is needed, the health workers can build up local confidence and, through this, enable the community and individuals within this community, to access their potentials and their capacities, their local strategies, so to speak. Neither the community's needs, nor the support provided, are necessarily health-related.

The narrative also directly addresses the importance of working towards the needs of the communities, to their agenda and timetable, rather than preset external targets. Through this process, a rapport, a relationship of mutual respect and trust, is established and the health worker attains the necessary credibility in the community to carry out their work. Organisational targets are important but they are not necessarily congruent with the needs of the community and these needs must be respected.

To address the many needs of communities, the health worker and the organisation must rely on an extensive network of referrals and contacts to address communities' needs, as most of these needs fall within the remit of an existing government department or another NGO. By utilising these existing structures, community needs can be addressed at no additional financial expense to the organisation. By giving people guidance on how to approach officials, and where to turn for assistance, the community members acquire confidence and skills for future encounters, encounters in which they will no longer need assistance, and skills they can share with their neighbours.

The organisation talks of targets and of hiring new health workers, but they fail to see beyond what health workers do, to form an understanding of how it is they do what they do. As such new health workers may "*do better work on paper, but not in the field*".

Within the organisational structure, the daily efforts of health workers are measured and evaluated against their ability to meet certain pre-set targets in terms of case detection, community capacity building, health awareness raising and support of general health staff. However, in the eyes of the communities they serve, the health workers are seen as 'resource persons' who can be approached for any number of problems. Thus, the everyday working existence of health workers is very different from that which one would surmise relying only on outcome measures for insight. As the health worker enters the field they become a community asset, and this is a role they must fulfil in order to build rapport and trust in the community. Without this relationship they will not be able to fulfil their other

duties, as mutual respect is a basic requirement for community participation in scheduled programmes, health forums or voluntary referrals. Thus, their work goes far beyond the remit set out in their job description, and the impact of their work has ramifications far beyond that which can be captured in standardised outcome measures.

Much of the time spent in the field is dedicated to gaining access to the communities and populations they seek to serve, through a process of bartering for time and respect. However, this process is rarely, if ever, recorded, appreciated or understood within the organisational setting or within public health evaluations in general. Thus, it is important that we understand the 'nature' of health workers' work in the field, in order to fully appreciate these working practices and the process through which outcomes are achieved through the application of unrecorded strategies like empathy and 'care'. Let us move on to look at some of these issues in more detail.

### 7.1 Above and Beyond... Duty, Social Service and Necessity

When the activities of the organisation were diversified and the remit of the health workers increased from pure leprosy work to include other diseases, it marked a radical shift in their activities but also in terms of how they were viewed by the community. From being seen as 'leprosy workers', or 'patches doctors' to being viewed as 'multipurpose health worker'. This, in turn, meant that though the health workers are often seen as 'leprosy workers', or more broadly as 'disease workers', within the organisation, as people who are 'limited' (and I use the word limited intentionally because it tends to be seen as a negative thing) to working with disease, be it leprosy, malaria, TB or HIV, the community see only persons of authority who may be able to help them with a broad range of problems, be these specific or general.

The Community Health Organiser job description defines their role as: "to enable people of a defined geographical area in participatory approach to involving

community, CBOs to understand common health problems and issues related to development which are relevant to his/her area so that appropriate and timely measures are taken by the people/community to improve the quality of life with particular reference to health". This is a very wide and unspecific aim. However, looking at the reporting formats (see *Appendix 6*), it is clear that the format in which the health workers' work is reported back to the organisation is rather more structured and target oriented than their job description indicates. The tasks of each health worker are defined through daily, weekly, monthly Advanced Tour Programmes (ATPs) and their performance, relative to this plan, is measured in quantitative outcomes. They focus on how many leprosy cases detected, malaria smears performed, TB cases referred, as well as, how many group talks were conducted, school education programmes performed and people screened for eye problems.

Quite how diverse the health workers activities were became apparent to me as I, after 12 months of meticulously recording time series data, sat down to analyse my findings. 10 categories became 20 categories became 30. How does one categorise a visit to a community leader where some land issues were discussed, an impromptu group talk on HIV was conducted and plans for next week's community meeting were finalized? After much consideration I settled on 11 categories which seemed to encapsulate the most common features of their work. These categories were again collated into 4 main themes. As discussed in chapter 1.2.4, the time-series data have severe limitations in terms of their method of collection and the influence of the researcher's presence in the data. To avoid the worst impact I removed travelling time from the equation. As I spent unequal amounts of total time with each of the health workers I based the time-series analysis on data from one consecutive week with each of the health workers. In addition to these limitations in the data collection methodology, there is also considerable subjectivity in the grouping and categorisation of the data. Despite all these objections and considerable shortcomings, what is most interesting about the data themselves is how much time was spent on the Rapport/Presence category of activities, which denotes time spent in the community without specific disease or activity focus (see *Figure 14a* & *Table 4a.*).

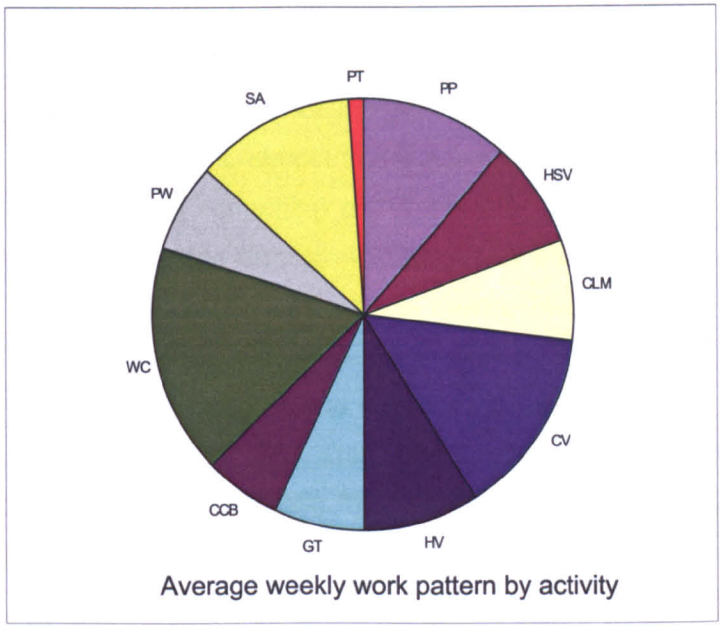



*Figure 14a.* Average weekly work pattern by activity from field

| Breakdown | | |
|---|---|---|
| *Clinical/Bureaucratical* | | |
| Paper Work (PW) | | 7% |
| Weekly clinic (WC) | | 17% |
| Health Staff Visit (HSV) | | 8% |
| | *Subtotal* | *32%* |
| *Rapport/Presence* | | |
| Community Leader Meeting (CLM) | | 8% |
| Home Visit (HV) | | 9% |
| Community Visit (CV) | | 14% |
| | *Subtotal:* | *31%* |
| *Awareness raising* | | |
| School Awareness (SA) | | 12% |
| Group Talks (GT) | | 7% |
| Community Capacity Building (CCB) | | 6% |
| | *Subtotal:* | *25%* |
| *Other* | | |
| Personal Time (PT) | | 1% |
| Preparations at Project Office (PP) | | 11% |
| | *Subtotal:* | *12%* |
| **Total:** | | 100% |

*Table 4a.* Field note activity

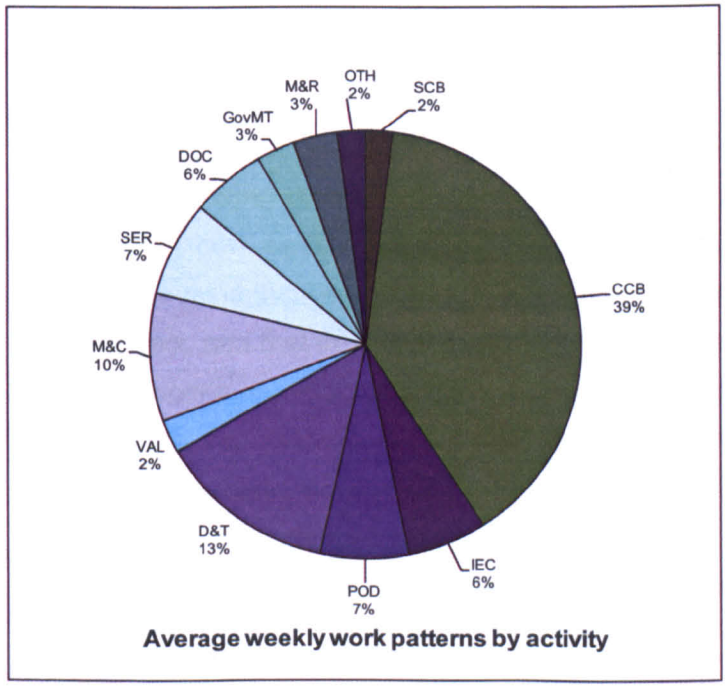



*Figure 14b.* Average weekly work pattern by activity ULP internal

| Breakdown | | |
|---|---|---|
| *Clinical/Bureaucratical* | | |
| POD/POWD (POD) | | 6.66 |
| Detection & treatment (D&T) | | 13.44 |
| Validation (VAL) | | 2.47 |
| Documentation (DOC) | | 5.59 |
| Gov. Meetings (GovMT) | | 2.88 |
| Montoring and review meetings (M&R) | | 3.31 |
| | *Subtotal* | *34.35* |
| *Rapport/Presence* | | |
| Community capacity building (CCB) | | 38.78 |
| Motivation and counseling (M&C) | | 9.55 |
| | *Subtotal* | *48.33* |
| *Awareness Raising* | | |
| IEC | | 5.98 |
| SER | | 7.22 |
| | *Subtotal* | *13.2* |
| *Others* | | |
| Staff capacity building (SCB) | | 2.02 |
| Others (OTH) | | 2.09 |
| | *Subtotal* | 4.11 |
| **Total** | | 100 |

*Table 4b.* ULP internal activity breakdown

In order to glean further information from the data, I attempted to compare my findings with those collected internally by the project. The project data is obviously also subject to a number of issues around reporting, honesty and transparency. Interestingly, each of the reporting health workers had worked 50 hours in the reported week, almost to the minute (see *Figure 14b.* & *Table 4b.*). This, in and of itself, says something about the validity of the data. However, since I will not be subjecting the data to rigid statistical analysis and since it is available, it is worth looking at in terms of general trends. The project data is subdivided using different categorisations than those I utilised. 6 out of 12 categories define clinical or bureaucratical activities but these 6 categories only constitute roughly 35% of the health workers' time. This shows an interesting disparity in terms of what the health workers are spending their time on and what the organisation in turn is interested in quantifying. On the other hand, the health workers spend almost 39% of their time on something termed Community Capacity Building defined vaguely as "contact with community leaders, Group Talks/Meetings and Capacity building" (for a full break-down of the components of the 12 categories see *Appendix 6*). More accurately, I would argue, this category must be understood as a catch all category for unspecified time spent in the community establishing rapport, renewing contacts etc, as discussed above.

Finally, by looking at the health workers individually, rather than as a composite, it is startling how similar their reporting and work patterns are (see *Figure 15.*). Bearing in mind that two of the health workers work half days as counsellors for an HIV project, and that this means less time in the community, the similarity between HW4-8 reports is remarkable. By ignoring all the detail, by stepping back from the proportional representation, and analysing in the pie charts as a visual group, it becomes apparent how homogenous the health workers are as a group, how similar the work patterns are and quite how much time is given over to this loosely defined activity, 'community capacity building' (dark green in the diagram and constituting 50% of work for these 5 CHOs). Interestingly, despite diversification of activities and the complex nature of community work, the health workers still report that 1/3 of all their daily work is leprosy related (see *Figure 16.*).

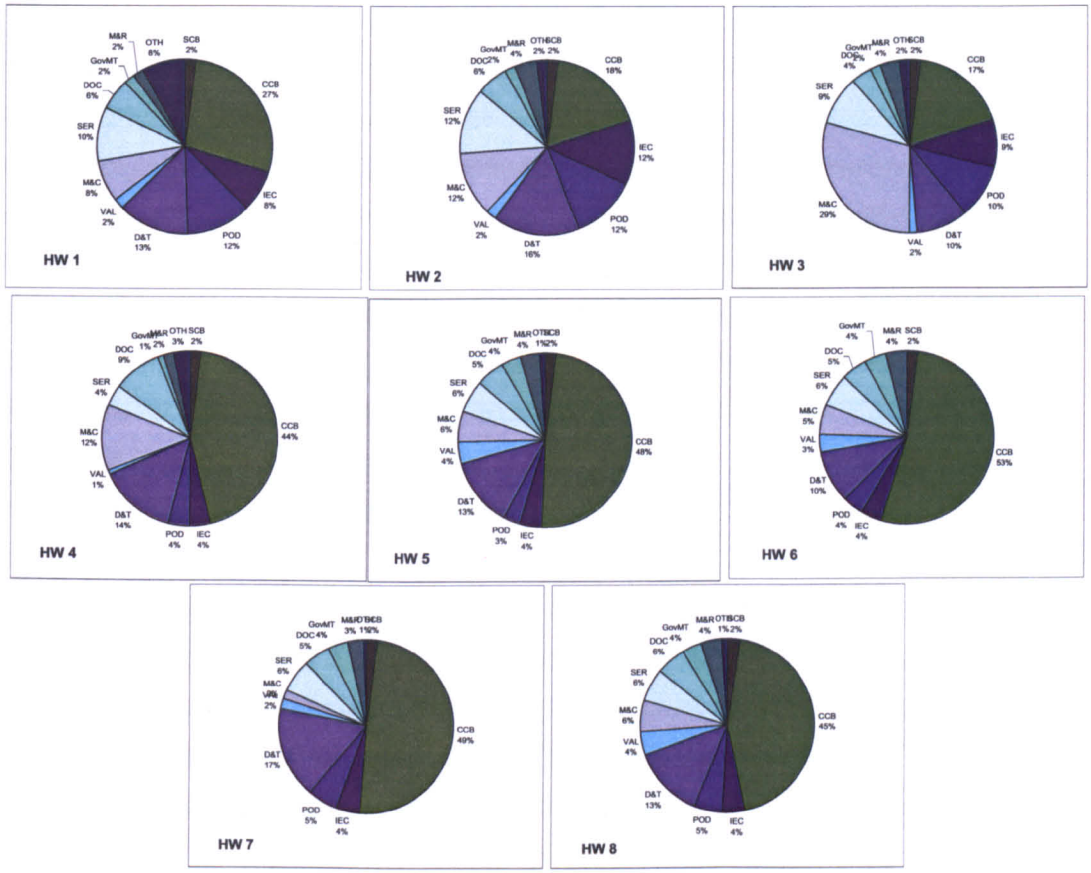



*Figure 15.* Weekly activity pattern of individual health workers

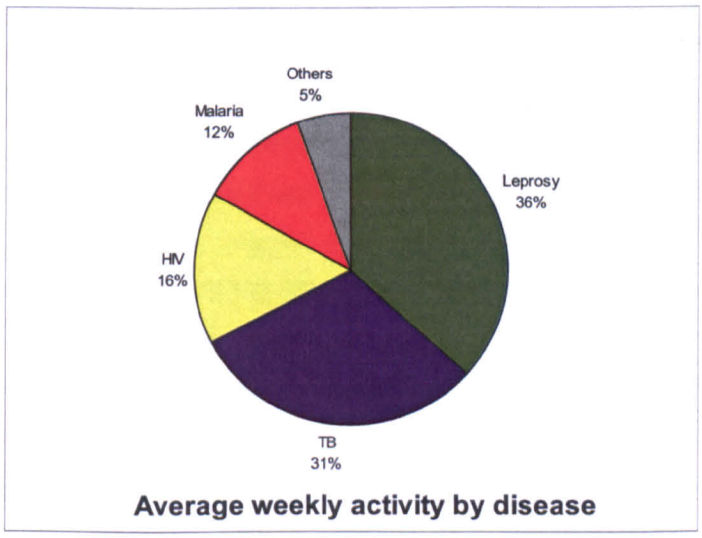



*Figure 16.* Weekly activity pattern by disease

Though the organisation might define the health worker's remit according to disease, and set targets according to epidemiological indicators or official priorities, the community see their presence as an opportunity to address any ill – social, economic, structural, or other. As Chapter 4.1 set out to communicate, there is nothing standard about fieldwork, no two days are the same, and the categorisation of wildly different tasks and duties into a handful of preset categories fails to capture the complexity of field work. In addition, it is clear that many of the tasks performed by the health workers go far beyond the targets or the reporting structures, if not beyond the very broad remit of their official job description. Though it is worth bearing in mind that, on a daily basis, it is the strict formality of the targets that defines the health workers' remit, not their job description.

Health workers routinely deal with anything from earache to marital issues, school attendance, bumps and bruises, pensions, ration cards, water access, kidney problems, fevers, etc. These generally fall well beyond the remit of the CHOs, yet they cannot afford to ignore these issues, as their interactions with the community are interactions with the lived reality of the community and their interactions with individuals are interactions with the complex and embedded lives of individuals. Thus, the everyday work tasks of health workers engage with issues that go beyond distinctions of health and development, go beyond the conventional definition of health to issues of life and approach Virchow's conceptualisation of social medicine, in which he "emphasised the economic, social and cultural factors involved (...) and clearly identified the contradictory social forces that prevented any simple solution. Instead of recommending medical changes like more doctors or hospitals, he outlined a revolutionary programme of social reconstruction; including full employment, higher wages, the establishment of agricultural co-operatives, universal education and the disestablishment of the Catholic church." (Taylor and Rieger, 1984:201). As health is seen to determine life and life to determine health, the health workers' approach, even to specific health issues, must be a holistic one, one which is determined by the demands of the community rather than the targets of a specific project.

The health workers themselves will use the word 'social service' to describe the work they do and to describe why they got involved in leprosy work in the first place. Though their performance is evaluated officially by their ability to meet preset targets relating to specific diseases, they acknowledge that their work cannot be achieved through this narrow focus but, rather, that it presupposes an engagement with wider issues of concern to the community. As a result, their daily tasks go far beyond the remit set by the organisation in order to establish rapport with the community, but also in an effort for them to achieve what they term 'social service' – for the successful implementation of their work, but also for their own personal salvation. As the great Gandhiji said: "Leprosy work is not merely medical relief; it is transforming frustration of life in to joy of dedication, personal ambition into selfless service."

The health workers recognise the importance of targets, both as measurements of their job performance and as a structural framework. However, they do not equate these targets, or their attainment, with the successful accomplishment of their work. The health workers motivation for joining the public health or leprosy field in the first place was a stated desire for secure employment, but also to be able to 'do good' and provide 'social service'. It is in relation to this 'social service' they themselves evaluate their achievements.

For the health workers the distinction between targets, 'social service' and duty roughly illustrates how they understand their accountability and the various ways in which their performance is evaluated on a running basis. 'Targets' is most often used as a euphemism for quantitative work, that which the organisation officially evaluates them according to, but has also come to represent the bare minimum effort required. In this, the health workers are not implying that the mere achievement of targets would be satisfactory for the organisation, though there are occasional insinuation that this might be all the 'funders', as a mythical category, care about. 'Social service', on the other hand, is how the health workers refer to the work that they do for; a) individual clients and; b) the greater good of society. It was in order to perform social service that they joined this line of work in the first place and it is towards the attainment of 'social service' that everyday activities are

truly directed. I found that this view was shared amongst all the health workers. The concept of duty, on the other hand, was far more diffuse (and one which I only heard utilised by some of the health workers) but which seemed to relate to issues of ethics, motivation and social conscience. The health workers who utilised this specific concept used it to describe their feeling of moral imperative to do good, to perform 'social service' and to ease the suffering of individual clients or groups of clients.

Perhaps even more telling than the way the health workers spoke of their own work, is the way in which they referred to the work and attitude of government leprosy workers, against whom they juxtaposed their work, for, as Wacquant deftly summarises Bourdieu's analysis of distinctions, *"taste is first and foremost the distaste of the tastes of other"* (Wacquant, 2006:9). Thus, listening to what the health worker say about government employees affords us a window into how they do not see themselves:

*"ULP Staff: Government people are not giving to this kind of service. Our motto is: only service, serve to the leprosy clients. Even though....in Gandhi hospital they can't do ulcer dressing.....in...we are doing here. They don't do. Giving some ointment and bandage and say: 'go'. Do dressing in their homes. First of all they are pressured: 'go, go, go'.*

*Interviewer: Still big problem with stigma, even in health professionals.*

*ULP Staff: [making funny scared sounds and pulling away] uah...leprosy patients. Still in government hospitals. ILO only doing the [making cooing sounds like he is calling the cows home] 'pochaiah come, anju come. Come, come'. ILO people are doing (...) Government treatment is different, government counselling is different, ILO counselling is different. How many.....in one patient. How much time you are spending in the evening time?*

*Interviewer: Long time.*

*ULP Staff: One patient we are given family counselling, their own counselling, and about all diseases counselling. Yesterday one patient came.... 45 minutes I given counselling. With the reactions came. Maybe stress, family burdens....disease burden. Why I am getting like this? This is also some reason. Of reaction. Of recurring reactions. Few cases are...only few cases but it is very important to tell the.....*

*Interviewer: And also with PoD all mixed...all mixed together.....*

*ULP Staff: The government people they are not doing. Even my missus also working....but they are not doing, government people are not doing the*

*PoD work. 1 to 3 patches is PB, 6 months course. 3-5 lesions give MDT 12 pulses. That much. Only."*

The health workers rarely talk about their relationship to their work directly. However, they frequently speak of government employees and others they see as not doing a 'proper' job, who only care about money and collecting numbers for the reporting structures, the inference being that they, the health workers themselves, care about something beyond money and numbers. By drawing on Bourdieu's analysis of distinctions, we can attempt to build an understanding of the health workers relationship to their work as an inverse expression of what they say about others. When they talk about how incapable the government employees are of doing their job, how they do not care about people affected by leprosy and how they are merely in it for the numbers and for the money, they are effectively saying the opposite about themselves. Since I did not spend any extended time with APMOs, I have no idea whether or not these allegations are true. Nor do I think this is the most interesting aspect of these statements.

As seen in the dialogue above, there is a frequent emphasis on working outside of official working hours. This constant assertion must be seen as a crude expression of the health workers' understanding of the distinction between work as social work, and work as 'punching the clock'. This can be seen as one way of proving their dedication to social service to themselves, as long hours and suffering demonstrates dedication to 'social service' in their minds (see nostalgic narrative in Chapter 6.5). Even if it is not strictly necessary to stay late ULP staff tend to feel they ought to. To habitually go home at the end of the day is to work *'time to time,'* which is one of the things the health workers accuse new staff of, as well as not being dedicated to 'social service' and duty, but merely to the pro-forma performance of their work. Another example of the importance of working late came one night when I popped my head in to the computer room before heading home and called to Daksha *"Don't work too hard and don't stay too late"*. To which he called back *"even if I go home now my family will say, why are you home, what is wrong?"* I laugh and finish the sentiment for him *"....have you gotten fired?"*

Laughing he adds, *"it is like an addiction, a drug addiction. Since 1989, a ULP addiction. Even if I plan to home early, always there is some work..."*

Health workers' statements about government leprosy workers effectively illustrate how the health workers perceive their own work as having inherently more value than that carried out by the government officials as they, the ULP health workers, care about the clients and wider social values, whilst government health workers do not. These allegations, particularly when levelled at the public sector takes on new importance in the age of integration and, if correct, raise questions about the general health sector's ability to handle the more complex aspects of leprosy work.

As argued in Chapter 5, current strategies for integration were conceived at a time when the primary focus of leprosy policy was on a biomedical and pharmaceutical cure. This level of interaction with the disease gave rise to clear manuals and treatment protocols. However, recent leprosy policy has begun to recontextualise leprosy services and, in recognition of the lifelong care required by many people affected by leprosy, the leprosy policy community have started to look to strategies like the WHO's Innovative Care for Chronic Conditions (ICCC) (WHO, 2002) framework for inspiration for future directions of interventions. This framework goes beyond the biomedical paradigm to include further components in its rehabilitation framework. The Indian government has only now incorporated a rehabilitation component into the NLEP strategy in the form of the Disability Prevention and Medical Rehabilitation (DPMRP) framework, which sets out guidelines for biomedical interventions such as physical rehabilitation and reconstructive surgery, which are well suited to integration into the general health system. However, recent research has shown that the impact of disability prevention lies less in explaining the correct procedures of self-care and more in the providers ability to empower the individual patient. This requires in-depth knowledge on a case by case basis and can only be achieved through a process of counselling and considerable time investment (Cross, 2007). It is questionable whether or not the government services will ever have the time or inclination to provide these services through the general health system, and whether or not this is indeed the proper arena for such interventions.

## 7.2 Double-Edged Sword

> *"Part of the enduring appeal of the community based health agent lies in the fact that there are forms of trust and legitimacy in health services which do not derive from the professionalisation model but are much more firmly embedded in local social relations, and such agents – embody this (...) But this kind of embeddedness is a double edged sword. Practitioners may be trusted by locals. They may also be enmeshed in local patron-client relations which discriminate against the more disempowered, and they also may be providing incompetent treatment." (Standing et al., 2008:2105)*

Clearly the distinction between 'social service' and 'work' is one which is of utmost importance to the health workers and their social identity. Laudable as this emphasis on social service may appear, it is not without its problems. As leprosy health provision changed from a care-rational system to one that focuses on bureaucratic categories and cost-effective justification, the health workers consciously retained a strong care focus in their approach to work. However, the care system can be seen to be double-edged; on the one hand there is a strong commitment to organising services around the needs of clients but, on the other hand, there is a paternalistic element to the approach, in that it creates and maintains an artificial dependence on the system by its clients (Howe, 1994, Myking, 1999). This paternalistic attitude can also be seen amongst the health workers, especially in what I experienced as their 'Gandhian' streak. This approach was most clearly expressed in their interactions with individual community members in a do-what-I-say and it will 'fix your life' attitude.

As the community reconceptualises the health workers' role as 'resources persons', their work increasingly involves tasks and issues, be this pensions, water access or medical issues, that fall outside of their official training and remit and, thus, the health workers increasingly find themselves answering questions and addressing problems for which they have had little or no training. This broadened remit corresponds well with their stated ambition to provide social service but it can also be seen to be an expression of their paternalistic ambitions vis-à-vis the community, as well as part of a process of establishing power and credibility. This is an issue that needs to be considered when thinking about the innovation and creative implementation as performed by health workers. Though I never observed

any negative impact or direct abuse of power during my fieldwork, there is an undeniable potential of this here.

The particular answers or solutions to non-programmatic issues, provided by health workers in the field, indicate that they are determined to a large part by the individual health worker's personality, experience and belief system. Though the suggestions themselves show great variance, they are based on a shared understanding that they, the health workers, hold the answers and that what is needed is the careful application of these answers by the community and its members. This approach directly contradicts the health workers' stated position, as illustrated by the health worker's narrative in the introduction to this chapter where he argues that communities hold the answers to their own problems. It is true that many of the health workers made statements akin to this, however, in my observations, their interactions with individuals tended to revolve around 'teaching them what was right' and correcting wrong notions. Thus, interventions easily go beyond care and cure to control, control over how people live their lives.

Therefore, when investigating the influence of health workers on the relationship between people affected by leprosy and the organisation, we must remember the potentially double edged nature of the care-approach. Health workers are not impartial brokers or change agents, rather, they must be seen to be the carriers of powerful discourse, representing a set of immutable 'truths' determined by this discourse into which they were trained. There is a 'right' and a 'wrong' way of doing things and, faced with alternative perspectives, they believe it is their duty to correct these 'wrong notions'. Thus, in meeting with community they are not impartial delegates but representatives of a particular world order.

However, now that leprosy organisations are diversifying their activities, these methods are coming into question. Due to very different background of policy discourses of leprosy and HIV, and the active engagement of civil society in the creation of HIV discourse, organisations are implementing novel interventions targeting unfamiliar areas and giving unprecedented levels of control to clients and communities. Still, these approaches are only slowly carrying over into leprosy

work. There is still a perception that patients get leprosy and people get HIV, which can be seen in interventions that provide drop-in centres to people living with HIV/AIDS and footwear to patients affected by leprosy – and sees nothing strange in this, even though both are chronic stigmatising diseases.

### 7.3 Building Rapport

As previously established, although health workers are embedded within the structure in which they work, it would be a mistake to assume that they are limited to this structure. Clearly, the designation of their work as 'social service', rather than as merely 'work', indicates that their ambitions extend beyond those outlined by the organisation's basic target structure. The health workers feel that, through their shared policy narrative, they share an understanding of the organisation's underlying ambitions and they utilise this understanding to shape and frame their interactions with the community. By looking at how the health workers achieve their targets in the field, we can understand how they utilise agency within this structure to achieve their aims. As discussed above, the vaguely defined category of community capacity building serves as a catch all category for health workers' activities in the community and it is here that we need to look to understand what is happening on the ground. When asked to categorise these varied activities the health workers would often use the phrase 'building rapport' to describe their activities. Again, this is a composite category which, I will argue, encompasses the main elements of the health workers' application of creative agency in the field. Let us attempt to deconstruct this category and see what we find.

Beyond the rhetoric of personal salvation and the desire to execute social service, there is a more practical reason to address the concerns of the community. The successful execution of the work of health workers relies on good rapport with the community. This word – good rapport – is something that comes up in almost every conversation I had with the health workers regarding implementation. When I asked the health workers what they saw as the key components of achieving successful implementation, during the focus group discussion, their answer was

building rapport with the community. In addition, the first step in most implementation plans is the asserted need to 'establish rapport with the community'. Yet, what exactly is meant by this phrase is rarely explained, nor is specific time or resources allocated to the activity in planning, rather, it is treated as something that is a 'natural' part of the implementation process. However, during my fieldwork, it became abundantly clear that this was not a 'natural' or 'automatic' process, far from it. In fact, it was one which required more time and manoeuvring than most of the health workers' other tasks, despite its lack of clarity of purpose, as can be seen in the amount of time spent on community capacity building (see *Figure 14b*).

The health workers would summarily refer to these diverse activities as 'building rapport' but the act of establishing such relationships is far more complex than this easy categorisation implies. In addition, the ramifications and implications of the process, as much as the activities themselves, have impacts which go well beyond the stated intentions. In order to build rapport, the health workers need to establish a relationship with the community by approaching the community 'on their own level', by speaking their language, by listening to their lived realities and by taking their needs seriously, even if these fall outside of their official remit. One of the best ways of building and grooming such relationships is through time investment in the community. These actions serve to build relationships of trust and respect through signalling the health workers' willingness to take community concerns seriously, as well as their willingness to devote time and effort to these issues. The health workers' ability to address these needs depends on their ability to establish their 'credibility' as resource persons in the community. In addition it is through this status, as credible resource persons, that they gain the access they need, within the community, to carry out their scheduled activities.

When articulated like this, on paper, the process seems pretty straight forward and unspectacular, but this belies the ingenuity and creativeness that goes into establishing, and the constant finessing of, these relationships. It is a perspective which challenges the myth of the passive recipients and allows us to understand the interaction between health workers and communities as flexible, creative, and

the product of the constant renegotiation of each party's agenda. Let us look at how this process is played out in the field.

### *7.3.1 Tricks of the Trade*

Establishing rapport was brought up time and time again as the first step in community capacity building but it is an unspecific category without clear guidelines or frameworks. When pushed on the subject, the health workers identified a variety of different aspects which they saw as fundamental to establishing rapport with the community; to speak to them in their own language, which in turns shows respect for their lived reality; to listen to their views and to treat people, and their views, with dignity; to take time and to work to the communities' timetable; to show empathy and to take them, and their lives, seriously; to demonstrate a willingness to touch their lives as they would touch a leprous body in the past; to build credibility in the community; and to show respect and gain respect in return.

Again, these are broad terms. Terms that cannot easily be codified or included in training manuals, abstract terms which gives us few clues as to how rapport can be achieved in practice. However, the everyday working practices of health workers offer just these clues to the practical aspect of reaching out to the community. As described in the introductory interview excerpt to this chapter, language is of utmost importance. Further to this, is the willingness to engage with the community at their 'level' which is expressed amongst other things through the use of local slang. Finally, the willingness to listen to the community's issues, and often the very act of listening in itself, is crucial to communicating respect for the lived reality of the individual and solving seemingly complex problems. The following are two examples of different ways in which 'listening' is key to implementation and the building of rapport. First, an example which illustrates the importance of listening as a means of accessing therapeutic solutions, but also the importance of the act of listening and the affording of time in themselves:

*"ULP Staff: One [lab technician] came: 'Sir, the patient not coming. The patient is refusing to take TB treatment'. I've seen the card. So many absences is there. Why these absences will occur. 'No, the patient is not coming, we have so many times visited in his house. He is not coming to take treatment'. Once I visited....I sat in front of patient: 'what is your problem?' ' Sir, I don't want treatment Sir. You go'. 'No actually what is the problem?' Person tell problem, then I will tell 'if you don't want to you don't take treatment'. He told: 'I have diabetic and that thing we have..... what we'll tell in English.....eh...he will come and he will fell down...that is....? Disease, that disease...eh.....*

*Interviewer: Epilepsy?*

*ULP Staff: Yes, epilepsy. He have epilepsy, he have same time diabetic. So many problems he have. 'While taking TB treatment I have so much of that epilepsy. And I have to take more food to...eh...take to TB treatment, but I have to take less to take diabetic. What I can do?'. That...for that I don't have an answer. Babu, you came to our medical officer. You tell as much as possible correctly. What he will tell you have to do. Then he came.*

*Interviewer: Also if diabetic is not under control the leprosy...eh...TB treatment will not work. So...*

*ULP Staff: Yeah. That is the problem. Our people what...LT....'Sir, he is refused. He is not coming'. What is the reason? First you got the reason. Otherwise why don't he take. He will take.*

*Interviewer: Have to talk to the person as a person; as a human being.*

*ULP Staff: Yeah. He told like that first also: 'I don't want treatment, Sir. You go!'. Then...I given 5 – 10 minutes. 'what is your problem?'. 'Just now told you Sir. You go! You don't come my house!'. When I will come I will tell our bosses also, he is refused. Give time to them. First listen to patient."*

This idea of counselling, and especially of listening as a counselling technique, is fundamental to the ULP staff's approach to patient care; to listen to what people are saying, to understand their problems and their needs are and, then, to unravel these to find a solution. As one of the health workers is very fond of saying, '*this doesn't cost the organisation a paise*' [a *paise* being 1/100$^{th}$ of a rupee]. In addition, the ULP staff doubt, probably with good reason, the general health staff's capacity and willingness to provide this level of care to leprosy patients, even if this is often the key to breaking ulcer cycles, recurrent reactions and other associated problems. This doubt ties in with Dr. Cross's insights regarding the rehabilitative quality of empowerment of the individual patient, as discussed in chapter 7.1. Another example, of a more delicate situation which illustrates the importance of

listening follows. In this situation it is perhaps the act of listening itself which holds the remedial potential.

*"ULP Staff: (...)listening is very important. Listening. So...once...listening means...so many problems will be there. Sometimes they will tell....otherwise you can't.....for example, I remember one person. He is taking the...this treatment. What he thought...our neighbours said, we don't know. He is not leading family life. Means....eh.....he is not.....what we call.....what we say.....?*

*Interviewer: He is not married? Batchelor?*

*ULP Staff: He is married but...eh....not.....eh....with wife. Because of leprosy. And neighbours; relatives..... somebody told to....his wife: 'Don't allow him. Because he is leprosy. You may get leprosy'. Like that. So....he can't say that word to anybody. Because...eh...she is thinking like that....that's why she is not allowing me to....eh....do.....everything. so, like that he...he...but he is getting depression. That is also main point. But where they are, what is there....we can....because he is actually facing trouble. So, after one month or one week...he tells me. 'Sir, this is like that'. He also tells not directly: 'Sir, what happened Sir. Not like this, like that', he will tell. So, if we probe, he will come out.*

*Interviewer: It is very personal.*

*ULP Staff: Personal. Very personal. And also unable to express ourselves. That...that point he feels shy that means. Feels shy. Because that is a very delicate point. Ehm. And also very difficult point also. He can't....say that word...she is not allowing me, like that. So...these things...they create reactions, that is the problem. That psychological...eh...pressure given recurrent reactions. So, if I probe he tells me. (...) first main thing is we have to identify the problem. Maybe psychological, maybe physical, or whatever it may be. Family problem or neighbours problem. So identification. Once identified, how to treat that. Treatment. Social treatment, medical treatment, physical treatment, psychological treatment, what ever. (...) So, but.....this PHC, means UHP, doctors don't have time. So many...they have to see all the skin diseases, fevers, motions, diarrhoea, da da da. Like this. They can't spend. 'Ok, you have leprosy. Ok. Take this strip. Come back after one month'. That's it. But internally there are so many things you have to take.....give treatment. This is not enough. This strip is not enough."*

Listening is important in one other aspect. It demonstrates the willingness to dedicate time to someone's narrative. It confirms the importance of what the speaker has to say, it shows a willingness to be in the moment with the individual and to understand quality of care from their perspective (Britson, 2008).

### *7.3.2 The Simple Things in Life*

*– Health Care via Family Photos*

The examples mentioned above are small, seemingly insignificant interactions, some of which transpired years previous, yet, they were brought up in an informal interview setting by the health workers in order to illustrate their everyday activities. Every health worker has dozens of these stories, and each of those stories is unique as in terms of its scenario, yet, interchangeable as in terms of their underlying qualities, the emphasis on time, trust and respect.

In order to establish relationships of trust, the health workers feel it is necessary for them to learn to speak to the community in their local slang and to listen to what they have to say about their lives and problems in order to gain their confidence. By treating people with 'humanity', and by showing respect for the lived reality of the community, they themselves gain the trust and respect necessary to carry out their duties. It's all the little things that matter: home visits; having that glass of water you really don't have time for; looking at photographs of their children and demonstrating that you see them as human beings and not just merely recipients of health education. To take the time, it matters less what for, but is significant in the giving, as it communicates clearly: 'you are important enough to me for me to spend a few minutes quietly sitting in your world'. Through engaging with the community on this level, the health workers become immersed in 'community health', whether they intended to or not, and the community's main concern is rarely infectious disease but, rather, poverty, unemployment, problems with pensions or ration cards, water supply, access to vocational training etc... How the health workers engage with these challenges, defines their relationship to their work.

The everyday presence of health workers in the community is an expression of time invested over years within the same communities. As the same health workers have worked for the project for more than 10 years, their interactions with local communities, despite migrations, go back decades. To illustrate this with an

example, let me recount an interaction which took place one day when we were conducting group talks in Puranapool:

> "I had gone to a slum in the old city with two of the health workers to conduct group talks. The health workers explained that this was a very dangerous slum after dark as most of the people would drink gutamba (ಗುತ್ತಂಬ), local spirits distilled from sugarcane and rice. The health workers explained that in previous years the community would not accept them entering the slum; community members would refuse to give their names; and, they would start loud arguments. However, by now the health workers' presence had come to be accepted by the community as they had *'come to this slum a thousand times'*. Still, they couldn't come here after dark when people have been drinking. The primary occupation amongst the slum's residents was the sale of seasonal fruit and vegetables and, as it was the season for fresh chickpeas, the slum was littered with empty husks and women sat on every street corner stripping chickpeas from branches. We had stopped to buy a bunch from a street vendor as a midmorning snack, when (from my field-journal): "20 or so curious people collect around us as we stand around eating fresh roasted chana [chickpeas]. [The group] look through the [health worker's] 'Leprosy Atlas' (2000) and say that there is someone in the community with these symptoms. A boy will take us to him/his house. [One of the health workers] turns to me and says: *'this is community ownership. Give awareness to a community and they will think not only of themselves but of others in the community. They know everyone and see them every day, so if anyone has symptoms they will tell us. Look, now this man is thinking not of himself but of community members*' (...) Turned out the man in question suffered from psoriasis, not leprosy."

This is an incidental example of the effect of cumulative time spent in a community, time spent over the years and time spent in unassuming presence presently, and I could recount any number of similar examples, as these were almost daily occurrences. However, the very triviality of these examples communicates the notion of presence, not as something spectacular or singular, but as something continuous and incremental. To be in the community, to spend time there and to share in the lived reality of that community is something that perhaps ought to be obvious and natural to all implementation but, unfortunately, can be something of a rarity. One of the strengths of community health workers, as conceived by Primary Health Care, is precisely that they hail from the communities they serve, and thus, hopefully, already have this established relationship of respect and trust. For outsiders, the process of establishing this relationship is not something that can be

rushed nor quantified. The ambition to establish community rapport is not the same as having such rapport in reality.

The health workers' investment of time in communities is not an expression of a carefully staged and calculated strategy but, rather, it is a far more haphazard enterprise dictated as much by opportunity as by tactic. "Trust can be a precursor to, as well as outcome of, participation. Trust is not traditionally considered in health service design", however, a "significant time commitment is needed to build trusting relationships and to develop the skills of both communities and health professionals to work together" (Gryboski et al., 2006:19). Much time and effort is directed at the creation of trust in the community, where trust is understood as "the optimistic acceptance of a vulnerable situation in which the trustor believes the trustee will care for the trustor's interests" (Hall et al., 2001:615). This definition sees trust as relational, voluntary, defined against future expectation and based on the assumption that the other party will have your best interest at heart (Gilson, 2006). Thereby, trust is defined as much by a shared understanding of motivations and intentions as it is by outcomes (Hall et al., 2001).

### *7.3.3 Street Cred'*

When a health worker walks into a community looking for leprosy cases and seeking to impart health education, the community themselves see a health worker, an authority figure, a resource person and, as such, they approach with every bump, itch and ache. Though target structures tend to compartmentalise activities, the community members will naturally seek to get whatever help may be available. So, the health worker effectively becomes a social worker, and this fits well with their description of their own work as social service. As argued above the trust of the community on the belief that the health worker has the best interest of the community at heart. However, this will only get the health workers through the front door and, eventually, they must prove that not only do they have the desire to act in the community's interest, but that they have the ability and the 'power' to do so. To become credible 'resource persons' for the community, they must prove that

they can address community needs, which can be anything from advising on medical matters to helping the community access desired resources, such as clean water or vocational training. The health workers feel that, if they fail to communicate their willingness to address these concerns, the community will not have confidence in them, in their intentions or in their health education messages.

One day on a routine visit to an urban slum with a health worker, we were invited into a woman's hut to share a glass of water, and out came the photos of her children. As I looked at each of her children in turn she told me of their success; imploring *"do not look down on us because we are poor and have no education, we have small huts but big hearts"*. On many levels a similar statement can be made about the work of health workers. In their daily tasks they are faced with a myriad of community problems. Their ability to address these are limited by a very small budget, restrictive targets and narrow parameters but their efforts are driven by their desire to do 'social service' and their capacity for empathy. It is often said that you cannot make those, who do not want to, listen. By building respect and credibility, however, you can make people want to listen. Similarly, you cannot teach to those who do not have the capacity to listen but, by enabling people to satisfy their basic needs, you can make them able and interested in listening. Since there are no resources allocated for this purpose, the health worker must rely on his/her experience, innovation and network to make the impossible possible.

Prior to establishing this credibility in the eyes of the community the health workers remain untested entities, entities that provide a service and a set truth which the community have little reason to choose, above the plethora of other 'solutions' and 'truths' available to them. Once the health workers have established their credibility, this changes the nature of their relationship with the community. From a programmatic point of view, it moves the work closer to community health interventions than is indicated by quantitative outcome measures. The impact of credibility goes well beyond day to day activities. In a climate where legitimacy and reputation are scarce resources, not just in relation to funding and implementing partners, but equally in terms of meaningful engagement with the community, then credibility becomes a commodity (Mosse, 2006).

This is especially so in an urban environment where increased access to services, as well as increased number of pseudo professional providers (with varying degree of skill and honesty), means the health workers face increased competition in the field and can no longer rely on a 'captive' audience (Leonard, 2005). Local 'beneficiaries' can no longer be seen merely as passive recipients of interventions and, as implementers, the health workers' efforts to establish relationships with the community faces stiff competition for the attention of a target audience, that audience being the poor urban slum-dweller, who is subject to a barrage of contradictory information from political parties, commercial interests, government officials and NGOs (Standing et al., 2008).

Local communities want tangible benefits, material outcomes and 'curative services', not prevention or health education lectures. As representatives of an organisation, that primarily provides the latter, the health workers face a complex challenge. Health workers lose credibility if they have no curative skills or services to offer (Standing et al., 2008) especially in an environment where such services are offered by other agencies. As literacy and communication has improved, communities' access to information has greatly improved. As such, the challenge of establishing relationships of trust has become increasingly demanding, the health workers face a struggle for legitimacy in a pluralistic environment (Bloom and Standing, 2001, Standing et al., 2008).

As a result, the impact of establishing credibility goes beyond the mere ability to carry out interventions in the field as it reaffirms access to communities, validity of information and lays down the potential for future partnerships.

### *7.3.4 Access, Potential & Process*

The process described above allows the health workers to build rapport with the community, through bartering time and respect, to establish access and rapport. Locally, communities do not sit passively by and wait for someone to happen by with some health information, nor do they see the health workers' activities as

something that will necessarily benefit them. When asked to attend a health forum or a health education session, it is not uncommon for the community members' response to be something like: *"how much will you give? If I come, how much will you give me? What is my necessary there, why I will come?"* [as recounted by a CHO]. Senior managers or other non-field based staff will often argue that it is difficult for health workers to motivate the population to attend health education and the like, without having something concrete to offer them in return. When confronted with this statement, the health workers recognise that it is a problem that they cannot offer direct benefits to communities, as in terms of food or other necessary items but do not see this as a serious hindrance. Instead, they would speak of respect, understanding and humanity.

Having already established a relationship of trust and credibility which allows them access to the community, access which goes beyond the mere physical presence, the health workers do not feel that lack of material resources is necessarily a hindrance. As we discuss this process one evening, one of the health workers argues [excerpt from field journal]:

> *"Now they are getting confidence in us. Not a one day process. Continual process. One has one capacity, another, another capacity. Must bring out potentialities. Success through unity approach. No need for rules and regulations. We have to tell people it is your health forum not ours, only then can it function. You have to feel that which you are suffering as a problem, if you need assistance we will give you boost. One person comes into the forum and refers a TB case. Later can see that person has a life, has health. They feel achievement. Is your achievement, not ours. They can feel so proud. This is empowerment. They must go themselves rather than spoon-feeding. Can get some knowledge experience. Now they are asking for us to come. Want a resource person to discuss problems with. Before this did not happen, did not push."* I ask him what if the health forum only discusses gossip and TV serials, what does he do then, and he replied: *'that is also OK. Through this they will build trust and relationship. After this they can speak openly about other things'.* I asked him why there is such a strong focus on women. He explains that *'women are backward in educational aspect, literacy. Women are the main persons in the house, whole family caregiver. If we strengthen her automatically community and family becomes strengthened'.* He says there is a Telugu proverb: Intiki Deepam Illalu (ఇంటికి దీపం ఇల్లాలు) [Trans:*wife is the light for home*], then he asks rhetorically: *without light, how can we develop?"*

In this narrative the emphasis is on identifying potential/talent in the community, and developing this (whatever it may be), to a point where the community is empowered enough to be able to receive and respond to the health education conveyed. This 'potential', as discussed by the health worker, resonates with the wider anthropological and public health debates surrounding 'local strategies' and the need to build on these to improve the impact of public health interventions. The process described above, with the establishment of trust, credibility and access can be seen to be part of this same paradigm, though the health workers utilise different vocabulary. This is an exciting aspect of implementation, and one which draws extensively on the agency and creativity of the implementing health workers.

In simplistic terms, the building of rapport is about establishing relationships of trust and respect through respectful interactions. The health workers' willingness to go beyond the official remit of their work, to engage with the problems of the community, shows respect for the concerns of the community, and their utilisation of pre-existing knowledge and referral networks allows them to help the community to solve their problems in creative ways. Once some of these problems have been addressed, regardless of a successful outcome, the health worker has effectively demonstrated their respect for the interests of the community and thus established their credibility as a resource person. In return, they gain the respect and credibility which allows them to carry out the tasks with which they are officially charged.

The focus on rapport is interesting, because it redefines the interaction between health workers and community, from one which casts the community as passive recipients to one which recognises the extent to which meaning is created in the interaction between the community and health worker. This is especially so as we recognise how important the 'little things' are, and start to build an understanding of how health workers do the thing that they do, rather than merely focusing on the results of their actions in the form of outcome measures. By looking at implementation as a process, we can build an understanding of the extent to which roles and relationships are worked out continuously at ground level, rather than divided up prior to engaging with the community. Intervention can then be understood as based on partnerships of necessity, rather than stated intention, as

both parties have something to gain from the process. For the community this might be access to material resources whilst for the health workers it is simply a matter of access to the community. The partnership is structured around the 'real' rather than 'perceived' needs and capacities of communities and constantly renegotiated at field-level and this is something which many interventions are too rigid in their focus on plan and outcome to achieve. Innovation, partnership and negotiation rely on organic flexibility and individual approaches, which are difficult to plan for as they involve relinquishing a certain amount of control and rely on trusting in the skills of health workers. As the concerns of the community change over time, the relationship must be constantly re-negotiated and adjusted. It is not simply a matter of establishing rapport and leaving it at that. Relationships, much like gardens, must be tended. In addition, the partnership between community and health worker is embedded in the physical locality of the community and is navigated in real-time. It is not planned or scheduled in board rooms or encoded in ATPs. Rather it unfolds in real-time in the field and must, therefore, be flexible and responsive enough to deal with all eventualities, without becoming hostage to them. The ability to navigate this partnership relies on a good rapport with the community, on respect for their needs and belief in their potential as well as empathy with their lived reality.

I would argue that the process itself is what is important, nevertheless the process is often forgotten. If we shift the emphasis of analysis to the process, rather than the specific outcome of the negotiation, it becomes apparent that, in many respects, the 'product' the health workers barter for is not physical access or simply the ability to impart knowledge, but an issue of establishing the credibility required for the community to accept the knowledge they are trying to impart as, not only correct, but relevant to their lives. This access then, arguably, becomes the organisation's greatest asset, whether or not they recognise it as such, as this relationship grants future access to the community for any number of activities, and the credibility of the health workers increases the likelihood of meaningful uptake of the knowledge which is imparted. In addition, the increased access and respect creates a forum in which the community are willing to share their concerns and problems more openly, meaning that a wide range of concerns can be addressed

through these same channels. Once established, these channels can also be utilised to identify potential within the community and to develop this, to empower community members to access available help through referrals and coaching.

Thus, if we shift the focus from outcome to process, we can see that the 'product' ILO offers as an organisation is not so much structural services as it is 'human services'. It is not so much structural interventions or material resources that are crucial to the outcome but rather the investment of time and empathy by the health workers that enable the organisation to achieve outcomes on the ground. Yet, human resources are, more often than not, classed as an expense rather than as an asset within the organisation. In addition, the application of time in such an unspecific manner, with only vague promises of future benefits and increased legitimacy, is not unproblematic, as one of the health workers lamented: *"patient want more and more time, but we are very busy workers. We have targets we want to reach but people want more and more time. That is not good."*

### 7.4 Qualitative Work in a Quantitative Reporting Structure

> *"Main, especially with ILO, is quality. Quality work is there, not quantity. Meaning....always thinking about quality. We have a certain formats, we are...people are devoted persons." (ULP staff member)*

All work at ULP is conceptualised through monthly work schedules referred to simply as ATPs (Advance Tour Programmes) and these structure working practices, as well as targets. They are drawn up, signed at the bottom and then, more often than not, they are disregarded. Day to day work is ruled by opportunity, cancellations and chance. The commitment to targets and achievements is made with the signature at the bottom of the page, but success in the field depends on the ability to adapt to changing circumstances and to exploit unforeseen opportunities, as and when they present themselves.

On the 1st day of my first visit to ULP, in January of 2006, I met with the project officer in order to finalize the itinerary for my visit. I left the office with a detailed

schedule of my next two weeks in hand. From that point on, nothing I did bore any resemblance to the planned activities, as programmes were cancelled, opportunities seized and adaptations made. At another point during my fieldwork I was attempting to get a 6 week ATP signed off by the relevant parties when a senior manager sees what I am doing and says smilingly:

> *"HO [Head Office] used to insist we make plans for every month. Ok, we do. Then we had planned meeting at ESRA Hospital and taken permission. Madam was also coming. And when we are in vehicle on the way HO calls and says, 'no, you come here. We have meeting'. So, how can we plan? But we make plan. Ok. When completed, 100% different doing. (..) I remember one time we were in HO. Big meeting. Making plans for future, 1 year, 2 years, 3 years. Like that. Then someone asked 'what are we doing tomorrow' and everyone said 'oh, we will see about that tomorrow. See what happens'. But we are making plans for years, but tomorrow no one can plan."*

The distinctions between quality and quantity, is about more than a crude differentiation between text and numbers. It determines where the organisation chooses to place its emphasis, and it relates to the perception of the health workers within the organisation. Health workers work to quantitative targets, but tend to evaluate themselves against a qualitative definition of work, against the achievement of the elusive 'social service'. As one of the health workers phrased it, targets are one thing, but outcomes, defined in qualitative terms, are what the organisation is really about:

> *"Numbers. They collect numbers. Like account. Like bank. But you cannot calculate human service. Ok, we can have targets. But this is not what ILO does. What we do. (...) Targets are not outcome. Outcome is in our mission statement, not in the monthly report"*

Thus, in the eyes of this health worker, the real outcome of their work is, as the organisation's mission statement says, to restore hope and dignity to those suffering from leprosy and related diseases. The emphasis is on the individual or rather an endless string of individuals. Much has been said about the need to develop leprosy policies which include the needs of the individual. But to the health worker it has always been about individuals. Their empathy with the lived reality of the community and the individual sufferer makes it hard to see outcomes in numbers as being in any way relevant. The lines that exist in our minds, in our

targets and in our reports become insignificant, fluid and blurred in the field. This is the reality of the working situation of health workers, this is their lived reality, and as we must strive to understand the lived reality of clients, we must also aim to build an understanding of the lived reality of health workers, in order to understand and appreciate (or replicate) the outcomes generated by their diverse activities. Health workers are doing qualitative work within a quantitative reporting structure and this, in reality, means that there is little understanding of the actual work they carry out in the field, as this is rarely documented. In a report an ulcer is an ulcer. Three ulcers healed is a tangible and measurable achievement which can be reported to management or to funding bodies. However, the reporting of three ulcers healed tells us very little about the work that went into healing them as in terms of how many hours the health workers invested in treatment; how much counselling; what detailed knowledge of the client's life, their constraints and activity patterns; how many home visits, coaching sessions and follow ups; not to speak of the cumulative impact of relationships going back years establishing relationships of trust, credibility and respect. The treatment of an ulcer may appear simple according to manuals but as one starts to unravel the treatment 'process' it soon becomes apparent that is all but simple. Quantitative measurement of what is essentially a quantitative process fails to recognise this simple complexity.

Though quantitative outcomes are impressive enough in their own right, it is to a large extent the 'soft outcomes' that determine the impact of health workers' activities. Firstly, the notion of 'quality' is emphasised as USP by everyone at ILO from the very bottom of the organisation to the very top. However, the quality of the work often goes unreported. It is retained in the attitude of patients, staff and the organisation's reputation. There is a tacit understanding of what 'quality' means within ILO but, as this understanding has not been coded into formal policy thereby creating structured consensus, this understanding remains anchored on the assumption of a 'shared knowledge' within the organisation. The notion of quality, if formally defined and disseminated, could constitute a point of stability in a period when the organisation is undergoing rapid changes, however, some have expressed concern that 'quality' will in fact be the first casualty of these changes. Secondly, documentation of quality is important as a signifier that this is truly

something the organisation recognises as an important part of implementation. At present, only quantitative outcome measures are recoded, which places the emphasis on targets and achieving the numbers for the reports rather than on the 'real' outcome which can be seen in more complex qualitative reporting processes. The health workers are evaluated on their ability to reach the set quantitative targets and, as such, their daily activities are "*not matching with our work. In one or two cases we can do, sure no problem. But continuously we want to do that activity we should have that plan of action also.*"

There has been great emphasis put on the need to recognise the strengths and capacities of clients in order to improve interventions. I would argue that it is important that the organisation be equally mindful of the strengths and capacities of staff at all levels, including the staff at field-levels, and to utilise these in order to grow as an organisation. The quality behind the quantity, the story behind the ulcer, lies with fieldworkers. The organisation and others outside, need to hear these stories. In addition to the lessons to be learnt, it is important for how health workers, and the work they do, are perceived within the organisation.

### 7.5 The Secret Ingredient

> *"I am not telling greatness or anything. Just what I am telling, because in this 18 years of my experience. Here, between the patient and me – love and affection.(...) Respect is always there. Even though he is a patient is also a human being. We should give respect also. There is no order. Because our....he came here, means that is our lucky. People should think. 'oh I am here to do. That's why he came'. Not like that. Because I am as an instrument.(...) So, respect is there. But maybe these people are getting....giving affection. Main affection is there. Once affection, means we can do anything. Means we can heal the patient and....that is holistic approach, what I said.*

There is great individual variety among the health workers in terms of skill and approach to engaging with the community and building rapport. However, they all share a commitment to what they term 'social service', or what I might term a willingness to engage with people's lived reality, which drives them to find creative

ways of addressing the needs of the community. What drives this commitment is empathy, a shared, deep empathy with the situations and problems faced by the many individuals and communities with whom they interact. Driven by this empathy they have built extensive networks of resource persons, governmental and non-governmental, to which they can refer people with problems that ILO cannot address, due to lack of resources or differences of remit. Thereby, they transform themselves into powerful 'human resources' in the face of limited material resources. Thus, their role becomes to spin straw into gold through utilising these networks to provide outstanding health and social care on a shoestring. Faced with limited resources, they find innovative ways of utilising what is available.

The organisation's slogan is 'Touch me, See me, Heal me, Hear Me'. The inference here goes beyond the symbolic act of touching the leprous body to include the touching of mind, hearts and, ultimately, to the touching of lives. The slogan signals an approach based on respect, empathy and a willingness to engage with client's lived reality and embedded lives. The health workers at ULP have empathy in abundance, perhaps occasionally to excess, but this must be seen as an effect of both their long entanglement with the field and, partly, as a result of their stated desire 'to do good', to do social service. However, empathy is not something which can easily be codified in training manuals or taught in seminars. Therefore, it is crucial that the principles of empathy with the service user are somehow maintained through organisational continuity and, importantly, encapsulated in future leprosy policy.

What runs through the process of building rapport, as described above, is an emphasis on the importance of health workers in forming relationships of trust with local communities. Health systems are an agglomeration of different people, structures and capacities all of which play a crucial part in the achievement of its goal. And, if all aspects work together towards a common goal the effects can be remarkable: *"Health worker can give the treatment, doctor can prescribe the treatment, official can provide the salve and administration, the donor will provide the money... enough? All, these all groups should be mutual understand. The official can rule them properly, the doctor can assess the proper problem and*

*prescribe the medicine, and health worker go and catch the cases and develop the network, rapport, confidentiality and bring to the...eh...bring the cases to the doctor. This all network – when strengthened – automatically person feel come himself, or her, ... themselves."*

The process by which outcomes are achieved can be seen as a long journey, the very foundation of which lies with the health workers dedication to social service and empathy with the people they serve. The importance of empathy as a motivating factor and as a guiding principle is visible at every stage in the implementation process and is crucial to unifying qualitative and quantitative approaches, as expressed in their dual emphasis on the importance of both targets and 'social service'. As motivation, empathy drives the health workers' engagement with the community. Yet, this encounter is also dictated by the structures and discourse within which the encounter takes place. Empathy can thus be seen as the secret ingredient, the factor which drives the health workers to go beyond the remit and parameters set by the organisation and apply improvised agency in their interactions with the community. Through this process of implementation the health workers create more than outcomes, they create meaning, meaning which is crucial to how they understand themselves and their social identity but, also, meaning which is crucial to how we understand implementation and its outcome measures.

### 7.6 Off the Cuff and On the Fly

> *"Maybe seeing a little work here that particularly I have to do because this job has been given to me. And I have to do it. It doesn't work. One must have innovative skills to do it, because it is not something which you read in books or someone will teach you 'do it like this'. And there is some many innovative ways. He did it like that. We did not tell him each and every line you do it like this [referring to CHO setting up Health Forums]. He has done it by himself. So, that each individual skill is, the refined skills are there. All they have very good rapport [meaning all CHOs]."*

As expressed by the senior member of staff above, the everyday work of health workers requires significant improvisation and this improvisation constitutes innovative agency and creative action based on a sense of security in shared knowledge. Faced with limited resources and guidance in the field the health workers rely on improvisation and creativity and, as such, much of their work is based on spontaneous, off the cuff, adaptations. As discussed above, the health workers also take considerable direction from the communities they interact with. Implementation in this way is not merely a series of isolated actions but the expression of an ongoing relationship.

As demonstrated in previous chapters the health workers are part of a wider discourse which determines the questions they ask, their expectations and, to some extent, their actions in the field. It is this discourse which constitutes what can be termed their 'shared knowledge'. It can be argued that it is not the health workers' intention to be innovative and thus all their actions are based on their shared understanding of the goals and intentions of the discourse. However, discourses translate poorly to field conditions and, in addition, communities do not share the heath workers' discourse and could not care less what they and the wider leprosy policy and public health field intend as the outcome of the interaction. As such, the interaction in the field becomes a renegotiation of intended outcomes between the discourse of the health workers and that of local communities. In many ways this is the essence of the health workers' challenge in attempting to reconcile local strategies and organisational intent, and the true outcome of the process discussed above.

Faced with a pluralistic and competitive health provision environment and local 'beneficiaries' who are active participants in negotiating their relationships with NGOs and other service providers the health workers' efforts to establish trust, credibility and access constitutes a renegotiation of the relationship between organisations and communities thereby becoming the axes along which the terms of engagement are established.

However, by drawing on the strengths and capacities of the community itself, by transforming themselves into a 'human resource', where their contacts, knowledge, time and experience become the main ingredients in an ongoing partnership between themselves and the community, they can provide the results the community expects despite material restraints. These trust relationships are often relationships established between individual health workers and specific members of a community and, though they are experienced by the community, as a whole, as a relationship between themselves and the organisation, they often fall by the wayside if an individual health worker is moved or removed. Through redefining their services, from non-medical assistants to 'social workers', the health workers re-conceptualise their work from service provision to providing networking, enabling and empowerment; from organisational overhead to a resource.

### 7.7 I See Multi-Dimensional Health Workers

These insights enable us to elucidate two further issues the way in which discourse is created through local interactions in a dialectical relationship to international discourses and the relationship between structure and agency in the work place. Firstly, the negotiation and renegotiation of relationships at ground level illustrate Comaroffs' (1992) assertion that discourse is not merely imposed by international agencies but is equally the result of local interactions. This relationship, between local and global discourses, cannot be understood as merely hegemonic, where the local view is subjugated to a dominant global discourse but, rather, can best be understood as two equally polyvocal discourses in a dialectical relationship to each other. Thus, the 'shared knowledge' that is crucial for creating the environment in which the health workers feel free to exercise their agency, safe in the knowledge that their actions constitute 'social service' and 'duty' and that there is a shared understanding of what constitutes 'social service', can be understood as a product of the interaction between local and global discourses. The particular 'shared knowledge' in this case might be, as discussed in Chapter 5, a direct result of the efficacy of the elimination narrative in generating loyalty and shared empathic understanding. However, public health, in general, is reliant on 'shared knowledge',

perhaps even more so than most other work settings; with its strong bio-medical associations it often asserts knowledge of 'right' and 'wrong'; public health practice is often anchored in individuals desire to 'do good' and programmatic mandates to relieve suffering; with its focus on population health, rather than individuals, public health retains a utilitarian undertone; and, with its emphasis on equality and standardisation, it often relies on guidelines and frameworks premised on shared axiomatic beliefs. This 'shared knowledge' can perhaps more accurately be termed paradigmatic rather than hegemonic but, either way, it can be seen to exert a strong standardising influence on the field. In this capacity this 'shared knowledge' is crucial for expedient implementation and a fundamental component in the social identity of most who work in the field. As discussed earlier, health workers' interactions with local communities revolves around negotiating relationships, these negotiations can be understood as dialectical interfaces between global and local discourses. This dialectic can be seen reflected in how the health workers define their work, their job satisfaction and their role in a wider hierarchy.

Secondly, so far in the thesis I have focused on the extent to which the health workers are embedded in the wider structures within which they work and how these structures in turn shape the health workers' discourse, what they think and how they think it. To this end, I have draw on Bourdieu's concept of the Habitus as an analytic framework. However, for Bourdieu actors fail to demonstrate agency outside of that defined by their habitus (Bourdieu, 1979). For Bourdieu agency is the result of *praxis*, which can be seen as the result of the unconscious, pre-reflexive rules (Bourdieu, 1977, 1990) thus, for Bourdieu, agency is limited to a choice, a selection between predefined options, set out by the field and habitus. This framework will be discussed in detail in Chapter 10, and at this point it will suffice to say that I find this approach to agency fails to sufficiently emphasise the importance of the health workers' actions and agency in reframing relationships within the structure.

Let us look more closely at this term *praxis*. It is not my intention to give an overview of the history of the term praxis as, after all, it has been kicking about since the days of Plato, occupying a central position in Marxism, existentialism and

hermeneutics although everyone does apply the term differently. In general, the term praxis is used to discuss actions which take place somewhere between practice and theory, to denote actions informed by wider influences, conscious or unconscious (St. Clair et al., 2005). By focusing on this landscape between theory and practice the concept allows us an opening for discussing the construction of agency in the work force. Marx splits praxis into the reflexive and the non-reflexive, where "the reflexive praxis is understood as the moment in the dialectic change, and the non-reflexive as the routinising mechanism operating within the ideologies as a reproductive or status quo maintaining" (Madhu, 2005:15) and, he argues, it is the habituating non-reflexive praxis that leads to false consciousness (Woznicki, 1976).

Work is more than the creation of products, it also creates meaning. Anthropological studies of worker relations in Eastern Europe during the Soviet era demonstrated that workers were not merely alienated and objectified but that they created their own meaning through play and social relationships (Haraszti, 1978, Burawoy, 1982, Harris, 1987). From a Marxist perspective, industrial society is seen to transform creative subjects into passive objects by removing the worker from the labour and creating a worker alienated from the work, from himself and from his fellow workers. This perspective often does not distinguish between physical and mental work and creates an image of a one-dimensional man where the body's subjection to alienating working conditions equals the mind's subjection to false consciousness. Antonio Gramsci (1971), on the other hand, argued that the automation of labour accomplished the opposite, as the automation of labour freed people up to think, dream and reflect on the nature of their situation, arguing that the worker cannot necessarily be seen as conformist. Having said that, Gramsci did agree with Marx that the worker was subject to mental subjugation but, he argued, the workers themselves were complicit in this subjugation through a hegemonic process; where he defined hegemony as the manufacture of consent, as an order of things where there is a shared moral language.

This shared moral language, shared knowledge and goals, is exactly what the narrative of leprosy elimination has achieved in the workforce. Dedication and duty

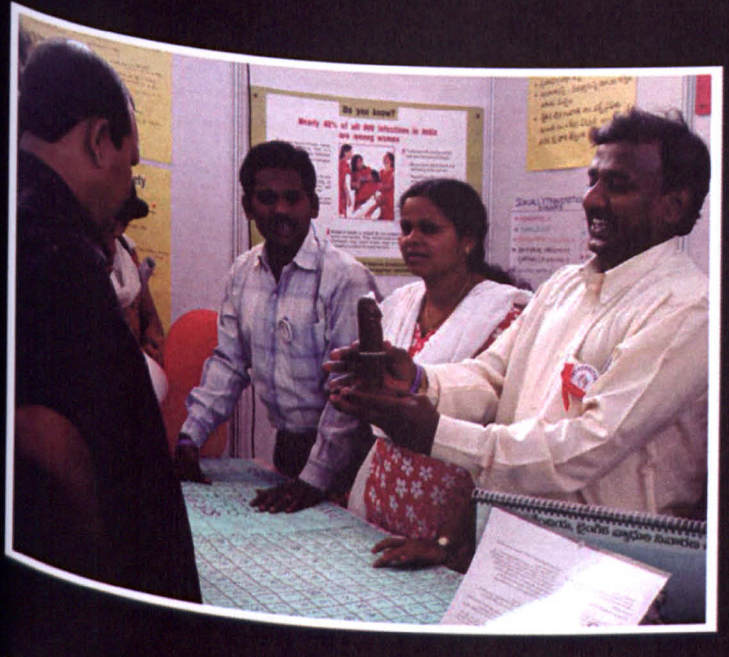
is not the product of fear or habit but the attachment to, and agreement with, a civil order and ascribed accountabilities. The health workers can be seen to be complicit in their own subjugation through the reproduction of the system, hegemony or whatever you wish to call it, through the acceptance of the prevailing social order. In the case of the health workers this attachment to the civil order is mirrored in their attachment to a hierarchical social order in general and in the work place in particular. As will be discussed in a later chapter, one of the primary means of advancement through the Indian work hierarchy is through the patronage of a superior and, in return, the subaltern offers their total dedication, loyalty and protection. The significance of this relationship of client-patron lies, in this context, not in the power differential or in the willing subjugation of the worker, but in the quality of patronage as culture (and class) (Gilsenan, 1977).

Clearly the ULP health workers do not constitute merely an alienated labour force. To understand how the health workers daily activities in the field create meaning as well as outcomes we must look beyond the hegemonic nature of their working relations by expanding the analysis beyond the one-dimensional man. In his book, *"Two-Dimensional Man"*, Abner Cohen (1977) argues that in order to understand working relations we must understand the extent to which the stability of systems is created and maintained through symbolic relationships and that we must recognise that culture is as important as power in these relationships. Thus health workers' acts of agency within the structure must be understood as more than mere expressions of hegemonic relations and must be seen equally as symbolic acts with implications for the culture and discourse of the organisation. This analysis of meaning creation through daily activities ties in with a wider debate surrounding implementation and the role of health workers as street level bureaucrats, as lackeys or as liberators. By applying insights from modern social theory, we can build on these insights and move towards an analysis that transcends this tendency to either focus on a subjectivist analysis of how workers perceive their world or on an objectivist analysis of how workers are objects of the wider structures they work within.

The assertion that work creates meaning as well as profits may perhaps seem a little less interesting in relation to the not-for profit sector than an industrial sawmill but the perspective still offers some relevant insights as in terms of social identity creation, what outcomes are deemed important, and how local discourses are established and maintained. In addition, it holds important implications for the creation and sharing of organisational culture. Of course, not all acts of agency are as subtle as those described above and, at times, the health workers would find occasion to apply a more manipulative and direct brand of agency, as we will see in the next chapter.

SAY NO TO HIV
YES TO LIFE!

సురక్షిత సెక్స్‌కు కండోమ్
(నిరోధ్) వాడండి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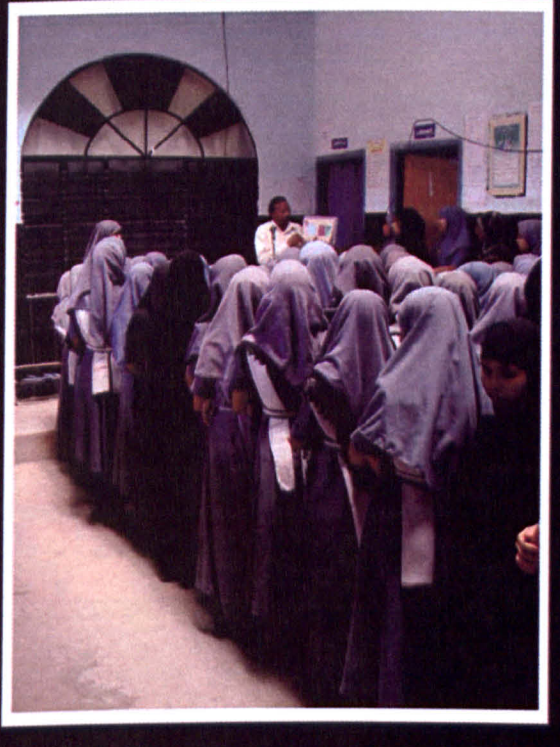

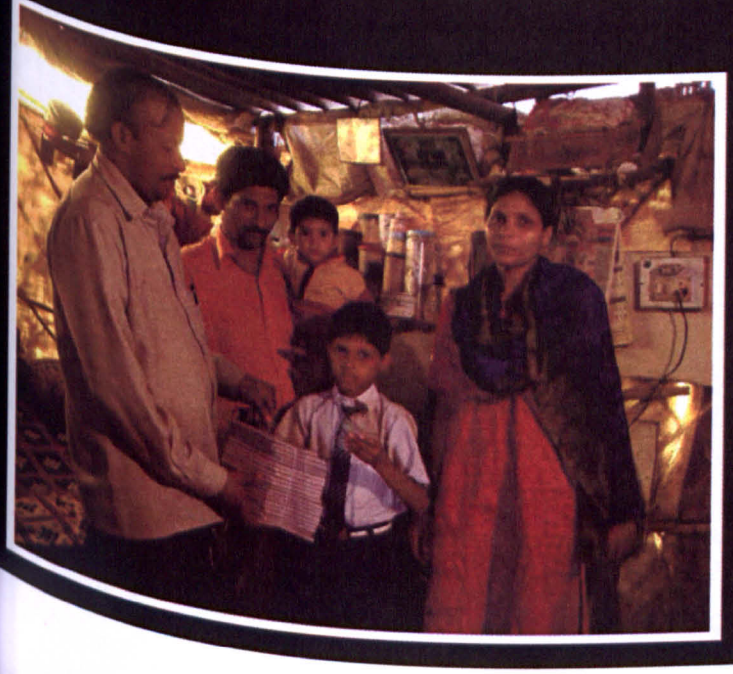

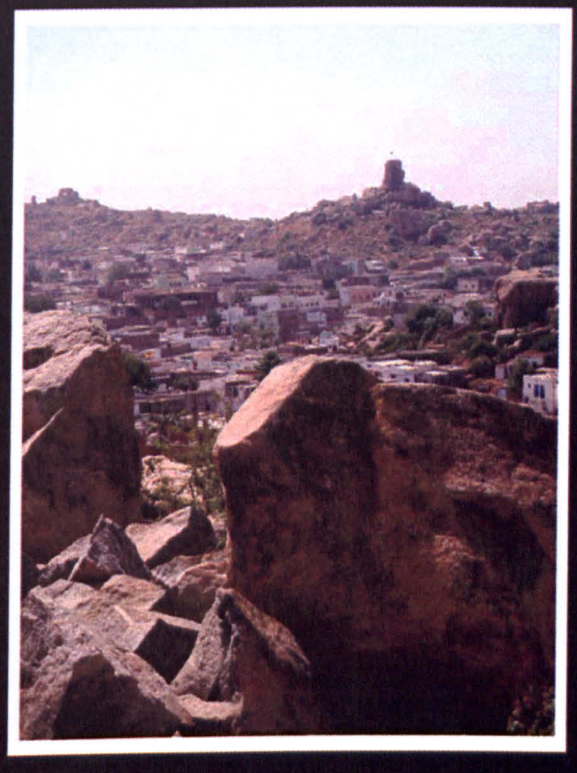

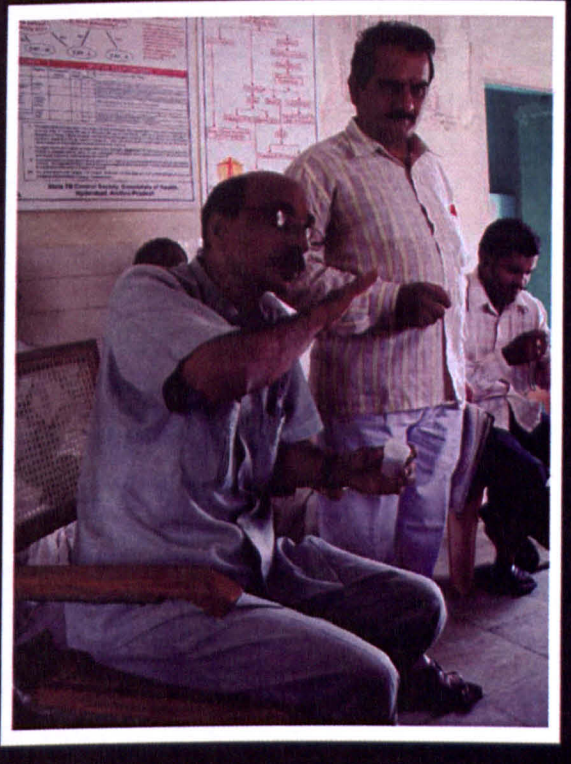

Yuvachaitanyam 2007
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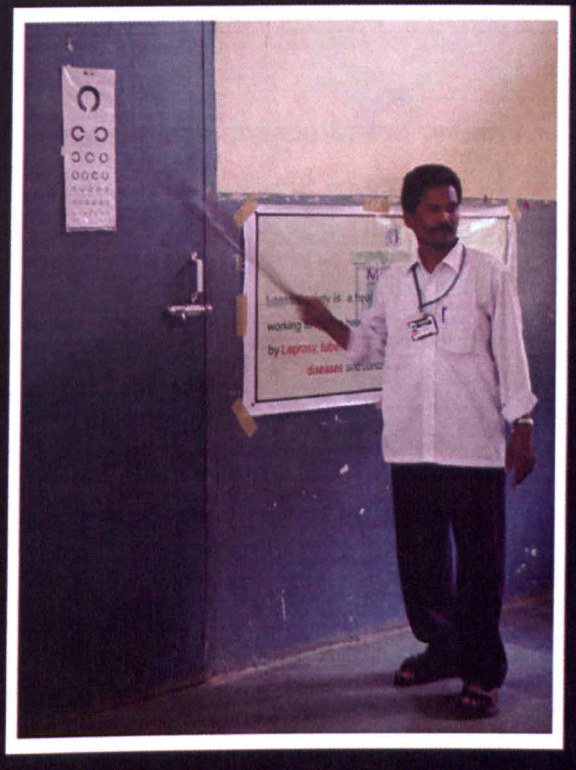

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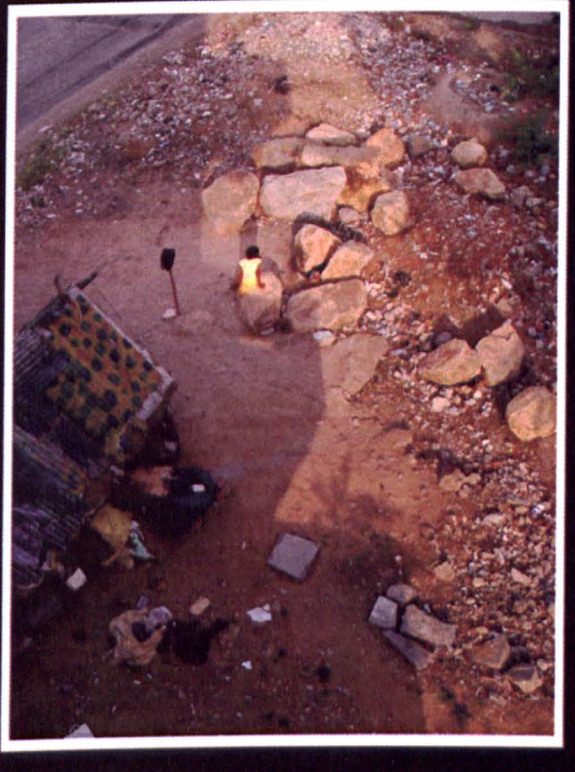


## 8. Manipulative Agency

Clearly the ability to exercise judicious agency, by working outside of the preset framework and remit of assigned tasks, is crucial to the successful completion of the work of ULP field-level health workers. They listen to the expressed needs of the community and adjust their work as a result of ongoing negotiations, thus establishing rapport and a relationship of trust. This enables them to achieve the targets the organisation has set for them and ultimately contribute to their perceived larger goal of 'social service'. However, their agency is not limited to merely working beyond their remit or exercising judicious agency. Some acts of agency entail a direct and conscious circumvention of the very structures and systems the health workers work to implement and maintain. However, these acts of agency cannot be understood merely as acts of resistance or defiance to a constricting system (Abu-Lughod, 1990). In order to understand these acts we must try to form an understanding of the underlying motivation behind them. Motivations which I will try to demonstrate are related to a desire to cut through bureaucracy in order to 'lubricate' the system and aid in the attainment of the underlying goals of the project's set targets. Some of these acts are direct manipulations of records and underhand methods of motivating clients which may have unintended consequences and implications. The application of innovative approaches serves to illustrate the importance of agency, even within the structure, despite the embedded nature of health workers which has been discussed in previous chapters.

### 8.1 Working to Targets, Working around Targets

In the previous chapter, I discussed the importance of understanding the role of qualitative work even within a quantitative reporting structure. Building on from this, there are instances where the health workers experience a direct conflict between the official targets and what they see as the 'real' work of ILO. Health workers work to targets as this is how their performance is reviewed but, also, because they

agree with these targets. However, they recognise the limitations in their application and often stress that you can achieve your targets without having provided social service, and it is in the social service that the real test of your achievements lies. It is also worth noting that, whilst health workers habitually speak of respect, understanding and humanity, programmatically and internationally, we speak of targets.

In this respect, targets are both something that health workers work towards and something they work around, particularly when targets are perceived as counterproductive to 'social service'. For example, when filling in the government's Simplified Information System (SIS) reporting system, the health workers would often have to weigh the consideration for the needs of the person affected by leprosy against that of the needs of the reporting structure. Recognising both as equally important they would find a way to make space for the individual in the structure through the conscious and intentional manipulation of the system.

On the government SIS patient cards there is no space for comments or notes where the health workers could make note of irregular circumstances. However, the health workers would often make allowances for the particular circumstances of individuals. For example, when it came to the timing of distributing or administering 'pulses' (monthly medication regiments) for a particular patient who is going home to their village for a festival and require their pulse in advance. In this case, the health worker provided the patient in question with the pulse and made a note in ILO's internal records, whilst entering the 'correct' or 'anticipated' date the patient should have picked up their pulse in the SIS records, thereby, in their minds, satisfying the demands of both parties.

This is only one arbitrary example of such accommodation for individual circumstances within the system. Though working around the targets in this manner can never be included in plans or quantitative reports, it is often crucial for the success of interventions in that it offers flexibility and responsiveness to individual needs, which are clearly too complex to be easily planned for or accommodated in standardised reporting structures. Yet, they are often of the

utmost importance to the success of an intervention both in qualitative and quantitative terms.

This is not merely a question of administration or documentation practices. It is a question of social identity and where the emphasis is placed in the intervention and in the organisation, on achieving the targets or on doing social service. There has to be a balance between the two in order for an intervention to be successful.

In addition, an understanding of the way in which the delicate balances between individual and programmatic needs are maintained at field-level is crucial as the organisation moves towards more client driven and rights based approaches in new initiatives.

### 8.2 28 Days Later...

Record keeping raises interesting questions. The integration of services into the general health system was preceded by a simplification of government records. According to the health workers, the thinking behind this move was dual, to standardise record keeping in order to facilitate better data collection, monitoring and evaluation, as well as to enable non-specialist service providers to maintain records. However, the downside of SIS is that what used to be a detailed record of each consultation, counselling session, medication provided and a monitoring of skin and nerve involvement over an extended treatment and follow-up period – a veritable book varying in length from a few pages for simple cases to whole case files of 10-20 pages for more complicated ones – has now been reduced to a single A4 card, recording the bare essentials and, some would argue, not even those. This shift, though standardising the system for mass implementation, entails a loss of detailed monitoring and provision of individual case management for each patient.

SIS has been in place since 2003. According to the NLEP II guidelines on integration of services, leprosy cases should be held by individual UHPs and

records maintained by that UHPs staff. However, I found that, in the area covered by ULP, it was the ULP health workers who maintained all records and merely had the monthly report 'signed off' by the Medical Officer in charge of the UHP. This raises interesting questions around 'accountability'. According to NLEP II, the Medical Officer at each UHP is responsible. However, the DLO has effectively 'outsourced' the leprosy work in the area to ULP, making ULP responsible for supporting integration, collating data and reporting back to the DLO. Whichever way you turn it around, ultimate accountability lies with the state and, therefore, the system maintains the pretence of having Medical Officers sign off on reports they know little about. This kind of NGO-ization is not uncommon in public-private mixes interactions of this kind and the confusion around accountability is a oft reported side-effect of the process (Nazneen and Sultan, 2009).

The SIS consists of 4 sets of records:

L.F.01 – individual patient card. 1 A4 page giving bare minimum of details.

L.F.02 – combined records of all patients under treatment at one UHP

L.F.03 – MDT drug stock record (including batch numbers and expiration dates)

L.F.04 – monthly reporting form (cases added/deleted, active cases, drug stock)

There is agreement amongst the health workers that the official SIS records must be kept in 'pristine order'. That they must be correct, no matter what. One health worker told me that the guidelines stipulated that the L.F. forms could only show a variance of 1-2 days in the individual treatment logs and that it was vital to ensure this was the case as the records might be audited at any time. I did not have a chance to verify this interpretation of the guidelines. However, the rigour of the official system is ill suited to replace the detailed records the health workers have been used to keeping, and is ill equipped to handle the level of flexibility that the health workers are accustomed to extending to their clients.

The health workers do not usually perceive differences between the needs of the local community and the organisational targets as in terms of a conflict. Even in instances where a conflict is blatant, the health workers are reluctant to phrase it in

these terms. Rather, they speak of situations that must be systematically worked through in a manner which will satisfy both local needs and system requirements.

Such a conflict often arises in relation to the official government records where the health workers resort to creative bookkeeping in order to balance the needs of the person affected by leprosy against that of the needs of the reporting structure, as in the instance below (from my field notes):

> "We arrive at M_____UHP at 9:30 am, chat briefly to the ANMs and say hello to the Medical Officer. The UHP currently has 9 active cases (7 MB, 2PB) and we sit down to *'engage with'* records as Mahesh phrases it. I ask Mahesh why there are so many cases at this particular UHP and he explains that a large Lambadi slum is part of this UHP area, plus some new cases were identified through the rapid survey we carried out. All the patients at this clinic attend the ULP Out-patient clinic for care and treatment, but records must be kept at the UHP for *'proper procedure'*. Mahesh explains that he cannot come all the time to maintain records, so he comes once every month or so specifically to update SIS (...) As I sit there watching him Mahesh writes down that one of the patients received their monthly pulse on the 26th of this month, I point out to Mahesh that it is only the 20th. Mahesh explains that the 'expected' date of the next dose is always a month minus 3 days. So, since the patient picked up their last batch on the 29th [of the month before], then this would be the date they should pick up their dose. From the ULP file that the health workers are maintaining in parallel with the SIS records we can see that the patient had, in fact, picked up their dose on the 5th from ULP when they came in to pick up some steroids for a reversal reaction. Mahesh says: *'We know the patient and understand what they need. Sometimes they need to pick up medication in advance. Then we need to let them do that or maybe they will not take the medication at all. We know the patients and have time to do. In the future, who will do? ANMs not even filling in paperwork now, when integration and they are told to do they will fill in paperwork but no space in paperwork for information on client. SIS paperwork must be clean and logical. So people can come and check plus see prevalence etc. Otherwise too confusing.'* (...)
>
> Mahesh sits at the table filling in records with calendar in hand. Not transferring information from ULP patient file to the government record in order to record when they received treatment in practice but, with a calendar in hand, in order to calculate 28 days from last date. Justifying this, Mahesh argues: *'Numbers here [meaning dates] will not match numbers there [meaning ULP internal files]. Here will be official dates, 28 day pulse. Even government told us to do like this. A course [of treatment] must be finished in 6 – 12 months, like that. If patient is late just fill in correct date...'* In jest, I ask if he could not just fill in all the date at the very beginning when the patient was first registered – and he looks shocked and answered in all earnestness: *'No, madam, not like that'*. So I tell him I understand. It is for auditing purposes etc. To myself I think that the end result is the same, i.e.

> official records will show 100% compliance and accuracy in dates. This is not very helpful as an indicator. (...) Since no patient take treatment here, no actual drugs pass through the UHP. Even so, the drug register at the UHP needs to show drugs coming in and going out. So, Mahesh updates the [L.F.03] drug register, complete with fictional restock from ULP, by using whatever batch/serial number he has at hand for incoming/outgoing pulses. This means that batch numbers in the record bears no relation to batch numbers consumed by patients. Even though records meticulously record who received what and when, as this bears no relation to reality, there is no way of tracing the recipient in case there is a bum batch or any other problem. Because [this record keeping process] is all an elaborate fiction – making sure that all the different books make sense and dates correlate and drugs correlate etc – is quite a feat and takes quite some time. Mahesh stays seated at the desk with all the papers spread out in front of him completing a complex jigsaw puzzle. At 11:30 we have finally finished updating the records for 1 UHP and 9 active cases. Creative book-keeping is time consuming. Even if you have a B.Com degree."

This is not an isolated incident but something which I observed most of the health workers doing and, when I confronted them about the practice, they all confirmed that this was the 'proper' way to maintain records. The health workers utilise creative bookkeeping to balance, not the books, but the needs of the clients with the needs of the system.

Unorthodox as this practice might have seemed to me, there was little indication that government officials were particularly uncomfortable with the practice. They certainly were not with the outcomes it generated. According to the health workers, it was government officials themselves who had taught them how to complete the reports and explained to them the importance of keeping the records 'accurate'. Considering how homogenous the reporting practices of the health workers were, it is certainly clear that someone had taught them, however, if this was government officials or not is hard to say.

There were signs that official policy was shifting in this regard. As leprosy prevalence fell, the government aimed to carry out more detailed analyses on treatment outcomes and other factors. In doing this, the 100% outcome measures were no longer useful, but had come to constitute a hindrance to data collection. In a project meeting to discuss a new report the government wanted ULP to generate

for all their UHPs one of the senior members of staff argued: '*What I feel when I see your 100%, is how is this possible? In AP all patients come on time? When patients come you fill in next month in advance with correct date. Should not be like that. If patient comes on a date we should put that date only, correct date, not change*'. If this does indeed entail a real change in reporting practices, what will this do to the health worker's creative bookkeeping and the space for flexibility created by this?

In summary, SIS records are generated for the benefit of the system rather than for the patient, to count indicators rather than keep track of an individual's treatment, progress and health. Knowing the health workers, I feel confident they will find some other way of reconciling the needs of patients and reporting structures as their ability to accommodate individual variance, to be flexible, is crucial to their everyday working practices and how they understand their role and social identity. The way the health workers see it, if a patient comes seeking treatment and are told that they cannot receive treatment at that time or place due to bureaucratic restrictions, the likelihood is that the patient will not return at the appointed time or place but will be lost to treatment. Creative bookkeeping affords the health workers the flexibility they need within the most rigid of structures.

### 8.3 Let the Record Show...

The Simplified Information System was not the only context in which the health workers had cause to apply this kind of manipulative agency. Another example of manipulative agency could be seen in relation to a rapid survey carried out by ULP and government staff in December 2006 and January 2007. Interestingly, this second instance also revolved around records and book-keeping. This is perhaps not surprising, since the written records of an organisation is very often the most concrete manifestation of the structural limitations health workers face on a daily basis and, thus, their way of dealing with these limitations will often be a tangible reflection of how they deal with the wider structures. Below follows a summary of the survey work, the events surrounding the survey, the debates it sparked

amongst the health workers and, finally, an account of the manipulative agency as exercised by health workers to achieve their targets in what they perceived as the most 'useful' way to do so.

What constituted the most 'useful' approach was hotly debated amongst the health workers and the situation resolved in different ways by different actors. The debate itself was less about the underlying principle and more about what specific course of action would be most 'useful' as in terms of achieving maximum social service. The health workers generally agreed that this kind of rapid survey was a waste of time and that it might even be counterproductive. They argued that their efforts would be better spent doing a proper survey, the way they used to do them, or by doing group talks and health education to raise awareness. However, what was hotly debated amongst the health workers was what they ought to do about the fact that they felt that the targets, the ordered action, did not tally with their understanding of what they ought to be doing. Half the health workers argued that they should follow their instincts and the other half argued that it did not matter what they thought, that they should simply follow orders despite any reservations they might have. Thus, the debate was over the importance of hierarchy and following orders versus acting in a way that they themselves felt would achieve maximum impact on the ground. Having said this, through manipulative agency and a bit of wrangling, some found a way to achieve both.

The rapid survey lasted for roughly a month from December 2006 to January 2007. One afternoon, just as we were wrapping up and getting ready to leave for the day, one of the supervisors called an impromptu meeting and announced that 'orders' had come down from the District Leprosy Officer (DLO) and the Collector to conduct rapid surveys in targeted areas. The decision had been taken to conduct morning surveys from 7:00 to 12:00 commencing the next day. The female staff protested that they could not change their schedule with no prior warning, they would need to make arrangements for food and child care. The women argued that had it been a one-off thing they could have managed somehow, but as this was to be a semi-permanent arrangement they would need time to make adjustments.

The health workers were to split into two groups, one North and one South of the river, with each group aiming to reach at least 250 households each day. All other duties, such as UHP clinics would continue as usual with OP duties from 14:00 to 17:00. In addition IEC van show schedule would carry on as usual in the evening, meaning that the health workers would be working from 7:00 to 21:00 at least one day a week.

The rapid surveys would target slum areas surrounding UHPs without registered active leprosy cases. He explained that there was concern that voluntary reporting was not working properly and that, as a result, cases were going unreported. Specifically, there was concern that detection was not working in government areas as case reporting in the ULP project area far exceeded that in the remainder of the city. ULP covers 26 UHPs with 9 CHOs and detects an average of 6-7 cases per month in their project area. The government covers 26 UHPs with 26 Assistant Para-Medical Officers (APMOs) yet only detect 1-2 cases on average in their area. Initially, there had been concerns about systemic over diagnosis by ULP staff but, as all cases had been independently verified, the concern had now shifted to whether or not the government APMOs were doing proper work. The government annually spends several lakhs on APMO salaries and wanted to make sure their money was well spent. Or, at least, this was the justification the supervisor gave us for the survey.

There were very mixed feelings amongst the health workers about the directive but, in Mahesh's words: *'This is the way it is. We are only fieldworkers. So we follow what we are told. This is the way it is.'*

On the day of surveying I am picked up at 6:45 with breakfast still in my hand and only half a cup of coffee in my system. I jump on the back of the motorcycle and we barrel down uncharacteristically quiet streets, through the cold morning dew, towards the meeting point we agreed yesterday. It is January and quite cold in the air, the sun doesn't really take until 8:00-8:30. When we reach the meeting point it takes a while for everyone to gather and, impatient to get going, we head into the slum to get a head start. Everyone knows where we are going, and we are hardly

inconspicuous, so the stragglers find us quickly. We proceed to go door-to-door, knocking and asking people for the correct house number, the name of the head of the household and the number of people residing in the household. Then we show them the pictures in the flash-book and ask if anyone in the house has any kind of skin patches or loss of sensation. Due to my halting Telugu, I leave most of the talking to the health workers and play the lovely assistant presenting the flash-card. In the early hours of the morning we reach quite a few people but from about 9:00 we encounter more and more padlocked doors and empty residences as people have already left for work.

It is clear that the health workers are enjoying working as a group again and spirits are relatively high. Even so, the usefulness of rapid survey as a methodology remains hotly debated in the group. Some of the health workers are very brief and business like. *'Any patches? No? Name? Number? Ok. Bye'*. Leading to the others arguing, *'you are not doing it properly. Not explaining properly. What is the point if we do not explain?'* Indeed, walking down an alley that has already been covered, chatting with one of the health workers, a woman sticks her head out of the door and asks us why 'that man' came and 'took their name'. This is one of the dangers with rapid surveys, that people are left wondering what just happened and what it was all about. There is little time to explain about leprosy or, indeed, why we are inquiring about skin patches in the first place. Rushing through the process, and not taking the time to explain or listen properly, it is very likely that people do not have time to process what is going on and often answer 'no' to our questions just to get rid of us.

The crux of the health workers' discussion is whether or not this rapid survey is a waste of time and resources, or if it can potentially be useful. Most of the health workers feel that their time would be better spent raising awareness through group talks. Indeed, some of them utilise every opportunity they get to give impromptu talks to any group of people hanging around, justifying their action by arguing that: *'Survey interrupts all the work we have been doing. Need awareness building so people can understand their problems and come to us with their problems. Cannot explain in 2 seconds – get 15-30 people together with leaders and anganwadi*

*worker, then we can explain well and the people will understand. Not just individual but whole community. This is waste of time'.* Whilst others feel that there is no point in arguing the issue, they have been given a task and have a target to reach so they should just get on with it and get it over with.

Clearly, conducting group talks on the side limits the number of households that individual health worker can cover in a day. Mahesh and Sadguna have covered about 500 people in 100 families between them. Manoj on the other hand has been conducting group talks and jotting down people's names but no house numbers or family sizes. Instead he fills in approximately the same number as the others on the reporting sheet arguing that he conducted 20 group talks with between 5-15 people and that each of those people would represent a family of 5-10 people. Thus he has theoretically covered about 300 people in 100 households. Based on this assumption, he then goes back through the survey sheets and fills in each cell with a fictive number of household members for each entry, erring on the high side so there will be no questions of his (or his method's) efficacy. The big difference in his eyes (and I would tend to agree) is that when you go door-to-door people are going about their lives and are busy doing other things. They do not have the time to talk, to listen or look. But when you conduct group talks, people stop to listen and take the time. Indeed, Manoj was the only one to find a case today. I have no doubt this methods is just as good as any of the others, possibly better, but why bother with this charade book keeping, filling in each household membership number by random and adding them up to create a fictive total to report? It really doesn't tell anyone much about anything except, perhaps, about the nature of bureaucracy and the importance of appearances. Despite their vocal complaints and expressed frustrations the health workers are actually amazingly insightful when it comes to the rules of the game and they manipulate the system masterfully.

Another day, another survey. Each of the health workers is clearly more enthusiastic and motivated about the survey when it is taking place in 'their' area. By 10:30, some of them are running out of steam, so we sit down on a stoop and start collating the paper work. Officially we have covered a total of 258 houses, 336

families and 1778 people today. As we sit there on the stoop, tallying up the day's statistics, a man comes over and shows us a patch on his abdomen, a hairless patch with some loss of sensation. He also exhibits thickening of one of his earlobes and some possible infiltration of the forehead. We refer him to ULP office for formal diagnosis and skin smear. Vibhavasri complains: *'this morning one whole slum and no cases, because we run, run, run. Now we sit and one case comes. People are unsure and need time. Not just running and running saying 'curable skin disease', 'curable skin disease'. Need to explain and give time. Then cases will come. When we sit'*. However, running is kind of a defining point of a 'rapid' survey. This is not surveying in the manner the health workers are accustomed to and that is part of the contention. However, I understand where they are coming from. It does seem like an elaborate exercise in collecting numbers rather than reaching a maximum number of people in a meaningful way.

As we are on our way to leave we pass a physically disabled child with the most aggressive scabies infection I have ever seen but it does not seem to bother him particularly. Two of the health workers stop to talk to his parents, who say he is deaf and has some 'neurological' problems. The health workers write down the details of a few organisations and schools nearby that specialise in disabled children for the parents and instruct them to go to the UHP to get some sulphur cream to clear up his scabies. As we are leaving one of the health workers even finds time to give some young men hanging around the cigarette stall an impromptu lecture on the dangers of smoking, and me a lecture on the benefits of fresh neem branches for cleaning one's teeth. Even within the rigid confines of a rapid survey the health workers find scope to go beyond their remit and do social service.

By the end of the survey period the DLO issues new instructions to ULP to stop door-to-door surveying and concentrate on group talks instead. When I ask the health workers why they think the DLO suddenly changed his mind, and at such a late stage, they waggle their heads and say *'it is all politics. Some people are not doing their jobs properly. Since now we have passive case finding we need to raise awareness but the government sector is not carrying out any awareness raising*

*activities thus they are not finding any cases. This is why the DLO and collector set up the rapid survey, to get people to work. Not ULP, they are working fine, but the government staff. This is not the time for a survey, but as long as it gets people to work it is a good thing. What we really need now is increased awareness'.* By the end of a month of rapid surveys, we had found 16 new cases, more than double the monthly average.

### 8.4 Manufacturing Compliance

Both the previous examples of manipulative agency, where health workers go outside of the system to achieve their goal, have focused on ways in which health workers create flexibility in a rigid system in order to cater to the needs of their clients. However, manipulative agency goes both ways, and is more commonly, though less dramatically, employed as mechanisms for creating compliance with the needs of the system and the organisation's intent amongst their clients. The very nature of leprosy policy in its current manifestation, like much public health policy, can be seen as a mechanism of control and compliance (Ogden, 1999). The application of these mechanisms, which are designed to facilitate the manufacture of compliance, do not, in themselves, constitute acts of agency but, rather, can be seen as an expression of the intended function of the policy itself. However, sometimes health workers exercise manipulative agency in how far they push the application of these mechanisms and how calculated the manipulation of the client is. One dramatic example of this was recounted to me by a member of staff at ULP who describes a situation where he utilised blackmail and intimidation as a legitimate (in his eyes) strategy to achieve compliance:

> *"Starting to the....persons psychology we have to tell. One tribal child is there in S___ Nagar. Huts. So many huts is there. Small, like this. Children 7 years I think. She has multiple lesions all over the body. What I am told: 'you bring her, otherwise she will come like this* [showing claw hand]. *Compulsorily you have to....you child will take treatment, otherwise she will very dangerous situation'. She didn't come. Like that we said: 'you come, otherwise your huts will remove from here'. I told. Then one auto person came, in that locality. Near about 20 huts will be there. 'ah, who are you. We have some leader. I will tell to your office. Why you are remove this?' He is*

*some literate. The auto person. He knows some literacy, like that. Same time, what I am doing, at that time I will call the auto people separately. I told: 'the all officer who are there. Just fear to him. Why you are in between came and you are telling like that? Her daughter is having lesions, by that I told like that. She will take medicine it will OK. Otherwise she will like this* [showing claw hand]*'. 'Oh, that's....I will convey'. The auto person went to that person: 'no, no, no. Sir, is very good. You go to for that treatment. Otherwise, why Sir will tell like that'. She has taken treatment. She is OK. Sometimes they don't know. They are illiterate, eh. They don't....he is illiterate, he don't know. The auto person some...a little bit know. Asked: 'Why you are removed the huts? We have big leader, we have minister and so many things we are doing'. Sometimes happens. According to person's psychology we have to tell. If they very well educated we have to tell softly: 'Sir, it may be leprosy. You can come and you can take treatment'. OK. For that people. If you don't take treatment you will such a...we have to create like us. Some fear will compulsory came."*

For the health worker, the threat to take away someone's home if they do not follow the treatment plan seems a legitimate way of getting the patient to follow directions. When questioned by other members of the community, their explanation was simply that they must do whatever it takes to get these 'uneducated' people to take treatment, to 'save them'. Not all manipulative agency can be seen to be ethical, or even positive. As a mechanism to short-circuit the system the strategy also carries with it the potential for abuse of power and for bypassing some of the safeguards built into the system specifically to protect both health workers and people affected by leprosy from such abuses. Health workers are both lackeys and liberators, both social agents and self-interested individuals and, as such, their deployment of agency within the structure must be seen to have both positive and negative consequences.

### 8.5 IMPRO-WISE: Now, Add a Pinch of Jugaad

*"Ganesh appears in some unofficial versions of the Mahabharata, a Hindu epic, as a scribe, whose quill pen breaks in his haste to record the poem as a sage recites it. Not to be beaten, Ganesh snaps off one of his tusks, dips it in ink and does not miss a line. Those virtues of determination and improvisation explain much of the success of India's celebrated IT firms, such as TCS, Wipro and Infosys. Each firm has its epic tales of deadlines made and obstacles overcome." (Economist, 2007)*

What I have termed manipulative agency above is not a new concept in the Indian context as it corresponds quite well with what the design and management literature would term 'Jugaad' (जुगाड़). Jugaad is a Hindi word which means 'an improvised or jury-rigged solution; inventiveness, ingenuity, cleverness' (DTD, 2008) and has its root in the Sanskrit 'yukti', meaning 'to solve a problem where typical linear logic will not work'. There is no English word that provides an adequate translation; the closest we come in a European language is perhaps the French term 'bricolage'[2]. In the English speaking world the term jugaad is perhaps best explained with a reference to the hero of the popular 1980's TV show "MacGyver" who was distinguished by his ability to transform everyday objects into tools, the ability to fashion a chainsaw out of a toothpick, a shoelace and some fertiliser, in order to overcome impossible situations. Jugaad implies assimilation, adaptation, innovation, ingenuity, cleverness and improvisation. Though the term is not used by the health workers I studied, and I could find no equivalent term in Telugu, the concept is very much present, both in its positive and negative manifestations.

These days, jugaad is hailed in management literature, almost uncritically, as the secret to Indian success. However, a few years ago, the term had a more negative connotation in that it was used to refer to the utilisation of a connection or a source to get something to which you are not entitled and do not deserve. This usage is related to words more familiar to us in the West, such as 'nepotism' and 'cronyism'. However, in modern colloquial slang the term has taken on a new and more positive meaning. The term gained popularity as a name for a low-cost Punjabi vehicle fashioned with a converted water pump for engine. However, the term is now widely used to refer to "creative improvisation and finding alternative ways to do improbable things" (Gaurav and Singh, 2008).Even the potentially negative aspects of the term deserve to be taken seriously for, as Gupta (1995) argued in relation to corruption, it must be seen as an alternative political organisation

[2] I want to distinguish my use of the term bricolage here from it's established association within anthropology with the theories of Levi-Strauss and his distinction between bricoleur/engineer, primitive/modern, concrete/abstract in 'The Savage Mind' (Levi-Strauss, 1968)

functioning as a legitimate form of political action within the specific context (Barnard and Spencer, 2002).

The term jugaad correlates particularly well with the type of manipulative agency observed amongst the health workers, in that it emphasises utilising the system to your advantage rather than working against the system. Jugaad is not an expression of opposition to a system, but rather the ability to work the system to achieve the seemingly improbable. There is no such thing as a perfect system, and even a system like the SIS records, that have been purposefully perfected and honed for their specific purpose by top-down leadership, has limitations in the face of real world complexity. In this case, it is the willingness and ability to apply flexibility and to work through the system which ensures success; through jugaad or through manipulative agency. The health workers are committed to, and part of, the system and would generally wish to avoid openly defying it, however, to forgo the opportunity to achieve something merely because it is against the rules would be considered immoral for, "in India, a lost opportunity is an unforgivable waste. And improvisation is the mother of survival" (Varma, 2006).

However, the concept of jugaad is not without its critics. Some argue that the Indian willingness to go outside of the system, to break the rules, to achieve results means that the system is never critically challenged and, thus, never developed in its own right. *"Jugaad has flourished and has become an unavoidable part of the system, because we are governed by a passive state of mind, dominated by the who-will-bell-the-cat syndrome. Unfortunately this tendency only offers a make-do system, but fails to offer permanent solutions for betterment and perfection"* (Shukla, 2002). In other words, Indians may not be constrained by a system but work outside of it only as a means of not having to change the system.

The ULP health workers believe ferociously in the system they are part of but also believe in their right to side-stepping without feeling that this threatens the system in any way. They express their agency within the structure rather than in opposition to the structure. To recast their behaviour using popular anthropological perspectives of 'resistance' or' weapons of the weak' would be to gravely

misrepresent their point of view, as the health workers themselves would see their behaviour as quite the opposite, as working to maintain cohesion, co-operation, and hegemony. They would even argue that their behaviour is sanctioned by agents of the system, if not officially by the system, for obvious reasons. This dedication to, yet irreverence for, the system was very difficult for me to understand as an outsider, and I had to take great care not to rephrase my informants' relationship to their reality to suit my own preconceived ideas.

### 8.6 Beyond the Incidental

Following on from the above discussion, I would like to suggest that, if we wish to understand agency in an Indian context, we need to attempt to build an understanding of how agency is expressed within the structure, as actions not in opposition to the structure but rather as innovation to uphold this structure. We need to move beyond a dichotomous view of agency and structure and move towards a more nuanced understanding of the motivations behind health workers' agency. We must aim to understand agency as a proactive act, rather than merely a reaction to subjugation, to analyse how health workers' understanding of the structure drives them to exercise agency in order to cover-up what they see as short comings in policy and strategy, and to understand how this enables them to achieve their targets as well as maintain their social identity.

The health workers' actions also serve to create the illusion of successful planning by achieving the desired outcomes and meeting the requisite targets through the process of innovative implementation. However, as argued earlier, with the recent changes in leprosy policy and the changing culture and values in the organisation, we cannot merely assume that the health workers' understanding of the intentions behind strategies correlate with that of senior management. As the leprosy discourse and narrative changes, and in the face of a potential organisation schism (as will be discussed in the next chapter) it is becoming doubly important that we try to understand the perspectives and motivations of health workers specifically. In

order to achieve such an analysis we will have to draw extensively on a number of social theories.

So, if we accept that jugaad is at once a creative innovation and a force which fails to challenge the systems, thus simultaneously being proactive and reactionary, then the crucial question to answer becomes: Is there a way we can harvest this innovation and use it to develop the system without stifling future innovation? Dr. Deming famously said that 'nice people trying hard ain't a system' and this is true of the work of health workers too. As important as their manipulative agency is to their ability to do their work and for its impact on individual patients, it is also true that, unless we can extrapolate from their experiences, they will remain merely nice people doing nice things. By building an understanding of how the health workers exercise their agency within the system, we can learn from the creativity already at play in the system and use this to improve the system rather than to merely fix problems as they arise. We need to achieve this without stifling the creativity from which we draw our inspiration. This is where an anthropology of public health and an ethnography of implementation can play a role, as an improved understanding of the interaction between health workers and the system they operate within, as well as the wider process of implementation, might enable us to understand how to draw on capacities, creativity and manipulative agency already present in the structure in order to improve systems and future planning.

The possibilities for ground level insights to influence organisational, national or international discourse depend on the ground level perspective's ability to move beyond the incidental and to play an active part in ongoing dialectic processes of discourse creation. It depends on the presence of a structure capable of absorbing insights about health workers' activities and an organisational culture that both provides channels of communication through which some of these insight may be communicated and that is interested in propagating ground level experiences to a wider policy audience.

## 9. Organisational Culture - Considering the Framework.

In order to understand the changes that are taking place at ground level it is important that we look closer at the structures within which these changes are taking place. It is one thing to argue that health workers are deeply embedded within the structure that surrounds them, another to try to form an understanding of exactly what this structure constitutes at an organisational level. As discussed in Chapter 5, international policy is a key issue here but, though the project staff have access to international journals and grey publications by organisations like WHO and ILEP, it is clear that the primary discourse within the project is dictated, not by international and national policy directly, but by the organisation's interpretation of, and recreation of, these policies. In order to survive in a changing policy landscape, leprosy organisations have had to adapt to recent changes, changes that have had ramification all the way down to field-level in terms of working practices, discourse and social identity. Neither has there, from the perspective of the heath workers, been much opportunity for input by field-level staff on the direction or further implications of these changes. Recent changes go beyond affecting the allocation of resources, staffing structures or working practices to shaping the core values that guide the organisations operations, and its culture.

By applying some insights from organisational anthropology, I will attempt to demonstrate that organisational culture must not be seen as something an organisation has, as a tangible object that can be shut up in mission statement, boxed away and brought out for meetings and national holidays. Organisational culture is something that is constantly negotiated and recreated through daily interactions, internally and externally, of the organisation. Organisational culture is something the organisation is, rather than has, and it is something that different actors within the organisation have varying ability to affect and direct. Thus, the daily interactions of the organisation can be seen as a constant power struggle for influence over the organisation's culture. This process could simply be understood as an internal power play between personalities within the organisation, interesting in its own right but, ultimately, without significant ramifications beyond the career path of the individual. However, the implications of organisational culture go far

beyond this, as it is ultimately a question of meaning creation and discourse determination.

Organisational culture can be seen to directly impact how service users experience the health system, as it is instrumental in formulating service procedures. However, by applying Comaroff's double dialectic perspective, we can move beyond this literal understanding and come to see the struggle over organisational culture as a struggle to exert influence on the local dialectic process and contribute to the formation of future discourses on a local and global level. As such, the barriers to bottom-up communication influencing organisational culture are the very same barriers that limit the understanding of the qualitative aspects of health worker activities, and the capitalisation on these existing creative capacities that would allow a move towards more innovative and interactive planning.

The main focus of this research is on ULP, on the project and its staff, not on the wider Indian Leprosy Organisation. Nevertheless, to ignore the fact that ULP is part of a wider organisational structure and all that entails would be untenable. However, since my research was not based within the upper levels of management, my data on this is derived from a handful of interviews, official meetings I attended and a lot of hearsay and speculation within the project and the wider organisation. Thus, I feel I need to be careful not to make unsubstantiated generalisations about the organisation. Therefore, I wish to stress that this chapter will focus on how the health workers perceive the current situation within the organisation, merely providing senior management input when it is needed for clarification of issues the health workers do not have access to. Thus, in the below account it matters less if these conditions are 'true', i.e. whether or not conditions are like this on the ground, and more that, regardless of 'reality', this is how the health workers experience their reality.

Let us first look a little more closely at exactly what we mean by organisational culture.

## 9.1 Power Play - Organisational Culture á la Geertz

Organisations, and the people working within them, have been the subject of anthropological studies for almost a century; from the first crude 'experiments' of efficiency in industrial production, through functionalist studies up to recent work on organisational culture and power relations. The organisations studied were often industrial facilities. Even so, the insights garnered from these studies are equally valid to other sectors. As with implementation studies in public health, there has been a tendency in the past to dichotomise the management/worker, top-down/bottom-up dynamic. More recent work on culture and power in the workplace has largely moved beyond simple dichotomisations to look at the mechanisms by which organisational culture is created, and to focus on the role power relations play in this process. The history of anthropological studies of organisations is summarised in *Table 5.*below.

| Era | Trend | Characteristics | Method | Examples |
|---|---|---|---|---|
| Pre 1920's | Fordism | Organisation as a machine. Chaplin's Modern Times and conveyor belt efficiency | Experiments dislocated from everyday working conditions. Efficacy and physical conditions | (Taylor, 1947) (Mayo, 1933) Hawthorn Experiments |
| 1920 → | Functionalism | Organisation as organism. Management centred and top down. Agenda derived from management for whom there was a problem on the 'floor'. No wider social, economic or political context. Focus on providing correct physical and psychological working conditions and results will follow. | Large scale interview programmes + covert observational studies | (Roethlisberger and Dickson, 1939) (Chapple, 1953) (Gardner, 1977) |
| 1950's & 60's | Structure /Change | Successive moments of equilibrium between workers and management objectives. Wider context taken into account. External roles carried into workplace such as class, age, gender, race, etc. | Participant observation and social theory to examine external roles and social groups | (Emmet and Morgan, 1982) (Cunnison, 1982) |
| Present | Power /Culture | Emphasis on studying up, from micro to macro. Debates about how to include wider structures into studies, as backdrop or causation. Focus on power relations and organisational culture. | Studies of organisational 'culture', systems of ideas and discourse analysis | (Pettisgrew, 1985) (Nader, 1972) |

*Table 5.* History of Anthropology of Organisations adapted from (Wright, 1994)

In the past there has been a tendency to approach organisational culture as if it was a set attribute of the organisation, as something an organisation has and as

something that can be seen to define the organisation. However, to understand what organisational culture entails as a concept, we must start with Geertz (1973) and his insistence on 'thick' descriptions which argue that interactions and culture alike are processes of constant negotiation about the meaning of routine actions, where different actors have different abilities to influence the process to their advantage. In this perspective, culture is seen as a process, which redefines our approach to recognise that *"organisational culture is not something an organisation has, it is something an organisation is."* (Smircich, 1983:347).

Organisations are only made real by being given meaning, through a continuous negotiation of the meaning of everyday routines. Through the creation of shared value and goals the organisation moves beyond the functional organisation of working practices and takes on a moral dimension. However, as culture is created by the competing influences of those who form part of this culture, we must recognise that there is no such thing as *a* culture, but rather a multiplicity of competing views. By looking at who expresses which view at what time and in which context we can gain valuable insights into the underlying motivations behind these different views. We need to understand what is being said by different actors, and why. By adding power to this mix, we can move the analysis beyond Geertz and progress towards an understanding of the extent to which different actors within the organisation do not just have different views but, also, *"different structural power and personal ability to impose their meaning on events so as to make their interpretations definitive... It is this political process, a contest to assert definite interpretations which produce material outcomes, that is the key to anthropological understandings of culture, of relevance to organisational studies."* (Wright, 1994)

Looking at the strategic deployment of nostalgic discourses by health workers, it is clear that these must be seen as attempts to influence the wider organisational culture through the timely and repeated expression of their own particular perspective. Thus, these discourses are part of the creation of, as well as, components of, organisational culture. Organisational culture works through a shared world view and, as such, it creates emotive ties to the wider aspirations of

the organisation by ascribing meaning to routine activities and by linking these to a shared past and the vision of a glorious future. *"The daily practices of workers in defending themselves against various modes of control are also struggles over cultural meanings, values, and goals. These cultural values are shaped, contested, and defended in different domains of power relations. While such conflicts may not necessarily result in structural transformation, the changes they effect in everyday attitudes and norms – or what Williams calls 'structures of feeling' (1972) – are part of the dynamics of civil society" (Ong, 1991:281).*

### 9.2 Be the Change

In the case of ILO, it is not only the organisation's culture that is changing. Change is all around. The policy landscape is changing, the working reality is changing, and the national and international context is changing. This is a time of transition for leprosy organisations as they attempt to diversify their activities, justify their existence and find a new discourse narrative to structure their interventions. Change is natural, change is necessary, but change is rarely comfortable. This is also true of the process of change taking place within ILO.

Whilst discussing recent changes, and the uncertainty these might introduce into the organisation's culture, with a member of senior management, he countered by arguing that these objections always arose in relation to impending change and described how change has been achieved in the past. He described how the decision to diversify the organisation's activities beyond leprosy had been necessary despite internal concerns. He argued that *"if you ask a person affected by leprosy what we can do to strengthen systems, they will say: give training. Of course. But we are not thinking about the millions of other people."* So, to assist these millions of other people, ILO's remit was expanded to include TB and malaria activities. The funding for these activities came in the form of a 5-year EC grant, but the EC wanted the organisation to move beyond a disease perspective and focus on 'health system strengthening'. Accepting this challenge is one thing, working out what this means in reality is quite another. He argued that

*"interpretation of the project was like 'blind men describing an elephant'. So many different thinkings were there on what the project was about. Actually, mid-way the government strategy was redefined. So we had to change with this. Since we work closely with government. Some new reporting was initiated, more scientific way".* Finally, through the act of compromise, the project was conceived in such a manner so as to aim to strengthen health systems and to bring down number of leprosy cases. In his mind, the current challenges faced by the organisation/project today constitute nothing new and can be resolved in a similar manner.

However, these practical changes also entail a wider cultural shift within the organisation. As the organisation redefines its organisational culture there are several factors which deserve a closer look. Firstly the extent to which external forces are driving these changes and, secondly, how barriers to communication within the organisation affect the health workers' ability to influence changes to organisational culture.

### 9.3 Fashion Victim - The Financial Imperative and Re-structuring

In general, the funding available in the international public health market has increased drastically over the last decades (Kates et al., 2009), nearly quadrupling between 1992-2006 (Farag et al., 2009). A lot of this increase has been directed at the growing HIV/AIDS crisis (Shiffman, 2008) and funding for leprosy specific work has become increasingly scarce as the prevalence rates have fallen.

There is a lot of talk of the hegemony of the international policy agenda. However, what is less often discussed is the mechanism through which this influence works. The impact of international policy is often diffuse and implemented through the mediated demands of donor agencies. The impact of donor demands and funder agendas have the power to determine the direction of projects in a way international agencies never could, even when it comes to organisations like ILO who are aware of their own strengths and core values and who can take a proactive approach to defining their internal discourse. Of course, donor and

funding body agendas are determined by international policy discourse to some extent but internal agendas, marketing considerations and arbitrary factors are also involved in setting their agenda. Complying with international policy recommendations can be seen as an intellectual discussion and an ongoing process. Funding, however, is not optional, it cannot be selected away, and there is a danger of organisations following the funding and shaping goals and targets after the requirements of the donors. As the organisation's discourse is the result of incremental changes, a result of numerous involvements with varying funding agencies, the internal discourse within the organisation risks becoming fragmented.

During my field work I was not directly involved with drafting funding proposals or with those within the organisation whose job it is to seek out and secure funding. Though, with falling leprosy prevalence rates and little money coming from traditional sources of funding, and as ULP's funding was coming to an end at the end of 2007, the issue of funding would come up in almost every project meeting and tended to revolve around what activities the project could get money to carry out, rather than what needed doing or what ILO as an organisation should be focusing on. However, these were discussions amongst project staff that were not in a position of much influence.

During a discussion with a senior member of staff in the organisation a rather different perception emerged: *"About funding – actually have to think about funding, who we take funding from. Have to have values and focus that match with our core values"*. He argued that organisations are increasingly forced to focus on specialized, short term projects, as donors are not interested in giving funding for core organisational structures. As funding for leprosy dwindled ILO had to take up new challenges:

> *"There was not enough leprosy for all these small organisations to survive. Have to have flexible approach. In this way we had to take up TB, malaria, health systems – like this. Actually thinking is there that leprosy organisation cannot do this kind of work. That they can only do leprosy. But we have taken up and made success."*

In response to this increased funding pressure ILO broadened their remit and instigated a number of new projects. He described how global market structure is pushing for growth and how, as an organisation, they must either grow or sink. He explained that the fastest and easiest way to grow is to take on bigger and bigger projects, which are then implemented through local NGOs, who are able to cover a larger area and population at lower cost. ILO's relatively horizontal pay structure precludes the organisation from taking up these projects as a direct implementing NGO, as the overheads would be too high and the interventions would not be cost-effective. In this way funder demands for ever larger interventions has led to an increase in the number of projects that ILO has taken up in the capacity of co-ordinating NGO.

This development has lead to a rapid growth in middle management over the last 5 years and a trend towards a more vertical pay structure within the organisation to make their implementing staff more competitive in relation to other potential implementing partners. With a workforce that has been with the project for more than 10 years, and has been receiving incremental pay rises for that period, ULP's staff is seen as impossibly expensive and, at the time of my fieldwork, staff salaries constituted 52.5% of the project's total budget. In the eyes a member of senior management this kind of project was no longer tenable and he went on to argue:

> *"we have to move from 20 crore turnover to 30-40 crore turnover. We have to grow. That is the way market is. HO cost is 100 million, project costs 50 million. How they can survive? We have to remember this is not my money, it is donors money. They want to see as much as possible going to the beneficiary. If we run implementation we can give 50 rupees to beneficiary and 50 to health worker. But if implementing NGO they can give 80 rupees to beneficiary. Actually donor does not want to pay my salary. They want to give to beneficiary"*

Growth in middle management has changed the staffing structure of the organisation, effectively inverting the organisation's HR pyramid in a very short space of time. This was expressed by one member of ULP staff thus: *"Before 20 fieldworkers and 5 people in head office. Now 5 fieldworkers and 20 people in head office"*. However, in the eyes of the field staff it has also changed the way they are perceived within the organisation. The field staff feel that, in the past, they were

always described as the pillars of the organisation. As the overall number of direct implementing staff has reduced and the role of the project co-ordinators that facilitate projects has increased the latter are becoming the new pillars of the organisation. As the point of contact between the organisation and the implementing branches, in facilitating NGOs, middle management become the new front-line workers.

Due to the preference for short-term, high impact interventions amongst funders projects usually between 2-5 years. Staff are hired on a contract basis for the duration of a project and may or may not be utilised again for future projects. This leads to reduced revolving overheads in the organisation, a wider range of skills available to the organisation at any given time and, thereby, to greater flexibility in what kind of projects ILO can choose to engage with. However, there is also a distinct danger that increased staff turnover can lead to loss of continuity and organisational memory within the organisation.

### 9.4 No Open Doors In the Chain of Command

### - Communication, Fear and Hegemony

There are barriers to free and open communication within the organisation that affect the health worker's ability to influence organisational culture. These barriers can be found equally in the structures and attitudes of the organisation as in the heads of the health workers. The health workers feel that they are not given the opportunity to express their opinion and to share their perspectives. However, these can also be seen to be excuses for what is essentially a beneficial arrangement for the health workers, as they themselves are dedicated to the hierarchy and rely on their superiors for patronage. The health workers themselves feel very strongly that they have little or no access to the level on which organisational culture is determined. During an interview with one of the health workers, we got to talking about the future of the project, who decides and who is 'eligible' to decide, etc.

*"Interviewer: (...)When you put staff in a room with one big boss...They will say 'What do you think?'*

*CHO: No one will say anything (...)That is the situation. Even here in ULP also there is a core committee, core committee is there (...) All senior staff. In that core committee, no one is...field worker is there. Field staff is not there. What they are discussing nobody knows. Most of the core committee members participate in the head quarter meetings, they have said you select the core committee. Core committee members never come to the field....lonely. They won't do any work there themselves. They always...eh...they work through field staff. That core committee members never share the ideas with the field staff. No, what they are discussing we don't know. They are just discussing, over something happened...What something, something what.? Please tell, tell. You never tell. They never tell (...) Who discuss with me? No one is discussed. Then so many times we told: 'Sir, what is the core committee? Who made that people?' They have no right to us. They have to think about the core committee. They are not doing any work directly. How they will discuss the problem. I don't know. Yes, Mam. Where it is, correct or not? How they are discussing? They are not eligible."*

Further to this point, I wish to briefly recount one of the most moving moments of my research. At the end of my focus group discussion with the health workers, one of them came up to me, took my hand and thanked me. Startled, I replied rather stiffly, *'no, no. Thank you. It was very interesting'*. And he looked at me earnestly and said, *'no, no one has come here like this before. No one has asked us our opinion before. That is why: Thank you'*.

### *9.4.1 Shooting the Messenger*

Whilst discussing barriers to communication within the organisation, with a member of senior management, I argued that there seems to be a culture of fear of negative ramification as a result of openness and that this is a hindrance to effective bottom up communication within the structure. His response stressed the importance of maintaining open channels of communications, but stressed that people must follow directives even as their objections are noted:

*"Yes. That is an important problem you have identified I think. There is difference between fear and respect. We must have respect and obedience. When we tell people what to do, they can say: 'I did, but I think this is wrong'. We must have openness so people can say this is wrong. Actually with*

*respect, there must be love. With fear there is no love. Actually, I think this is difference between respect and fear, love'.*

There are barriers to open communication within any organisation, whether these barriers are 'real' or not matters less. As long as they are perceived to be barriers they will contribute to determining behaviour within the organisation and, thus, their effect remains very real. Primary amongst the perceived barriers in ILO is a deeply entrenched sense of hierarchy and appropriate behaviour at each level of the organisation, which hinders free and open dialogue between staff. Despite a rhetoric of 'open doors', the health workers feel there are few opportunities to voice their opinions. They feel that there is a culture of blame within the organisation that ensures that if they speak up about their opinions or observations they will be blamed for the problems they have identified as there is a tendency to shoot the messenger for a quick and easy resolution of the issue. The health workers feel it is safest to keep any objections to themselves and to simply carry out the instructions of their direct line managers without objections. They fear it can be dangerous to hold opinions other than those held by people in positions of authority. One member of staff invoked a popular Hindi proverb to describe the situation:

"जल में रहकर मगर से बैर ठीक नहीं"
*(Jal mein rehkar magar se bair karna theek nahin)*
*(Trans: Living in water and being an enemy of the crocodile is not good)*

In invoking the proverb, she implied that, in order to survive in the organisation, a person is best served by keeping his/her head down and recognising where the power lies. This in turn breeds an environment where it is best to follow the principles of the three CCC's – conformity, comfort and conservativism. However, if no one points out the issue the problem goes unaddressed. Despite initiatives by individuals, this perception lingers and behaviour remains guarded. If there is no trust, there can be no communication. The health workers speak of this problem openly and insightfully when it comes to their relation to the community, as discussed in Chapter 7, but do not recognise that the same is true of relations within the organisation. Though, individually, everyone feels they limit their risk by

maintaining the current situation, in truth, collectively, they stand to lose as does the organisation as a whole.

### *9.4.2 Opportunity to Determine Representation*

This fear creates a climate where people are afraid to take initiative and act on their convictions for fear of being made into scapegoats should anything go wrong. This is in sharp contrast to the stated intention of higher management to be facilitators and enablers, allowing people at project level to act on their own initiative under management guidance. This fear to step forward also impacts on the reporting and documentation of qualitative work as there are strong sanctions against 'bringing yourself forward', i.e. to emphasise your achievements or to put yourself in a good light. Conversely, quantitative reporting is by nature anonymous, considering the achievements of a project or organisation as a whole and reporting this without emphasising any one project or person. Though this aversion to individual emphasis can be seen as an indication of a strong team spirit, it can equally be seen as an indication of who has access and ability to shape representations of the organisations work and input into organisational culture. Ultimately though, it acts to prevent more qualitative reporting for, when qualitative reporting is of good quality, it describes the problem faced, the action taken and the result achieved. It focuses on specific people or situations and necessarily brings out the achievements of a few, though this might be anonymously.

According to the health workers it is not merely fear of repercussions or hierarchical deference that limit their ability to influence organisational culture. They also feel they have very few acceptable forums in which their voices could be heard. When such occasions arise they often feel that their opinions go unaddressed or that particular opportunity is wasted in some other way. As one member of staff described it: *"They keep coming and asking CHOs for concepts and ideas for proposals. And they keep coming up with issues. But they never hear anything back. Already they have come so many times (...) Now they are coming again. How they can feel?"*

For me, one particular wasted opportunity for health worker participation in the determination of the projects future direction, for sharing ideas and for building morale stands out in my mind. A visitor had come from the UK to meet with people at Head Office and to discuss potential future projects for ULP. Senior staff from ULP, and myself, were invited to attend. Prior to this meeting, there had been a lot of discussion about hope at ULP. During my holiday I had seen a mural bearing the text 'Don't lose hope. Hope is a rope that swings through your life'. Since there had been a downturn in morale at ULP, I reproduced the slogan on the whiteboard in the conference room when I got back. No one really commented on it at the time but, later on in my fieldwork, people made reference to it from time to time. This was one such occasion (from my field notes):

> "We were driving to Regional Office to attend a meeting about the future of ULP and the mood is tense when suddenly, and out of the blue, a member of staff cracks a joke saying *'you know that thing you wrote, no? Ah. Well, hope is a rope. But ROAP is also a rope that can hang you'* [ROAP being the Regional Office of Andhra Pradesh]. Everyone bursts out in nervous laughter and it takes some of the tension out of the air. Very risqué, very un-Indian, very funny, and possibly very true..... For the first day of meetings no-one from ULP are invited to come. The project officer bring her right hand man, one of the project supervisors, even if she has been told by senior managers that this is not really appropriate as he is 'not on the same level' [as the visitor]. During the meeting the CEO asks why we have not brought more staff from ULP to be part of the discussion. So, the second day we bring 4 CHOs, 2 CHSs, one PT to the meeting. But we do not discuss issues pertaining to ULP, so the fieldworkers end up feeling doubly excluded. After the meeting I head downstairs to find the health workers and see what they had made of the meeting. Find them sitting quietly in a room by themselves. Balraj says: *'why did they bring us here? To increase our pain'"* As he makes the gesture of someone clasping their heart he says 'already we have pain'. Sadguna nodded and made the gesture of some turning a knife in the wound. Manoj said they *'had great expectations, and great disappointment. No use in bringing us here to listen to these things. No discussion on ULP'*. Mahesh just sat there and looked quietly and sullenly at his shoes. I explained that I truly believed the intention of bringing them had been to hear their perspectives, and that I did not know why it had not happened and that I too was very disappointed."

### *9.4.3 "Not in India, no?"*

*- Adaptability, Patronage and Opportunism.*

The limitations to communication cannot be blamed solely on organisational structures. It exists equally in the minds of the health workers, if we are to achieve open communication both must be addressed. As discussed earlier, the impact of health workers on implementation tends to be looked at in rather a simplistic, dichotomous way in much of the literature, casting the health worker either as liberator (through a bottom-up perspective emphasising agency as a positive innovative force) or as lackey (through a top-down perspective focusing on the potential for negative aberrations from procedure inherent in individual agency). Though these arguments can be seen as diametric opposites, they share a dichotomous perspective on agency and structure. Though shared, this is arguably a false dichotomy, and it might be especially so in the Indian context.

One day over lunch with an Indian colleague in the UK, I expressed frustration about the tendency to focus on an agency/structure dichotomy and to privilege an account of agency as acts of resistance to structure, whilst recounting my initial difficulty in engaging the health workers in discussions about the often contradictory demands of community and organisation. For a moment he looked bemused, the he replied sceptically: *"But not in India, no? You weren't going to study that in India? Maybe in other places they have these studies. But in India dedication to the system is ubiquitous. We do not resist or oppose, we adjust."* His reaction was telling and echoed the protests of the health workers for, in their minds, there was no contradiction, beyond the purely material, between what the community and the organisation wanted. Though the health workers often expressed disapproval, or even disdain, about the decisions of their superiors, this was usually about specific clinical or organisational questions, never about their right to make decisions or an expression of unwillingness to follow their directives. Indeed, during the focus group discussion, "loyalty" and "obedience" were ranked as two of the top five qualities of a good health worker.

Further to this point, during the evening English classes, the group would select social problems to discuss, and one of the topics that repeatedly emerged during these debates was the unwillingness of junior officials in the bureaucracy to oppose their superiors for reasons of social advancement and individual reward. The argument would go something like this: 'it is in the best interest of junior staff to cover up the mistakes of their superiors, as any negative attention for their superiors is ultimately negative attention for them, and, if you want a promotion in India, you have to find the patronage of a superior, show complete loyalty and hope that the day he/she gets a promotion he/she will bring you up with them. If you speak out against a superior no one will trust you in the future and you will never advance in the system'. Without explicitly acknowledging the parallels with their own situation, the health workers would habitually lament this as a social ill, arguing that India could not evolve as a country unless people were willing to take responsibility. When I asked them teasingly if they would act differently if put in that situation they agreed that they would probably not, for *"there is no choice, this is India"*. As discussed in Chapter 7, the health workers can be seen to be complicit in their own subjugation through their dedication to a civil order which maintains their subjugation. Their attachment to the civil order is mirrored in their attachment to a hierarchical social order in general and in the work place in particular. At one point during my fieldwork, I was having a discussion with one of the health workers regarding the strict hierarchical nature of Indian society, which I argued was a limiting influence on free communication and solidarity building, and he agreed. However, when I suggested that perhaps a more egalitarian model, within the organisation and in society in general, might be beneficial he reacted with horror and proclaimed *"No, no, madam. We must have hierarchy. We need hierarchy. Without hierarchy nothing would work. It cannot work without hierarchy"*.

Recognising the importance of cultural context we must recognise the Indian emphasis on hierarchy and loyalty to superiors in a way reminiscent of the traditional patterns of patronage in feudal society. Indeed, large tracts of the Indian subcontinent still live under de facto feudal rule with landlords, caste loyalties, political affiliations and family networks playing a part in determining most aspects of their lives. Or as Veena Das recounts: *"Anyone who has worked in institutions in*

*India will recognise that the subordinate staff invariably create narratives in which one is cast in the role of a patron and, depending upon temperament, one ends up lending money to deal with an emergency, negotiating admissions in schools and being pushed towards using one's 'influence' to get jobs for relatives. The boundaries between the formal organisation and its environment run through the organisation like rivers running through a territory" (Das, 2003:102).*

The significance of this type of client-patron relationship lies not in the inherent power differential, nor in the willing subjugation of the worker, but in the quality of patronage as culture within the organisation as it serves to establish modes of interaction (Gilsenan, 1977). Patron-client relationships are asymmetrical but not necessarily dysfunctional, though they rely on an ideology which cloaks the basic truth of class society. This can be seen in the Indian construction of patronage as a means of advancement when in reality it is, arguably, exploitation. Patronage, in this context, is politics with a small 'p'. It is the manifestation of personal relationships which is condoned, and perhaps even encouraged, in a society that endorses the political and economic power of myriad personal networks. Culture is as important as power (Cohen, 1977). The health workers do not adopt and accept the world view of their superiors merely because they are more powerful, they do so because they believe this is the correct thing to do and the course of action which will garner them the greatest reward down the line. Interestingly, this relationship can also be seen reflected in the health worker' rather paternalistic relationship with the community.

Though the impact of these traditional lines of control is somewhat diminished in the fragmented and diverse urban context, it is still very much a reality in the lives of the health workers and how they understand the world. Their emphasis was always on adaptability, patronage and opportunism, never on resistance. This emphasis on adaptability is the same attitude exhibited in the wonderful concept of *jugaad*, in both its positive and negative manifestations. This stress on adaptability, this reliance on jugaad, is, at once, the social and political capital of a hierarchical structure and an amazing ability 'to spin gold out of garbage' (as demonstrated by the amazing kabadiwallas of India) – to innovate, to make-do and get-by.

### 9.5 United we stand, divided we fall

As discussed above, organisational culture is not one thing but, rather, a multitude of voices competing for influence. This polyphony is a strength as long as it is not allowed to become a cacophony and this, in turn, depends on how strong the organisation's culture is, how well organisational intent is translated throughout the organisation, and whether or not there is willingness and ability to absorb diverse capacities by accessing views from all levels, understanding different perspectives, appreciating the strength inherent in diversity and enabling bottom-up communication.

At the time of my research three major discourses exist side by side within the organisation, as discussed in Chapter 5, in the simultaneous focus on disease/health/development and care/cure/empowerment. This is a strength in the organisation as it reflects the varied capacities of the organisation and allows for a multifaceted approach to public health, one which embraces change whilst at the same time retaining specialist technical skills. However, ULP health workers largely rely on the leprosy elimination narrative to inform and direct their actions in the field, even as the organisation's diversified activities pull it towards interventions that focus increasingly on development and empowerment. However, it is important to note that this is a conflict that can be found not just between field-level staff and higher management but that is present across the hierarchy, between different personalities within the management structure and different visions of what the organisation 'ought' to be. At any given time, competing cultures can co-exist within the organisation as long as they are bound together by an overarching goal or by a shared moral universe. However, what is threatening to happen as a result of this organisational schism is an imminent breakdown of this shared goal, as a result of the failure of management to effectively communicate policy changes down through the organisation's hierarchy, and to provide health workers with a coherent narrative for their work.

In this respect, effective leadership and translation of intent as well as targets can be seen as equally fundamental to the creation of a shared organisational culture

as strong channels of bottom-up communication. What matters is communication, in both directions, across all levels of the organisation and with local communities and stakeholders. However, it is not merely a question of increased communication. Efforts must be taken to ensure that what is established is meaningful communication rather than merely a confusing sea of voices. Communication can lead to communion and community, to intimacy and shared values, but it does so through the process of listening rather than through speaking. As expressed by Friedman,

> *"The colossal misunderstanding of our time is the assumption that insight will work with people who are unmotivated to change. Communication does not depend on syntax, or eloquence, or rhetoric, or articulation but on the emotional context in which the message is being heard. People can only hear you when they are moving toward you, and they are not likely to when your words are pursuing them. Even the choicest words lose their power when they are used to overpower. Attitudes are the real figures of speech." (Friedman, 1990:5)*

Systems must be put in place to encourage free and open dialogue between different levels in the organisation and emphasis must be put on the motivation of field-level staff, through a shared vision of the development of the organisation and a clear understanding of the health workers' role in this development. This motivation would also serve to maximise the output of field staff by creating op-in and dedication to the ideals represented by their work and by making their role/work part of a more encompassing vision and a larger context. For the perception of a shared goal is what binds an organisation together and creates moral responsibility. As expressed by one of the health workers:

> *"Tomorrow if one disabled person will come. Sir, please help me. In that time, how he is giving life expected to him? You are the source person, you can do a little bit of help to me. See, here what is - 'hear me, feel me, see me, touch me'*[points to organisational logo]. *What is the slogan, what is this emblem. We are wearing on our name. We are using on our identity card. What's there? How many people thinking about our aim, our emblem. All utilised, those who working attended to office administrator to, or even the nurse. Everyone should know what for we are working here. Then only organisation will run properly. Previously like that. When ILO...when I entered in ILO in 1994 all staff was like that. Same situation, and they are doing the work, the right person the right way (...) What use is your mission statement? Not for only health worker. This statement and emblem not for only health worker. All."*

So, it can be argued that the organisation is headed for a cultural schism between field-level health workers and senior management at regional and national level. But does it really matter? As argued above, interventions are planned on national and regional level and implemented through projects. This implementation relies, to a large degree, on the judicious and manipulative agency of health workers who are acting on the assumption that they can work outside of the system because they understand the ultimate goals of that system, as demonstrated in Chapter 7 and 8. As leprosy policy changes and the emphasis moves from cure to empowerment, from health to development, this schism threatens to grow ever wider and future interventions may not have the benefit of being based on such a unified understanding of the underlying goals. Health workers' productive agency and creative innovation then risk becoming reactionary and counter-productive strategies which threaten the organisations ability to achieve its desired outcomes. Further, it would constitute a terrible waste of this very agency.

### 9.6 Rising to the Occasion – Insight through Implementation

The future challenges for ILO and leprosy organisations in general are substantial. However, there are also exciting possibilities for implementation development and meaningful change. The organisation's ability to capitalise on this will depend on its ability not only to change its organisational culture but equally its ability to move beyond hierarchical limitations and capitalise on field-level insights, for

> *"a change of paradigm is needed, recognising people as subjects, not objects, and workers as enablers and not providers. Interventions must be supportive and responsive, empowering rather than diagnostic. They must include addressing the needs and resources of the community and extending its capacity"* (Dr. Arole quoted in Nichols and Smith, 2002)

> Further to this they argue that: *"A 'listening and learning' approach is essential. Such an approach requires a radical shift away from traditional hierarchical management. To build understanding, project managers must be ready to learn from field staff and other professionals. Fieldworkers must learn to respect the point of view of their clients. This open-minded approach must extend to a willingness to change project priorities or to reconsider long-standing assumptions."*(Nichols and Smith, 2002)

If insights drawn from the health workers' creativity in the field are to have an impact beyond the local interactions of organisation and community then there must be an understanding of just how, and if, these innovations can be translated through the hierarchy to influence planning and strategy. Within ILO, the health workers do not feel free to communicate their views to senior management, nor are there specific channels of communication for them to express their views through. Despite these barriers there is still considerable negotiation over organisational culture.

Organisational culture is a product of constant negotiation about influence on the direction and values of the organisation. Again, it is clear that changes in policy have influenced the relative position of health workers in this process, leaving them feeling increasingly powerless. Hindered as this process may be in the current environment, the negotiation about organisational culture must be seen as an expression of Comaroff's local dialectic discourse, as a process through which the organisation's prevailing discourse is negotiated. Whether or not this discourse can influence the international arena depends to a large extent on the organisation's willingness and dedication to promoting it. However, the potential impact of local discourses could be profound and could hold the key to moving leprosy policy forward. One example is the recent developments in international policy, recognising the wider importance of psychological and social factors in the clinical management of rehabilitation in persons affected by leprosy. However, professionalized health systems often struggle with this type of intervention as it means a redistribution of power from the provider to the client. Ground level health workers already implement many of these changes through their innovation and agency. Therefore, if leprosy care is to successfully navigate a change in this direction, it will need to draw on the expertise of front-line health workers with highly developed counselling skills.

The general dedication of Indian society to a hierarchical structure has always constituted a hindrance to bottom up communication, but the health workers feel their position has been further eroded and that the power to influence the direction and values of the organisation now increasingly lies with a cadre that works at a

remove from implementation. Understanding how this shift has impacted on the health workers' ability to influence organisational culture and discourse is crucial, if the aim is to facilitate an increased reliance on local strengths and capacities, as an indirect consequence of the marginalisation of front-line staff is a diminished capacity for accessing, understanding and utilising local strengths and capacities. The health workers can play a crucial role in this process as they are both embedded in the structure and able to exert agency within it. Their agency has the potential to influence the local dialectic discourse and, thus, to translate creativity from root to other parts of the organisation. Staff at all levels, as well as leprosy affected persons and their communities, must be involved in the decision making process.

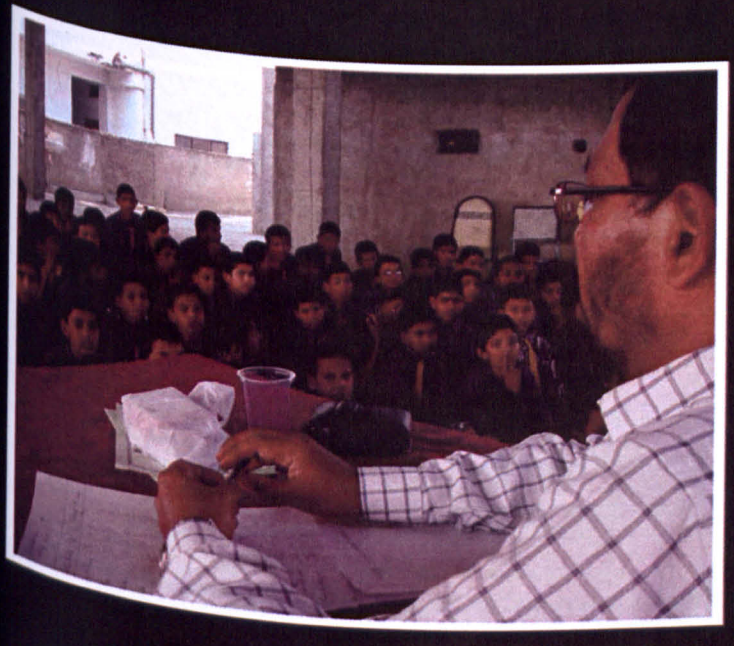
Before moving on to further discussions of agency and structure, I want to leave you with this story, or 'corporate myth', as it was recounted to me by one of the health workers. Sometimes the solution comes from an unexpected source:

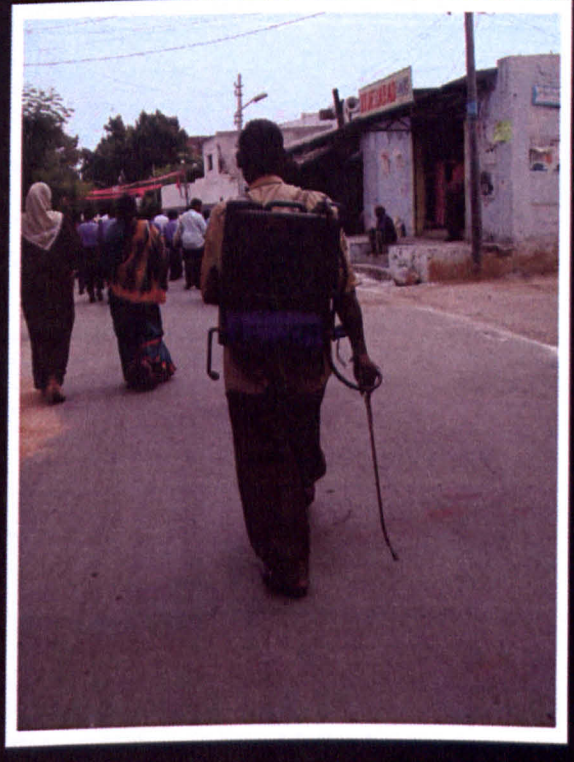
*CHO: Fieldworker... even in factory...who is developing the product? Engineer is servant, administrator is servant, material carpenter is servant, everyone is servant. But finally who is developing the item, designing and... and making the...eh...product (...). If he having proper knowledge and proper skill then only he is modified that product properly. And while doing experience he can add his innovative knowledge also, because they do not have experience. He is working, day to day, same object same activity, whilst that he may develop some new thoughts. While doing automatically it will develop (...)*

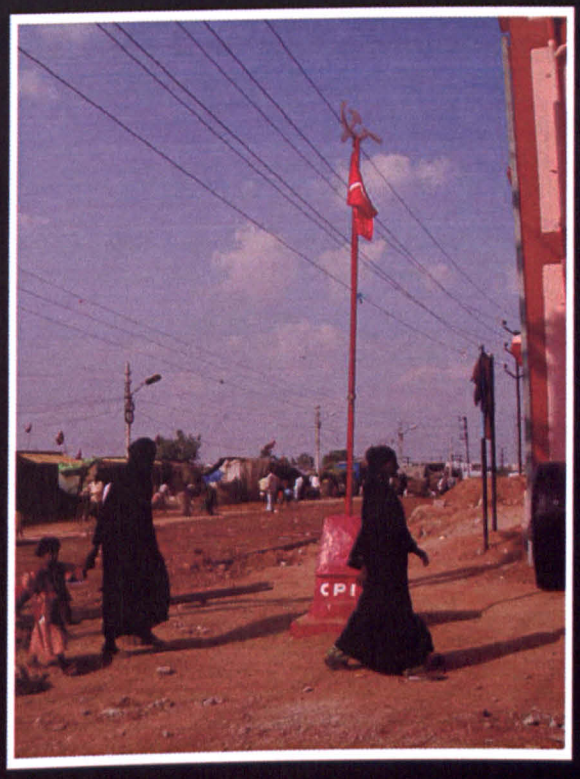
*CHO: You know about the coca cola advertise?*

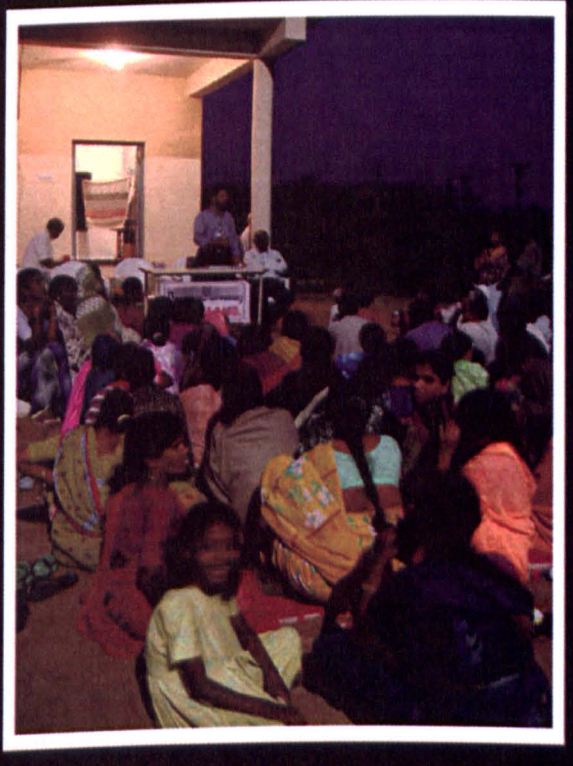
*Interviewer: Coca Cola advertising...?*

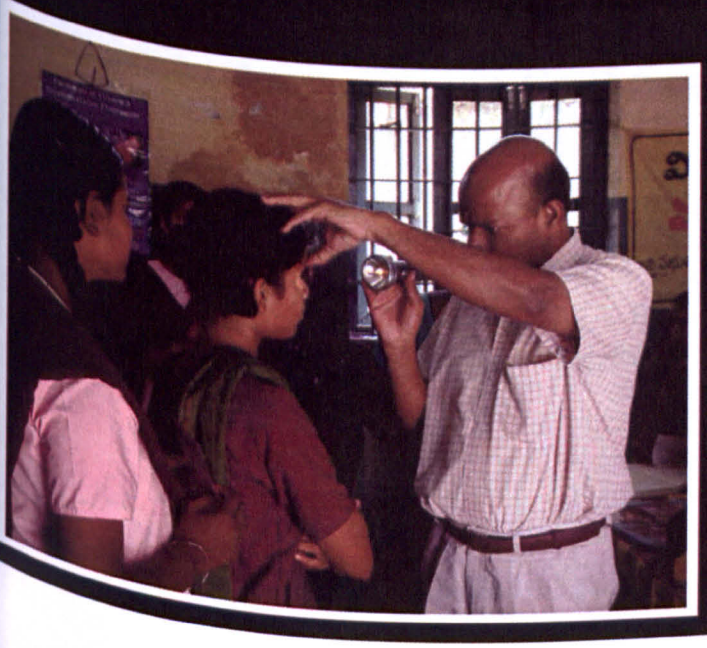
*CHO: For one purpose he has given 5 crores. If you have given good add/slogan they will provide 5 crore rupees. They hold event, by media and everything. For slogan making they are getting and analysing and analysing and... Their sweeper, what he said, just simple what he said: 'Danda Danda Coca Cola.' Simple. Simple slogan. 'Cool, cool Coca Cola'. He is... the right person asked: 'what you said, what you said, please? Repeat it' 'cool, cool coca cola'. What a wonderful word. (...) See. While experience. While experience he got...automatically it comes from his heart. From mind. Cool, cool coca cola. It is a very related word slogan. And he has announced regarding that slogan and he has given 5 crores to the labourer, that sweeper.*











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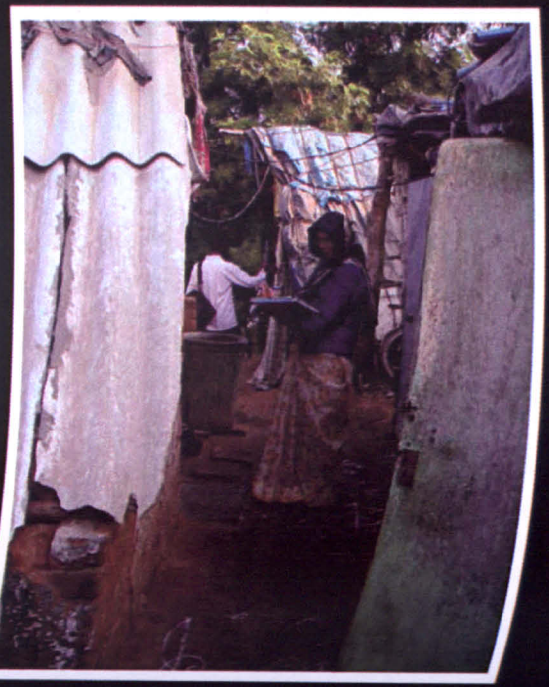
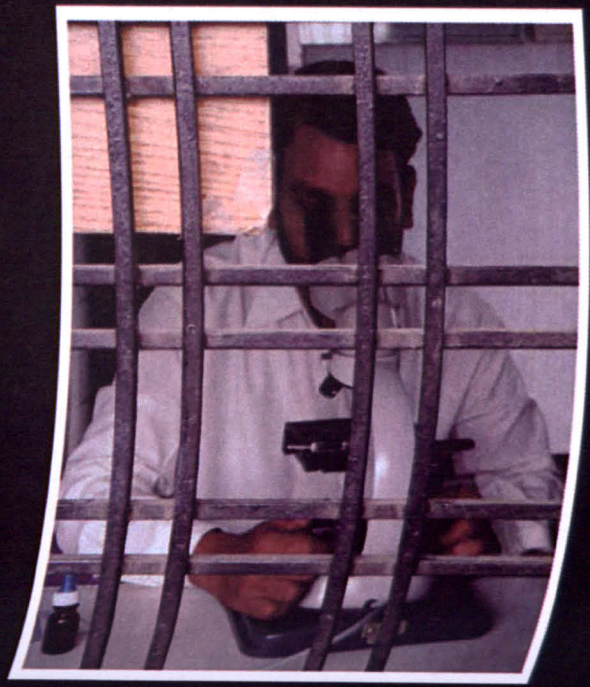
HIV / AIDS





## 10. Agency in Structure

As argued in previous chapters, health workers must be seen as deeply embedded in the wider structures and discourses they work within, through shared training, through prolonged involvement in the field and through a shared discourse and narrative. Even as their work environment and the policy landscape changes around them, the health workers continue to hark back to these shared values through their reliance on nostalgic narratives as a means to constructing 'technologies of the self' which they hope will situate them within the new world order but which may ultimately serve only to embed them even further in the organisational culture and discourse of the past. If we aim to understand implementation and health workers' perspectives, we cannot afford to ignore this aspect.

However, this emphasis on the health workers as embedded in, loyal to and the product of wider structuring factors, belies the extent to which they are active participants in the creation and transformation of these structures through their everyday agency in the field, be this through judicious or manipulative agency. It is clear that health workers act with a degree of autonomy within this structure, that they utilise innovative agency in order to build rapport and address community needs and, indeed, that they manipulate and contravene systems and structures when they feel that this is necessary in order to achieve 'social services', what they see as the greater goal of the structure of the organisation. As embedded members of the leprosy control and organisational discourse they feel that they have an understanding of the underlying goals of policies and that any action that works towards these goals takes precedence over system requirements. Through these everyday working practices, their praxis, the health workers produce more than outcomes, they also create meaning. This meaning is part of defining how wider discourses and organisational culture are expressed in the interaction between health providers and service users.

As discussed in the introduction to this thesis, implementation studies have had a tendency to take either a bottom-up or a top-down view of implementation, casting

the health workers as either lackeys or liberators and agency as either innovation or aberration. These approaches both imply conscious motivations on part of the health workers, casting them as rational strategising actors deploying innovations and improvisations as strategies to manipulate outcomes. However, innovation is not necessarily something which is well thought out or consciously implemented. Rather it is, more often than not, spontaneous, opportunistic and incidental, subject to a myriad of motivations and variables related to structural expectations, personal gain or a desire for 'social service'.

To take a bottom-up view of implementation, casting the health workers in the role of liberators and champions of grass-roots perspectives emphasises the 'good' of agency and of innovation, yet it denies both the health workers' loyalty to the wider structure and their various vested self-interests. To take a purely top-down view of implementation, on the other hand, to cast health workers as lackeys and mere automata carrying out pre-scripted plans, emphasises the primacy of the structure and the potential 'evil' of innovation and agency. Such a perspective fails to recognise both the potential positive impact of agency on implementation and on the experience of service users, as well as the effective long term impact that such agency can have on the reshaping of the very structures within which it is exercised. Or, as argued by Comaroff, the tendency to see discourse as hegemonically imposed by an international consensus in a top-down manner fails to recognise the polyvocality of such discourses both at global and local level. It also fails to recognise the extent to which health workers are "determined, yet determining, in their own history."

Such a dichotomous understanding of the relationship between agency and structure also casts the health worker's agency in opposition to structure rather than as independent acts within a structured framework. To understand health systems and the actions of health workers within these health systems, rather than casting agency and structure in opposition to each other, we should focus on building an understanding of how different actors relate to the system and how the actors' actions make sense within the system. The ULP health workers themselves do not see their dual role as lackey and liberator as conflicting, rather, they

recognise that they are both and neither at the same time and consciously manipulate their shifting roles to their advantage in different social situations, in recognition of the fact that you can't please all the people all the time. Tangible conflicts must be resolved, priorities set and resources allocated. Resolving these instances of conflict requires finesse, diplomacy and agency. Yet, their emphasis is on smoothing the bumps and bending the rules to get the job done, rather than on the conflict as the issue in itself. Agency is applied on a case-by-case basis, in a spontaneous and incidental manner, to resolve concrete issues, rather than as a strategic statement of intent. In dealing with the complex lived realities of real people, in an attempt to achieve deceptively simple goals and outcomes measures, the application of agency becomes a process of creating simple-complexity.

Social science has always sought to build an understanding of the structures that underlie the choices we make in life. Over the last few decades anthropology has moved away from a perspective which favours the description of the meanings and significance that events and circumstances have for people, towards an understanding of the structures that shape this understanding. In order to achieve this theoretical shift towards understanding the relationship between structure and agency, anthropology has looked to the theories of social scientists such as Bourdieu, Foucault, Gramsci, Bashkar, Berger & Luckman, etc. All of these theorists posit theories of agency and structure which vary in the degree to which real social change is considered a possibility and in the mechanisms of social control they point to, however, they all describe human agency as a product of overarching structures, be it in terms of enabling this agency or in defining its limits.

Though it is clear that we need an analysis which considers the role of both agency and structure in building an understanding of the perspectives of health workers and the process of implementation, there has been a tendency to artificially oppose these perspectives. Even within social theory there is a tendency to favour one or the other, agency or structure, in explanatory models. To move forward we must move beyond these dichotomies and their implied value judgements; beyond good and evil; global/local; lackey/liberator; agency and structure. We must recognise

that both aspects are integral to each other's existence, as well as our understanding of the world.

In this chapter I will attempt to demonstrate that, by drawing on established social theories, whilst recognising their limitations in a particular social context, we can build an understanding of the interrelationship between agency and structure in a particular context. Pierre Bourdieu offers us a particularity promising perspective, as his emphasis on the corporeal embeddedness of actors' agency correlates well with the corporeal nature of leprosy work. Though Bourdieu's framework may help us to understand the role of structures in shaping agency, it does not, on its own, adequately explain the observed agency of the health workers. In order to better understand the nature and impact of health workers' agency I have chosen to draw on the theories of another Frenchman, Michel Foucault. By combining these perspectives, we can work towards establishing a framework that allows us to understand how the simultaneous, and often contradictory, processes of structuration[3] and agency play out in everyday implementation, as well as in the construction of health workers social identity. Such a perspective will enable us to build an analysis that respects the complexity of the working reality of health workers as well as aiming to identify ways in which we can utilise these insights in order to truly facilitate the inclusion of local strategies in the implementation process.

## 10.1 Embedded and Embodied

### - Corporeality, Leprosy Discourse and the French Philosophers.

In chapter 6, I tried to demonstrate that the health workers are deeply embedded in the structure and discourse they work within and that it is important that we build an effective understanding of what such an embedded status means for their social identity and their understanding of their work. There are a number of social theorists who offer frameworks for understanding the process through which our

[3] To borrow Giddens' term (1993)

actions are determined by the wider structures that surrounds us and how our actions, in turn, contribute to shaping these very structures. However, for this particular piece of research, I will try to demonstrate that a combination of the work of two French philosophers, Pierre Bourdieu and Michel Foucault, offer an appropriate avenue of analysis. Both stress the importance not only of the psychological embeddedness of actors but also the way in which this embeddedness is created through the physical embodiment of actors, by favouring corporeal over psychological causalism.

Bourdieu argues that, as corporeal actors, we are intrinsically embedded in our environment, what he refers to as the *habitus;* a system of predispositions that structure our perception of, and actions in, the world. Bourdieu emphasises the role of habit in order to describe the process by which embodied individuals create and maintain their sense of belonging to this *habitus* through everyday practice. Thus, the agent is seen to be constantly recreating their bond with this *habitus* through physical actions, through being and doing, through the observation of the actions of others, and by being seen to do and be. Foucault's perspective focuses more on power, discourse and control and how these relationships of power play themselves out in the corporeal reality and on people's bodies in *the body politic.*

A similar emphasis on corporeality, on physical presence and physical touch, has permeated leprosy discourse since the very early days of leprosy care, from Jesus curing the leper through touch (Mark 1:40-45, KJV) through to today's emphasis on physical rehabilitation and reversing social stigma. In the early days, the absence of an effective cure placed the emphasis on the provision of care and providing services to make patients physically comfortable. In addition, the presence of social stigma and the fear of contagion faced by most persons affected by leprosy, even within their own families, made the reality of human touch a crucial part of any treatment.

However, the importance of corporeality is not merely a question of direct physical touch but equally is equally a question of control over physical presence and control over bodies and space (Foucault, 2003 [1963]). If we look back to the

stories surrounding the presence, and ultimate death, of Father Damian at Molokai, the story is usually told as a heroic tale of sacrifice, social improvement and of how the world was finally convinced of the infectious nature of leprosy (Edmond, 2006). However, there is another side to this story. As was the policy in most countries at the time, all people affected by leprosy were to be isolated, in this case, sent to the island of Molokai. In contrast to the enforced isolation of the people affected by leprosy, Father Damien was on the island voluntarily and refused orders to return to the mainland, until he himself eventually succumbed to the disease. Though the care givers and the people affected by leprosy on the island were confined to the same physical space, the power relations that led to their co-existence were very different.

History tells us that Father Damien reformed island life, created social structures and ended the segregation of care givers and people affected by leprosy (Gould, 2005). Though such coexistence was not the case in most other establishments, the debate surrounding the interaction between people affected by leprosy and their care givers has been a central topic in leprosy discourse through the ages. The corporeal interaction between health workers (or missionaries, or nuns, or doctors), or sometimes the lack of such corporeal interaction, has been a signifier of sacrifice, healing and humanity. The practice of segregation into colonies and, within colonies, segregation of the sexes, reiterates the extent to which leprosy was controlled and expressed corporeally. This is doubly important in Indian society, where the notion of untouchability already has such a strong social and religious significance, and where, regardless of which caste you were born into, once a person contracts the disease they are usually rendered casteless, effectively untouchable (Staples, 2003). However, as a person loses their caste status, concurrently they become united in their status as persons affected by leprosy. As effective as the European 'leper clapper' of the Middle ages, the status of untouchable marks the person out as unclean even without the characteristic physical disabilities, which would have rendered the ravaging of the disease obvious to the casual observer.

This new social status is thus not merely a marker of fear of contagion though physical proximity but the fear of spiritual contamination through the proximity to ritual un-cleanliness. In India, the dominant view of the cause of leprosy is still that it is a punishment from God. As such, like the picture of Dorian Gray, the person affected by leprosy is thought to be marred by eternal physical affliction to demarcate internal moral corruption (Drakos, 1993). This perception of leprosy, as both physically threatening and morally contagious, is not unique to India and Drakos (1992) describes a similar situation in 20th Century Greece. Though this view of leprosy is slowly being changed through health education, it is clear that people's physical aversion to touch a person affected by leprosy is still very much present in society and, as Gorringe & Rafanell (2007) argued with regard to interactions between Dalits and higher caste persons in Tamil Nadu, the "reason for our stress on embodiment is that the psychological cannot be divorced from the corporeal. Caste based emotions are embodied, and inspire feelings of revulsion or unworthiness that hinder social change and constitute hierarchical social identities" and, that even as caste distinctions have changed over time, "the gradual process of caste change clearly has to be embodied and materially manifest for it to have real meaning" (Gorringe and Rafanell, 2007:108-110).

In Andhra society and, probably equally so the rest of Indian society, the un-cleanliness of persons affected by leprosy is part of the *doxa*, it is part of the embodied learnt responses, even if the brain accepts another scenario, the body reacts with physical revulsion. Of course the health workers are as much part of the doxa of untouchability in Indian society as any others, and more than one health worker admitted to finding the prospect of touching leprosy patients repulsive when they first attended leprosy training, though they were always careful to caveat such statements with allusions to the horrors of past injuries and statement such as *"it was different then. Many advanced cases. Severe deformities and ulcers. Not like now, madam"*. However, this physical revulsion is not merely an Indian occurrence but is also still very much present in educated Western 'experts' visiting the project, as recounted by one of the health workers:

*Must think about our [own organisations] staff, they have sufficient knowledge about leprosy? When an officer came...to watch the organisation...even he is not willing to touch the disability case. How can I work here? (...) Psychotherapy methods... human touch is... human touch cures 50% of the disease (...) Human touch, by the soul, by the heart, is a very well. It's can cure your disease. when you...when you...get the support from your neighbour or father, mother, friend or anyone – automatically you're immune system will [indicates up with his hand]...up to that is becoming shrinken. But when a person come and touch and encourage you... automatically his mind becoming eased and he says 'he given a lot, OK'. Then he will pray to the God about my health and becoming a healthy person, tomorrow I may becoming a healthy person with God blessing and friends support. Automatically his... his immune system becoming activate. When the mind, the mental set-up activate and it will signal to all organs and... our functions... our hormones and lipids... chemicals... automatically it will activate... automatically. When functions becoming to activate that foreign body becomes to die. We are becoming to healthy.*

The above discussion emphasises the importance of touch as a principal component in leprosy discourse and the belief in corporeal interactions as a curative force. Here Foucault and Bourdieu's emphasis on embodiment seems to resonate well with the emphasis placed on working practices and, especially, on the importance of physical proximity to people affected by leprosy, described by the health workers. In the communal creation of their social identity through nostalgic reminiscence, a primary emphasis was placed on working practices, on habits and embodied routines. The emphasis was placed on the physical hardships they endured in their everyday work, on incidental stories of specific patients and families they helped, but also on the treatment of gruesome ulcers without the use of gloves.

The above account also emphasises how the health workers experience the hierarchical divide within their own organisation, as expressed in terms of physical distance from people affected by leprosy, and their disgust that officers in a leprosy organisation would hesitate to touch leprosy affected persons. There is pride here, pride in their embeddedness in the community, in their proximity to leprosy affected persons, as if this proximity 'proves' their dedication to healing and helping. Having said this, in my experience, senior staff did not exhibit a reluctance to touch leprosy affected persons. Still, the story effectively communicates a difference in perceived

embeddedness. The very fact that this incidence was recounted is significant, for, as the health workers describe their value to leprosy work it becomes increasingly apparent that they see their value very much in terms of their presence in the community and in their connection with people affected by leprosy – or, in more abstract theoretical terms, their embodied presence and in their corporeal relationship with persons affected by leprosy.

To the health workers, the embodiment of their work means more than merely maximizing work output, and it also promises salvation at the level of what they call 'social work' or, as Gandhi articulated it, "leprosy work is not merely medical relief; it is transforming frustration of life in to joy of dedication, personal ambition into selfless service". Incorporated in ILO's logo is the slogan "See me, Touch me, Hear me, Save me". Again, the importance of 'touching', of salvation through embodiment, is brought to the forefront.

This emphasis on touch, and especially touch with bare hands, without the use of latex gloves, as an expression of acceptance and trust in leprosy care has led to an interesting conflict surrounding the importance of safety versus signification. Leprosy workers see the touch of bare hands as a signifier of their special relationship with people affected by leprosy, as the marker of the ultimate victory over stigma and restoring dignity to their clients and, as such, touch becomes the physical manifestation of the special relationship of trust and respect between provider and person affected by leprosy. If people affected by leprosy were lucky enough to receive health care from other institutions this would often happen with latex gloves as a barrier between provider and client and as a symbol of the institutionalised stigma of leprosy. Front-line leprosy health workers see themselves as the only people to 'restore dignity', as they would phrase it, by touching the leprous body without gloves. Now, in the age of HIV/AIDS, the guidelines have changed and the use of latex gloves whilst providing treatment such as ulcer care is now officially obligatory, for the safety of the patient as much as the provider (ILEP, 2003). Eager to demonstrate their understanding of the reality of HIV, and their compliance with guidelines, most of the health workers would say that they use gloves whenever treating open wounds or ulcers. In my

experience this was true for some of the health workers who would habitually utilise the gloves provided, however, most would use gloves only if observed by others or if a summary judgement was made that the person they were treating seemed 'at risk of HIV'. A minority of the health workers stated outright that they did not use gloves as they felt it was sending the wrong message to the patients and would break the relationship of trust between them, especially with patients they had a long-term relationship with. How would they feel if they suddenly started using gloves when touching them?

Clearly, the physical relationship between the health workers and people affected by leprosy is something that permeates almost every corner of leprosy policy discourse, as well as something that is a consideration in the most intimate of interactions between health worker and client. Touch is the means by which the health workers break down the power barrier between themselves and their clients a means to build rapport with their clients but, at the same time, it is also a means by which they distance themselves from the rest of the health system including senior management in ILO. Touch becomes a signifier of their special relationship with leprosy affected persons and the 'quality' of their services, as compared to what people affected by leprosy can expect to receive in the rest of the health system but it is also a key signifier of the health workers social identity. Beyond the field of leprosy, we are only now beginning to appreciate and understand the importance of touch in the clinical encounter, as a mechanism that re-establishes human connections at a pre-linguistic level. This is not the 'objectifying touch' of the physical examination, nor the 'absence of touch' created by technological interventions rather than embodied contact, but the 'healing touch' that could potentially aid in re-integrating the patient's self and body, a relationship which has often been compromised by illness (Leder and Krucoff, 2008).

## 10.2 An Interpretive Science

Understanding power, agency and structure as something which is embodied and played out in our everyday practices means that the only way we can build an

understanding of the reality of these concepts as played out within the health system is through the observation of everyday practices alongside the physical experience of existence as experienced by the health workers themselves. Participant observation allows us to observe agency and structure as they are played out in everyday practices. There is a world of difference between what people actually do, what they say they do and what they think. Anthropological method offers us the opportunity to observe the differences between these layers. However, a mere reliance on methodology does not bring us closer to answering the question of why we find such differences or help us to identify the factors that shape everyday practices. To achieve this, we need to draw on social theories which aim to explain the underlying structures that structure our everyday practices and our relationships with each other. As argued by Lambert & McKevitt (2002) we need to move beyond merely incorporating anthropological methods into public health and towards a point where we draw equally on the theoretical contributions of the discipline.

Through observation and participation, we can access what people do and say they do, through interviews, we can access individual ideal constructs and, through methods such as focus group discussions we can access consensus views within a particular group. Interpreting data always introduces bias into the process, much as the presence of the researcher in the field necessarily changes that which is observed, interpretation will necessarily favour one set of analytical tools over another. Despite these limitations, it is the interpretive process that introduces meaning to the observed interactions, lifting them above the trivial, thus enabling us to understand the motivations behind that which is observed. As the esteemed anthropologist Clifford Geertz argued, anthropology is an interpretive science or it is nothing.

> Geertz asks us to imagine *"two boys contracting the eyelids of their right eyes. In one, this is an involuntary twitch; in the other, a conspiratorial signal to a friend. The two movements are, as movements, identical, from a I-am-a-camera, 'phenomenalistic' observation of them alone, one could not tell which was twitch and which was wink. Yet the difference, however un-photographable, between a twitch and a wink is vast (...) That, however, is just the beginning. Suppose (...) there is a third boy, who, "to give malicious amusement to his cronies," parodies the first boy's wink, as amateurish,*

*clumsy, obvious, and so on. He, of course, does this in the same way the second boy winked and the first twitched: by contracting his right eyelids. Only this boy is neither winking nor twitching, he is parodying someone else's, as he takes it, laughable attempt at winking"* (Geertz, 1973:6). And so on.

Without aiming for what Geertz calls 'thick description' to describe the context within which actions take place, by building an understanding of who is saying or doing what, where, at which time, with what motivation, we cannot hope to truly understand the actions of actors. In the case of the health workers, in order to understand why they utilise agency and innovation, how they construct their social identity and what effect the wider structures that surround them have on their actions, we must draw on wider social theories to illuminate our interpretations.

### 10.3 Manipulating Bourdieu and Marrying Foucault

Many social theorists offer explanations of how social conventions and power structures guide the actions of individuals, conversely, a great number of other theorists focus on how individuals express agency in opposition to subjugating power structures. Unfortunately there is a tendency in most theories to dichotomise this relationship. As we saw in the debate surrounding the role of health workers in implementation, the debate becomes a stylised discussion round two artificially constructed roles, casting the health worker as liberator or lackey. In social theory a similar dichotomy is often expressed through a preferential focus on the role of either structure or agency in shaping social life. As both agency and structure play a fundamental part in the everyday practice and the construction of health worker identity I would argue that we need to draw on the perspectives of several social theorists in order to build an understanding of the complex processes at hand.

Not only does the corporeal approach of Bourdieu and Foucault offer some insight into the physical reality of leprosy policy, they also provide fruitful frameworks from within which to analyse the observed working practices of health workers on the ground. Both theorists propose frameworks that aim to go beyond a dichotomised

view of objectivism (focusing on how structures dictate the actions of individuals) and subjectivism (focusing on the subjective understanding of reality). Foucault and Bourdieu attempt to bridge these two disparaging views by demonstrating the extent to which individuals are both the products of the wider structures that shape their lives and how they, in turn, shape this context, thereby casting power and structure not merely as negative forces that subjugate individuals but, equally, emphasising the way in which they contribute to the creation of subjects.

Bourdieu's framework argues that "human life cannot be studied without taking into account both how individuals are situated and constructed by social structures and how those individuals construct an understanding of and impose meaning on the world around them." (Dressler, 2001:455) This view offers immense scope for analysing how wider society directs the actions of individuals. It can, however, be criticised for leaving little room for agency and can thus feel stifling in the sense that the individual becomes a mere 'meat-agent' carrying out the prescribed actions according to their class, culture, location, etc.

Foucault, on the other hand, sees power as capillary, as something which permeates all social relationships and can be expressed or resisted by agents, thereby opening up an avenue for understanding agency as well as structure. For Foucault, power is something which both subjugates and creates subjects (Gledhill, 1994). Effectively, we are what we are because we can know ourselves only through the frameworks which society provides us. Yet, we are not totally restricted to this framework, for no framework is free from contradictions and inconsistencies, and it is these contradictions which individuals can utilise in order to effect change. In other words, we are dominated by a system of power relations but we are also part of creating and maintaining this system, thus, the system carries within it the potential for change which can be utilised by individuals, or groups of individuals, as they mobilise the 'technologies of power' to their own end. Let us look a little more closely at the frameworks these two have to offer us and how they can help us make sense of the perspectives, identities and actions of health workers.

### *10.3.1 Bourdieu's Toolbox*

The cornerstone of Bourdieu's framework is the notion of the Habitus, which is defined as a system "of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles which generate and organize practices and representations" (Bourdieu, 1990:53). This definition of habitus is almost tautological, as it "implies that these systems of dispositions are malleable, since they inscribe into the body the evolving influence of the social milieu, but within the limits set by primary (or earlier) experiences, since it is habitus itself which at every moment filters such influences (...). As the mediation between past influences and present stimuli, habitus is at once *structured*, by the patterned social forces that produce it, and *structuring*: it gives form and coherence to the various activities of an individual across the separate spheres of life" (Wacquant, 2006:7).

Utilising Bourdieu's concept of the habitus enables us to emphasise the structuring structures that shape our understanding of reality and enable us build an understanding of the extent to which we are products of the cumulative experiences which constitute our habitus. It enables us to recognise that, though we are free to make choices, the choices we make are not free. Rather, we pick from a limited set of predefined questions and answers, as the structures define the limited possibilities on offer. Thus, without attempting to build an understanding of the wider context within which actors operate, of the structures which determine their choices, we cannot expect to make sense of the choices people make.

The second key concept of Bourdieu's framework is his notion of *fields*. Recognising that, even though actors may share a habitus, this does not necessarily mean that the world they inhabit constitutes a homogenous social entity, rather, it must be seen as a series of social microcosms, what Bourdieu calls *fields*. Bourdieu identifies three key attributes of fields; firstly, they must be seen as 'structured spaces of positions' with their own set of determinants; secondly, fields are spaces within which people and institutions fight for influence and position utilising their *capital* on a 'battlefield wherein the bases of identity and hierarchy are

endlessly disputed' (Wacquant, 2006:8); and thirdly, a field must have a *degree of autonomy* from the rest of society.

The above mentioned *capital* is the third key element in Bourdieu's framework, where the concept of capital is expanded beyond materialistic possessions to include economic, social, cultural and symbolic capital (Bourdieu, 1986b). For Bourdieu, capital plays a dual role; firstly, it determines the set of predispositions, i.e. the habitus, that individuals acquire. Bourdieu argues, most eloquently in his investigation of taste, in his work *Distinction: A Social Critique of the Judgement of Taste* (1986a), that it is not aesthetic judgement nor inner sensibility that determines the tastes of an individual but, rather, the sum of his/her social class and their education. In other words, more than your personal taste is involved in the choice between fish fingers and foie gras, and, as such, the link between social class and habitus can be seen as inherent in Bourdieu's argument. The second function of capital is to constitute the means by which individuals and institutions position themselves in a social space and their primary tools for improving this position. In this relation it is important to remember that capital for Bourdieu does not simply equate financial assets and that every field involves a battle over all of the four above mentioned types of capital.

Last, but not least, Bourdieu employs the notion of *doxa*, describing the relative correlation between the disposition (habitus) and position in the objective social structures within which people act (fields). Doxa illustrates how the habitus and fields are bound together by wider axiomatic and unalienable beliefs that link the participants. Situations where there is seeming correlation between disposition and position lead to reproduction of the status quo, however, in cases where there is discordance between the two, a crisis may arise which leads to a process of transformation that gives rise to innovation and structural change.

Now that we are have explored the four main elements of Bourdieu's framework, the question remains; what, if anything, can these concepts and constructs really tell us about the actions and social reality of health workers on the ground in Hyderabad?

### *10.3.2 Manipulating Bourdieu*

For Bourdieu, fields come in various degrees of autonomy. Indeed, society itself must be seen as a field which itself contains a wide variety of fields, none of which are ever completely separate from society as a whole. Peillon argues that the first task of any analysis must be to try to understand the relative position of the field of interest in relation to the wider social sphere and to determine the degree of autonomy of said field, since "an autonomous field is characterised by a high level of specificity: it possesses its own history; a particular configuration of agents operate within it and struggle for a distinctive stake; it induces its own habitus and upholds a distinctive set of beliefs. Such an autonomous field is highly differentiated and marked by sharp boundaries, beyond which the field ceases to have any impact on practice" (1998:215)

Drawing on Peillon's definition of an autonomous field, it is clear that leprosy control in India has constituted just such an autonomous field, in that it only held meaning to those who were part of it, thus, it demonstrates clearly demarcated boundaries and a highly specialised discourse. This can be seen to be changing with integration of leprosy services into the general health system and the dismantling of the vertical implementation structure. Considering the importance leprosy discourse has in the life of my informants; the amount of time they spend at 'work' as opposed to in other social roles; the importance it has for their definition of social identity 'as leprosy workers', as well as its insular nature and sharp boundaries, I would argue that it constitutes its own habitus. One of the difficulties in analysing leprosy control as a field stems from the fact that it must be seen as both part of the wider social field of Indian society, the habitus into which the health workers were born but, equally, it must be seen as part of a wider international field of public health and public health policy into which the health workers have been socialized.

Clearly, Indian leprosy control is the product of a wider international policy process through which a consensus view of appropriate procedures is derived. Yet, Indian leprosy policy is equally the product of a uniquely Indian context and, thus, an

expression of national political, social and cultural concerns. Though the process of Indian leprosy policy formulation may seem odd to the outside observer, may sometimes be at odds with international policy and may seem contradictory, it constitutes doxa for the officials and health workers who work within this framework.

By combining the guidelines of international policy with the particular concerns of the Indian state, such as the quest for modernity and the ambitions and aspirations of the government, the national policy effectively reconciles the potential conflict between disposition and position that health workers in the field may have been expected to feel. National policy thus 'filters', as Bourdieu would have put it, international policy through the wider Indian habitus to reshape a national policy which, despite being strictly in accordance with international guidelines, still manages to be uniquely Indian in nature.

In line with international policy, Indian leprosy policy has moved away from institutional care towards community based rehabilitation. At the same time, other government strategies such as the new 'Disability Prevention and Medical Rehabilitation' (DPMR) plan, with its focus on 'clearing of backlogged deformity cases through RCS" (NLEP, 2007a), and the government's increasingly violent enforcement of anti-vagrancy laws, must be understood in relation to more national concerns such as the ambition of the Indian state to be seen as modern and as a developed country – an image which cannot easily be squared with the presence of leprosy-disabled bodies begging in the streets of its major cities (Staples, 2007).

The world view of the health workers is very much dominated by international discourse even at field-level. Many of the health workers read the Leprosy Review and hoard whatever WHO information they can get their hands on. Yet, whatever information or recommendations do not fit their view of India is absorbed, digested and then discarded as unsuitable for the local situation. By recognising that local leprosy control is subject to the influence of two powerful encompassing fields, we can begin to analyse how the different fields impact the habitus of the health workers. But how exactly does the realization that leprosy control in India can be

said to constitute an autonomous field, inducing its own habitus, add to our understanding of the lived reality of health workers?

Primarily, utilising Bourdieu's framework allows us to understand how it is that health workers make sense of their environment, and how it is that they have come to be so embedded in their context as was argued in chapters 4, 5 and 6. Crucially, people themselves are not necessarily aware of these structures, being embedded in the structures and, thereby, unable to see the forest for the trees. Thus, any analysis of the habitus necessarily severs a direct link between the stated perceptions of our research subjects and constitutes a step away from their direct lived experiences. Methodologically, this means that the researcher must attempt to read between the lines of statements made by their informants, to try to access the processes and predispositions that shape these statements, and to look for pattern in behaviour and ideal constructs that can give clues to the underlying processes whilst taking extreme caution not to superimpose our own structures or see flames where there is only smoke.

The notion of habitus as dispositions can seem rather static, vague and, in its tautological nature as both structured and structuring, not always particularly helpful in terms of analysis. Bourdieu's construct of the field, on the other hand, is highly differentiated and offers a perspective which allows us to tease out the mechanism through which people are positioned and position themselves with the use of forms of capital. In order to fully understand the contributions of this insight we must venture deeper into Bourdieu's conceptual framework.

As mentioned above Bourdieu sees the field as a battle-field – a social space where individuals and institutions are constantly jostling for position and influence within a defined 'force-field'. If we accept this as a premise, then, Bourdieu argues, the *"position of any individual, group, or institution, in social space may thus be charted by two coordinates, the 'overall volume and the composition of the capital' they detain. A third coordinate, variation over time of this volume and composition, records their 'trajectory' through social space and provides invaluable clues as to their habitus by revealing the manner and path through which they reached the*

*position they presently occupy"* (Wacquant, 2006:7). And this is where his contribution really begins to yield insights, for the position and volume of capital held by health workers within this field has changed drastically over the last few years. As argued in previous chapters, they have gone from being the pillars of the organisation to feeling marginalised and stigmatised.

As the field (leprosy control) has changed from an emphasis on direct service delivery to a focus on facilitation and development the health workers feel their role has been marginalised and their capital within the field, and the organisation, devalued. In response to this they have resort to validating and maintaining their social identity through the nostalgic, idealised recollection of their role in the past. This construction of social identity consciously draws on the health workers' trajectory within the field, and attempts to bind them together as a group and maintain their relative position in the field by creating an illusion of capital vis-à-vis each other, at the very same time as their capital is shrinking in real terms. Later, I will attempt to demonstrate that this re-emphasising of past discourses goes beyond merely attempting to short-circuit their trajectory, and actually taps into a much deeper debate surrounding truth and knowledge as in terms of the goals of leprosy policy. For the moment, let us focus on how the creation of this nostalgic social identity serves to create internal solidarity within the group and can be seen to serve to bond the health workers together in a process of mutual validation in an attempt to short circuit their trajectory. Simultaneously, this very social identity is sabotaging their efforts to reassert their importance in the field and retain capital, as the syntax they are using is out of synch with that of the wider field. This response is understandable yet, ultimately, counterproductive. As a subgroup within their field, they cannot co-opt capital without challenging, or at the very least engaging, with that of other groups. By creating the illusion of capital and influence in the new policy landscape, the health workers are effectively failing to engage with, and demonstrate their utility to, the 'new' social space within which they are now placed.

Ironically, this stance serves to marginalise the health workers even further just as the tide is turning and their particular brand of capital is coming back in fashion. As

the onus of international leprosy policy shifts from control back towards cure, from facilitation and sustainability towards empowerment and rights-based approaches, from health to development, there is a growing market for exactly the skills and experiences the health workers have to offer. Recent research has shown that the impact of disability prevention is less about explaining the correct procedures of self-care and more about empowerment of the individual patient, something which can only be achieved through counselling, which requires an in-depth knowledge of each case and a considerable time commitment to the process. However, the particular type of industrialised medicine which still dominates the Indian medical scene is ill equipped to effect such empowerment, as it entails a shift of power from the provider to the consumer, something which has traditionally proven very difficult in professionalized medical models (Cross, 2007). Having said this, health workers are already providing these services, are already on the ground providing counselling and empowering people affected by leprosy, and thereby constitute real time links to community perspectives which will prove crucial if leprosy policy is to effect the shift that current policy discussions seem to advocate. Thus, this is the effective capital that the health workers ought to focus on and work to improve over the coming years. However, whether or not this potential increase in capital will be recognised, or utilised effectively, ironically depends largely on the current capital of health workers within their organisations and institutional settings.

As was argued in previous chapters, organisational culture is something that is constantly renegotiated, and is to a large degree dependent on the ability of each individual or group to influence the process in such a manner that their particular brand of capital is recognised as important. The field of leprosy control is itself losing capital in the wider public health field, both internationally and nationally, as organisations and governments reassess their priorities and refocus their resources, or diversify their activities, to fields beyond leprosy control such as HIV/AIDS and TB. For organisations previously focused on leprosy care, falling leprosy prevalence rates necessitated this process, both to demonstrate the continued value of their organisation and, importantly, to continue being practically useful in a public health sense. In addition, changes in funding structure and the financial imperative of ever larger grant sizes has in many cases driven an internal

change in organisations, from implementation to management, thus increasing the sphere of influence of project officers and other planning/support staff at the expense of implementing field-based staff. Further, the lack of clear processes and structures for bottom-up communication makes it highly questionable whether or not the health workers can negotiate a re-evaluation of their importance and significance to the future of leprosy organisations – effectively, if they can manage to have the net worth of their capital re-evaluated. To some extent, this comes down to the ability of a group of largely junior staff to act strategically and politically, or to get senior project staff to advocate on their behalf, a process which is drastically hampered by the general devotion to hierarchy and the system of patronage which places the responsibility for, and faith in, advancement in the hierarchical structure itself.

Bourdieu's framework aims to reconcile the subjective and the objective, to create a framework which would enable us simultaneously to see the world as experienced by the health workers (habitus, disposition) and to analyse the social construction of that reality (field, systems of positions). By giving equal emphasis to positions and dispositions it becomes clear that we cannot fully understand the complexity of the social sphere without taking both the structured and structuring functions of the habitus seriously. Wacquant argues,

> "In lieu of the naïve relation between individual and society, then, Bourdieu substitutes the *constructed relationship between habitus and field(s)*, that is, between 'history incarnate in bodies' as dispositions and 'history objectified in things' in the form of systems of positions. The crucial part of this equation is 'relationship between' because neither habitus nor field has the capacity unilaterally to determine social action. It takes the *meeting* of dispositions and position, the correspondence (or disjuncture) between mental structures and social structures, to generate practice" (2006:8).

Applying this perspective to the health workers, it is clear that they exercise agency and take innovative action, yet these actions are not taken in opposition to the system. Crucially, the health workers retain their dispositions, they believe in the system. However, recognising that the system does not always work in an optimal manner, they innovate. They innovate in order to support the system, not necessarily in order to change the system. The health workers are fundamentally

embedded in the field, or perhaps Bourdieu would have said embodied in the field, thus their actions are not acts of resistance but maintenance through innovation or *jugaad*.

Let me give a less abstract illustration. Leprosy services have been in the process of being integrated into the general health service for a number of years and the health workers have played an important part in this process in terms of training and assisting the staff at the Urban Health Posts with both diagnosis and paperwork. However, the present situation is such that the health workers are still carrying out all work associated with leprosy care and documentation at most of the city's health posts. When asked what they think about integration, they say that it is essential for the future of leprosy care. Unwilling to criticise the government, they state that integration has been a success, yet, express careful concerns about its feasibility if their support was to disappear in the future. According to my own observations at the city's urban health posts, there is no such thing as integration in the area covered by ULP, beyond the fact that the NGO health workers are carrying out leprosy services in the physical location of the government health posts. However, because of the way that they are filling in the cracks of integration, the health workers are effectively hiding the fact that the system is not working and, in the process, carrying out a lot of work which is never recognised by anyone but themselves. From the way the health workers speak about their role in the integration process, there would appear to be some degree of pride in the fact that integration still relies on their presence, because it reinforces their view that they are needed in order for the system to function properly. Though this may serve to reinforce the nostalgic discourse and their social identity, it also simultaneously undermines their position in the field, as their action to supplement the shortcomings of integration is in effect working to make their role redundant. So, the actions of the health workers are geared towards making the system work, or appear to work, and simultaneously serve to reinforce their perception of their own importance, as they cannot, fundamentally, accept the notion that the system could survive without them.

The health workers are carriers of dispositions, of a certain discursive narrative and habitus that guide and motivate their actions. However, they are also actors with positions in a field where they must fight to retain their role and their capital, in their every day work and interactions with the wider health system and within ILO itself. As the leprosy policy landscape changes this relationship between dispositions and position is challenged as the health workers dispositions, or narrative, increasingly diverge from that of the wider field of leprosy policy. It is in this 'relationship' that we can most clearly see the developing disjuncture between the mental structures of the health workers and the social structures within which they work.

Helpful as it is to think about the relationship between disposition and positions this is also, in my opinion, one of the weakest points in Bourdieu's framework. For Bourdieu, this relationship is either one of resonance or dissonance, one leading to reproduction of social forms and one leading, through crisis, to transformation and innovation. A problem with Bourdieu's framework, and a common critique of it, is that it does not allow for enough agency or social change (Gorringe and Rafanell, 2007).The framework tends to see people as 'trapped' in their habitus. Effectively, this means that, as all experiences are filtered through the habitus, we cannot imagine anything else and we cannot exact agency towards that which we cannot imagine. Bourdieu also sees this entrapment as something quite physical and speaks of habitus as being embodied, implying that we to some extent perform habitual actions as 'physical reflexes' without much conscious thought. That we are essentially fish in a fishpond, or rather fish in a series of fishponds, each fish seeing their own pond as natural, as 'given' and change as something that ensues as a result of a crisis brought on by fundamental incompatibility between dispositions and systems of positions.

I feel that this level of insularity is less relevant now than ever. Agency must be given a greater role in an analytic framework. Globalisation, increased communication, plus changes in the nature and number of 'fields' that social actors inhabit cannot be explained merely by referring to an increase in the frequency of 'clashes' between habitus and field, thus producing crises that drive social change. We need an analytic framework that recognises the reality of continuous and

cumulative changes and the improvised nature of social practice. I would argue that we need to draw on thinkers such as Spinoza and Deleuze to recognise that though our social strategies are subject to a degree of constraint they, never-the-less, have characteristics of freedom (Deleuze, 1988, Connolly, 2001, Gatens, 1995). Though people follow dispositions these dispositions, I would argue, are less directive than Bourdieu's framework seems to imply. The people's practices are neither conscious nor unconscious but, rather, can be seen to form a kind of second nature in which people know without knowing what it is that they know. In fact, the rules are, arguably, constantly changing and being modified according to the situation, if ever so subtly. As a result we must act creatively, adjust and 'make up the rules as we go along'. Though all actions are mediated through the habitus, the dispositions of the habitus can more usefully be seen to form guidelines rather than rules and, accordingly, peoples' agency becomes an expression of 'strategies' rather than rules. Though this debate falls well beyond the scope of this thesis, it serves to point to one of the central weaknesses in Bourdieu's framework, because, for Bourdieu, strategies conceived within doxa are necessarily predictable in nature. Recognising that there is a distinct tendency to overestimate the degree of freedom and agency we have over our lives I still believe that there is greater human capacity for agency than Bourdieu's vision of the agent as corporeal meat-machines, as bodies performing rituals of habit, allows for.

It is not the purpose of this thesis to analyse the strengths and weaknesses of Bourdieu's framework as this been expertly done by others. Instead, I have chosen to focus on the aspects of his framework that I feel are useful to the analysis whilst identifying the limitations in its explanations for social change and limited scope for agency. As a result of these weaknesses Bourdieu's framework can only take us so far. In order to fully understand the actions and social identity of health workers within the current policy landscape we need to add a little something to the mix. Thus, to make room for agency and in order to be able to analyse the significance and implications of the innovative actions enacted by the health workers I will attempt to supplement Bourdieu's framework with some of insights from Foucault.

### *10.3.3 ... and Marrying Foucault*

To involve Foucault in our analysis we must first return to the concept of power. In the previous chapter we discussed power as something that is wielded by individuals in the process of influencing the creation of organisational culture, and this is certainly one aspect of power. However, in order to understand Foucault and how his theories can help us understand the agency demonstrated by the health workers in the field we must understand the central position that power occupies in his framework. For Foucault power is capillary (Gledhill, 1994) and something which saturates even the most intimate of relations, even that between mother and child (Scheper-Hughes, 1993).

Perceived in this way, power is not something that can be wielded by individuals or groups but, rather, it is expressed through the creation of discourse, the dialectic of power/knowledge. Foucault argues that, if we accept that power is an inalienable attribute of all social relations, then we must stop perceiving power merely as coercive might and "we must cease once and for all to determine the effects of power in negative terms: it 'excludes', it 'represses', it 'censors', it 'abstracts', it 'masks', it 'conceals'. In fact, power produces; it produces reality; it produces domains of objects and rituals of truth" (quoted in Thomas, 1994).

Again, we are brought back to this tautological relationship between what we know and what we can know. Throughout this thesis I have used the notion of discourse to talk about what constitutes appropriate and legitimate ways of thinking about the world. For Foucault discourse is one of his defining concepts, one which links language to practice. For Foucault language does not simply reflect reality but helps to constitute it through networks of statements ,discourses or 'regimes of signification', expressed in every field of social interaction (1991 [1975]). "Discourse, Foucault argues, constructs the topic. It defines and produces the object of our knowledge. It governs the way that a topic can be meaningfully talked about and reasoned about. It also influences how ideas are put into practice and used to regulate the conduct of others"(Hall, 2003:346). These discourses, or structured ways of knowing and speaking about things, constitute systems of

thought through which we organise our understanding of ourselves as human subjects (Foucault, 1998 [1984]). In other words, the power that constrains our choices as subjects is the very same as that which constitutes the discourse that allows us to know ourselves as subjects. Power both subjugates and makes subjects.

Like Bourdieu's framework, Foucault places the focus of his analysis on the relationship between agency and structure. However, for Foucault, the route to understanding this relationship lies through the analysis of the role of power in this dynamic. Foucault sets up his notion of discourse along similar lines to Bourdieu's concept of the habitus, in as much as it is seen to constitute the structure which regulates and directs our activities, as well as the framework through which we can understand our surroundings. Thereby, discourse both structures and is structured. For Foucault, discourse must be understood as the end product of the interaction between power and knowledge, determining the ability to establish 'regimes of significance' and 'rituals of truth'. In a way similar to Bourdieu's doxa, these inalienable truths which bind people together become 'real' for that group. However, Foucault argues that these are not merely the result of an accidental conglomeration or an incidental process, rather, the process itself is a result of disciplinary power "which 'seeks to transform the affective make-up of the individual' through the disciplining of the body" (Morris, 1989:2-3) as well as capillary power relations and the physical control over the bodies of individuals and groups of individuals. This focus on how power is inscribed on the body through practices of discipline and, importantly, on whom, through the creation of discourse demonstrates how certain themes and ideas gain legitimacy and become 'real' in the mind of the participants of this discourse. This discourse then becomes a key feature in the construction of social identities of actors. In this perspective, agency gains prominence again, as a creative force.

Going back to our health workers, it could be argued that their efforts to re-emphasise a 'glorious past' discourse goes beyond merely attempting to short-circuit their 'trajectory' and maximise their capital as Bourdieu would argue. The re-statement of commitment to a past discourse through the creation of a nostalgic

social identity could in itself be read as an act of agency in a culture where direct criticism of management directives or strategies is frowned upon. So, unable to directly express criticism of the current policy and strategies, health workers express indirect critique through the endorsement of a discourse which is essentially 'other' – or, to paraphrase Bourdieu, the primary expression of taste is to express the distaste of others taste. The fact that the discourse they have chosen to base this social identity on is one where their importance and standing within the organisation was higher than what it is today gives a good grounding from which to engage with the power/knowledge dynamic, from which to try to establish alternative regimes of truth' and actually taps into a much deeper debate surrounding truth and knowledge in terms of the goals of leprosy policy.

Whilst, for Bourdieu, actors are largely unconscious of the process of domination, Foucault, argues that actors are aware of it. The process of disciplining and self-discipline aims to create docile bodies which serve to maintain the status quo, to work in factories and man the armies. This process of domination depends on the ability of structures to constantly observe and control bodies through sanctions, however, the 'bodies' themselves are aware of this process of domination. For Foucault, the individual's identity is constituted through interaction, through relationships, and this same process of interaction gives rise to agency. So, for Foucault, much like power, agency is everywhere always.

Power does not reside in a structure, rather it is the structure, power is not relational, rather, it is the relation, power does not only work on people, it works through them. "Power is not an institution, and not a structure; neither is it a certain strength we are endowed with; it is the name that one attributes to a complex strategic situation in a particular society (...) Where there is power, there is resistance, and yet, or rather consequently, this resistance is never in a position of exteriority in relation to power." (Foucault, 1998 [1984] Vol 1:93-95).

Thus, all relations carry with them the innate possibility of resistance and the exercising of agency by individuals, though any such action must be read in relation to the relative cost, in the form of sanctions, of such actions. However,

sanctions are not necessarily levied by institutions or by a dominating 'force' but, rather, are exercised through the self-disciplining of the individual, as power works through the individual. For Foucault, as power, knowledge, identity and resistance are all part of the same process, embodied agency can be expressed as "we are not what we are, we are who we can become" (Caldwell, 2007:782). Sanctions effectively function to keep resistance and social change in check, for should all actors decide to resist the reigning discourse the social fabric as we know it would crumble. However, through acts of agency gradual and diminutive shifts in the power/knowledge balance are possible, either on a societal or sub-group level.

Thus, by drawing on Foucault's framework, and especially his understanding of power, we can complement the theoretical framework we have gleaned from Bourdieu in order to construct a conceptual framework that allows us to see structures as not just disabling but as simultaneously enabling. The combination of these two approaches provides us with a framework that allows us to understand agency as expressed within the structure rather than necessarily in opposition to it. As discussed in previous chapters the health workers are very much part of the structure within which they work and their actions are shaped by this discourse or habitus. However, it does not limit their actions to unthinking reproduction of these structures. As argued in chapter 7 & 8 the health workers manipulate the system, in direct and indirect ways, in order to achieve what they perceive to be the goal of the system. Applying Foucault's insights allows us to recognise these acts are in fact instances of embodied agency, through which the health workers act in order to refine the discourse. The acts of agency are not straight forwardly acts of resistance, for that the sanctions would be too high, emotionally and socially, but they are expressions of the seeds of resistance that all discourse carries within itself. As such they constitute a contribution to the gradual shift in discourse and can be seen as a mechanism through which the health workers regain some of their ability to effect change.

The work of both Bourdieu and Foucault has gained in prominence and popularity in recent years (Santoro, 2008) and the two are often lumped together as examples of post-structuralist theorists. This is not to say that the two theorists

provide a 'comfortable' match. It is important to remember that, though the two cover similar ground, they approach these issues from very different standpoints. Bourdieu was a social scientist interested in analysing how things work. Foucault, on the other hand, was a historian and a philosopher dedicated to describing how things are and were in the past (Callewaert, 2006) . It is true that the two theorists have different strengths and weaknesses, and that we should not be afraid to emphasise their strengths, especially if utilised together, as proposed above, to complement each other's frameworks. The danger here is that such an approach can reintroduce the dichotomisation between agency and structure and, either, re-create a framework that casts the two in a dialectic relationship or overemphasise one at the expense of the other.

## 10.4 The Myth of the Reluctant Participant – Agency, Structure and Resistance.

For this particular piece of research, Foucault and Bourdieu provide what I believe to be the best framework for understanding the health workers' agency within a wider structure. The combination of these two frameworks is not the primary conclusion of this research, rather, it aims to highlight the importance of establishing theoretical frameworks that aim to understand agency within structure. Though the enterprises of both Bourdieu and Foucault explicitly aimed at overcoming the dichotomisation of agency and structure in social theory, by proposing frameworks that attempted to explain the relationship between the two, it is an unfortunate reality that the way they have been utilised by subsequent researchers have tended to cast them on opposing sides of the fence.

Despite this trend, this research is not the first, or the only, to combine the two theoretical frameworks to understand social action; Gorringe & Rafanell (2007) combined the two perspectives in their attempts to understand Dalit social movements in Tamil Nadu; Ebrahim (2008) did so to study relationship between NGOs and funders; Decoteau (2008) combined the two in a study of AIDS in post-apartheid South Africa; and Bourgois (2004) utilised them to a study of everyday

violence of Hepatitis C amongst young female injection drug users in the San Francisco Area. The list could go on.

Nor are Foucault and Bourdieu's theories the only ones that can be utilised in this manner. As discussed above, there are a number of other theorists who offer solutions to understanding the relationship between agency and structure, and who could be utilised in a similar manner in different research. The crucial point here is that, whichever approach we utilise, we must ensure that we do not fall prey to the temptation to dichotomise agency and structure but, rather, strive to understand how agency is expressed within the structure.

Over the last 20 years, anthropology has sought to build an understanding of the structures that underlie the choices we make in life, to move away from a perspective which favours the description of the meanings and significance that events and circumstances has for people towards an understanding of the structures that shapes this understanding, regardless of what the people themselves might think of these. It has moved from a primarily constructivist to a structuralist perspective (Dressler, 2001) and towards building an understanding of the relationship between structure and agency, between subjectivism and objectivism. However, this shift in focus in anthropology has tended to utilise these theorists to illuminate relations of structure, rather than agency, by looking at the power of discourse/technologies of self and structuring structures/habitus, and has to some extent contributed to the creation of a sense of 'claustrophobia', a sense of being trapped in the circumstance of our lives, destined to play our pre-scribed roles set down by social realities outside of our control. Perhaps as a result of this, anthropologists have created a plethora of accounts of how agency can become the means by which individuals can use this very 'oppressive' framework that is structure against itself, to take back control over their destinies and their lives through acts of resistance and the deployment of 'weapons of the weak' (Scott, 1985). Of course, the 'discovery' of forms of resistance depends largely on the relationship between the researcher and their informants, as well as the conceptual framework of the research, as was demonstrated adeptly by the parallel research of Groves and Chang with Filipina domestic workers in Hong Kong where the two

found contradictory stories of resistance/submission and empowerment/control (Groves and Chang, 1999).

It could be argued that the joke is on us. That it is us, the academics and researchers, who are 'the weak' in this situation and that it is our own salvation that we seek through the construction of the mundane everyday habits of our subjects as 'epistemological guerrilla warfare'. As some have argued, the notion of resistance has received increased attention within the academic community at the very same time as the revolutionary ideals of the 60s have fallen out of favour and new social movements have sprung up in their place creating the need for new frameworks of power (Abu-Lughod, 1990). Thus, as a research community, we have propagated the myth of the reluctant participant through the construction of a discourse which casts the individual in struggles of resistance with the wider structure. The trend favouring 'resistance' as a research topic can be rather overpowering, as recounted humorously by Brown:

> "After hearing a half-dozen earnest candidates describe how their dissertations focused on the subject of resistance, the college's president, a distinguished medieval historian, turned to the other members and, genuinely baffled, asked, "Doesn't anyone study cooperation and harmony anymore?" His rueful comments were evoked by an analytical fashion that received far more acerbic treatment in an after-dinner talk served up by the Association of Social Anthropologists by Marshall Sahlins in 1993. "The new functionalism", said Sahlins, consists of "translating the apparently trivial into the fatefully political" (1993:17)" (Brown, 1996:729)

Rather than falling subject to the romanticism of resistance, we must focus on creating analyses that give subjects back their agency within the structure. Of course, there are 'guerrilla warriors' out there who live in resistance to the system. However, such a state is extraordinarily difficult to maintain, and as Foucault would argue, to truly live in 'opposition' to structure would mean not sharing very basic assumptions about the world with others in your group or wider society, and such a life would fall very close to our definition of 'madness'. For there is no one 'system', no one 'habitus' to be resisted. As Hebdige's (1981) analysis of the British punk movement so elegantly demonstrated, through the very act of mounting a conscious rebellion against the system, the agency of the punks in turn created

another discourse/habitus, no less structuring than that which they rebelled against in the first place. This new habitus is formed in direct opposition to the doxa of 'mainstream society' and is maintained through structuring structures of the sub-culture which take the form of conformity in non-conformity.

### 10.5 Agency In Structure

"It is our contention that Bourdieu prioritizes the social structural elements that configure individual embodied practices (habitus), whereas Foucault emphasizes how an interaction between agents underlies the embodiment of individual and collective subjectivities. In other words, a Foucauldian approach complements Bourdieu's model by foregrounding the processes by which structures are constituted and challenged." (Gorringe and Rafanell, 2007:98-99)

By drawing on the insights offered by Foucault and Bourdieu's frameworks and avoiding the temptation to place agency in opposition to structure, we can build a framework which aims to understand the extraordinary way that people influence the world around them through expressions of agency within structure. Drawing inspiration from the work of artists such as Richard Wentworth and Jane Fulton Suri in focusing on the ingenious, inventive, eccentric, trivial, mundane and often very funny ways in which people interact with the structures, material and other, that surround them we can build an understanding of what Wentworth calls the 'syntax of assemblage' (Heathcote, 2006). Each subject's creative agency within the structure must be recognised as part of creating this syntax, in other words, the use of a hammer to prop open a door or a pencil to put up one's hair are valid expressions of agency within a structured world and are part of the assemblage of agency that constitutes culture, even if they can hardly be called acts of resistance.

This does not, however, mean that we can disregard the role of power in the expression of agency or in our understanding of the wider structures that surrounds us. Oppression is real, power inequalities exist, and global forces influence local conditions. However, it is not enough to rail against 'structural violences', as

Waquant (2004) has argued, without recognising to what extent we as subjects (both researcher and research subjects) are part of these 'structural violences' and maintain this system through our everyday actions. To think outside our habituated structure, to think outside the box, as the popular managerial slogan goes, is extraordinarily difficult.

Paulo Freire (1996) argued that people must discover the conditions of their own oppression through their own lived experience, and that to be truly 'free' the oppressed must find ways of thinking about their existence that are not adopted from the oppressor nor constructed in opposition to it. Those who have the most to gain from acts of resistance to the structure (the oppressed) are busy enough just getting by, let alone questioning the structures that make their existence a struggle for subsistence. However, this does not mean that they are without agency or that they have no power to influence structure through the deployment of this agency. Individuals and communities creatively and strategically engage with their existence, their lived reality, in ways that maximise their gain. When, in public health or anthropology, we talk of building on local strategies, or reconciling local strategies with organisational intent, these are the '*strategies of existence*' we are referring and hoping to build on – agency strategically deployed within the structure to maximise the gain for the subject.

We must come to see agency, not merely as re-action to structure, but as creative action. The innovations and manipulative expressions of agency of the health workers I worked alongside were not acts of defiance of the system, it was not their intention to change, undermine or criticise the system. It could be tempting to reconstitute the 'creative bookkeeping' of the health workers as either acts of resistance to the wider leprosy control discourse (drawing on Foucault) or as a means by which they increase their capital within their field (following Bourdieu). In reality they are neither, or perhaps both. For the health workers their manipulation of official records is seen as a means by which they bypass inconsistencies or shortcomings in the system whilst maintaining their commitment to the system and its stated goals. However, this does not make their agency any less valid.

By pitting agency against structure we create a world view where only agency aimed at social change remains valid, when, in fact, much agency is expressed with the stated intention of maintaining the system. Though it may be less 'sexy', it is no less valid or revealing. As true societal change is a relatively rare occurrence and it could be argued that it is of less interest to the average anthropological analysis than an understanding of everyday change. In this respect, it is not subjects' 'acts of resistance' but their constant expression of agency within structure, be it in compliance or opposition to that structure, that adds to the syntax and ultimately drives change, if not in a Kuhnian (1996) sense. Ultimately it comes down to whether or not our subjects see their acts as 'resistance' or not – if they don't, we should be cautious of re-contextualising and, thus, losing sight of the larger issues. We need to move beyond the notion of resistance "the category itself is not very helpful and (...) the important thing is to attend to a variety of transformative processes, in which things do get changed, regardless of the intentions of the actors or of the presence of very mixed intentions" (Ortner, 1995:175)

From a public health point of view, this realisation is particularly interesting as much agency within health systems is expressed in just this manner. If it is our intention to understand the process of implementation and the role played by health workers in this process we must look for instances of agency expressed within the structure. As is the case with the leprosy health workers I worked with, and as is undoubtedly true of many other groups within the health system, their training and embeddedness in their field means they often share the goal and approaches of the wider structure they work within, if not necessarily down to the minutiae of working practices and guidelines. Thus, their acts of agency are often an expression of their understanding of the overall aim of the procedures rather than devotion to the procedures per se. Re-contextualising their actions as acts of resistance would belie their own understanding of their actions. Yet, it can be crucial that we understand these acts of agency as they are very often what actually constitutes implementation, and in many cases constitute the practical experience of service users.

There is a tendency within public health to assume, for the purposes of analysis, that the relationship between plan and outcome is linear. Yet, if we take the above realisations seriously it is apparent that what we are more likely faced with is a complex process of agency as expressed within a wider structure. This can, as I have argued in the case of the leprosy health workers, be an incredibly fruitful process, facilitating implementation in ways it would be difficult to plan for. Still, it assumes that there is concurrence in discourse between implementing staff and planners. In situations where there is a schism, as may be developing within the organisation I was studying, between the values and aims (discourse) of higher management and field-level staff, the creative expression of field staff would necessarily be detrimental to the intended outcome of the process, as both parties are not 'pulling in the same direction' so to speak. From the point of view of increasing our understanding of the processes of health systems and the role of field-level staff, we must move beyond a view of health worker adaptability as either positive or negative and recognise that it is inherently neither and both.

By recognising the role of agency within structure, we can build on the strategies of field-level staff in order to maximise output both in terms of benefits for service users and improved working conditions for health staff – this is very much in line with the idea of drawing on the existing strengths and capacities of the community. Of course, we must still oppose oppression and seek to 'improve' the structure or counter 'structural violences' but we must do so without reconstructing our subjects' acts of strategic adaptation into conscious acts of resistance. The most efficient way to influence the structure in this context may very well be to facilitate local strategies, thus maximising their cumulative impact on the 'syntax of assemblage', as this would increase their proportional impact and might and, thus, drive social change. Most importantly this strategy is flexible and open-ended, able to shift focus along shifting local strategies, and, thereby, it minimises the risk of negative impact on the local community. Simultaneously, the researcher needs to bear in mind the macro-perspective by lobbying against structural inequities and for improvements in the policy arena but, most importantly, for more bottom-up communication to facilitate greater impact of local strategies at the macro-level.

# 11. Health Workers, Local Strategies and Organisational Intent

*"My kind suggestion. Like this research is so need. Because a lamp is there. A big lamp is there. It is giving a lot of light to others but it is not hitting under that shadow. It is not hitting under that shadow. You have understood my point? He is feeling that lamp is giving a lot of power. To the surrounding people, it is not hitting under the shadow above me, above the client. If it is not hitting that shadow, tomorrow all people can ask 'you have some patch, some problem. You have to take care of yourself'. Like that. In my job, in my profession, I am getting like that problems. Working as a community health worker in a NGO sector. Those who are taking services from an NGO, service receivers, them or me, crores. Friend, this is not give life, full life to you. There is a lot of stress, you choose life of...ehm... service or NGO sector. After that we have given OK self, it is OK. You have to think of yourself, first yourself, then you stand properly you can serve others. But in NGO, like me, all are having like that. In that, if we think like that scenario, how can we serve the organisation and community?" (as expressed by one of the health workers)*

As the health worker expressed it above 'research like this is so needed'. It is needed in order to move leprosy services forward into the future, it is needed to demonstrate the importance of ethnographic research and the careful application of social theory to the understanding of public health problems and it is needed to build a thorough understanding of the work of front-line health staff, the process of implementation and the nature of health systems.

## 11.1 The Bigger Picture

This research set out to answer the question of what role front-line health workers can play in reconciling organisational intent and local strategies in the process of implementation. I feel that I have amply illustrated this role as well as highlighting its potential in the urban leprosy setting. I have also argued that the three; organisational goals, local strategies and the process of implementation, must be understood to be intricately linked. Organisational intent can be seen to be determined by a wider discourse and health workers can be seen to be the bearers of this discourse or this organisational culture. Further to this, I have argued that this wider discourse cannot be seen to merely constitute a hegemonic discourse

which is imposed on local communities uncontested. Rather, the discourse as manifest on the ground is dialectically created in the interaction between organisation and community as this interaction is embodied by health workers and re-negotiated on a daily basis. I have also tried to illustrate some of the ways in which this interaction is negotiated, from the point of view of the health worker, through the bartering in time and respect; through going beyond remit; and, through acting as a mediator between community and other social bodies.

However, there is a danger that any impact of the health workers' extended role is limited to individual interactions and relationships in the field. Admittedly, my perspective was very much that of the health workers but, from what I experienced of the organisation, the reporting structures, its hierarchical nature, the schism in organisational culture and the stigma surrounding leprosy work and leprosy workers, meant that there is little appreciation for, or understanding of, the work carried out by front-line health workers. In the absence of bottom-up communication channels, there are serious limitations to the possibility of these insights being carried into the planning or policy stage and, thereby, influencing future interventions in such a manner that these avenues might be utilised to identify ways in which to draw more directly and systematically on the strengths and capacities of local communities and, as a result, maximise the positive outcomes for both community and organisation.

When it comes to the future of leprosy services specifically, it is clear that in order to move leprosy policy forward and to achieve the goals that are currently being aspired to, a shift towards more rights based approaches and interventions that respects the individuals', as well as the public's, health are needed. Approaches that involve people affected by leprosy in a more fundamental manner and frameworks for bottom up communication are instrumental to achieving this. The thinking around leprosy and the involvement of leprosy affected persons in interventions has come a long way, however, there is a qualitative difference between interactive PoD services and equal involvement. Though dedication to quality services is one of the core capacities of ILO, one must take care to ensure that a dedication to service does not ground the organisation in the role of provider

rather than enabler. One way to do this is to utilise the creativity displayed by the health workers in the field to move beyond conservatism and identify innovative new approaches. Field-level health workers are a natural ally if we aim to introduce more client focused care. In effect, organisations already carry out many of the activities to which they aspire but, as most of these go unreported within the current reporting formats, many organisations remain unaware of the activities and achievements of their field-level staff.

Field-level health workers are not impartial conduits of bottom-up perspectives, nor are they particularly well suited as knowledge brokers. Yes, they are ideally placed in corporeal proximity to the community. Yes, they have an in-depth understanding of client perspectives, needs and views and they often act to preserve these even if this means acting outside of the system. However, they are also deeply embedded in the structures of the organisation and wider discourse, as well as acting in their own interest. The health workers' loyalty is to the underlying goals they share with the system, and client perspectives only fit into this framework if it does not contradict what the health workers feel clients 'ought to' want. The innovative approaches created in the field are the product of the interaction between health workers and communities. They must be seen as a product of prolonged negotiation and compromise. To merely ask the health workers to report on local strategies would produce responses determined by the dominant discourse's depiction of ideal scenarios and the health worker's own personal, political and religious affiliations. As part of this perspective, implementation must be seen as an ongoing, continuous, negotiated relationship between two active self interested parties, where both must compromise and barter to reach desired outcomes.

Leprosy is merely one field and ULP is merely one project. Nevertheless, the insight garnered through this research has the potential to have implications for wider public health perspectives. Anthropological methods have long been utilised in public health, however, there has been a scarcity of anthropological studies attempting to build an understanding of public health implementation through the application of anthropological theory as well as methodology.

The current interest in health systems research and primary health care has opened up exciting possibilities of truly multidisciplinary research around implementation and the role of field-level health workers as exemplified e.g. by the work of the Health Systems Development group.

As described in the previous chapter, the approach to understanding health workers, how they relate to the wider structure and exercise agency, emphasises the importance of understanding agency not merely as a reaction, or opposition, to structures but as something which is carried out within these wider structures. This research utilises a combination of Pierre Bourdieu and Michel Foucault's theories to build an understanding of the interplay of agency and structure and the role that power plays in this relationship. Though these theoretical frameworks serve best to illustrate the situation examined by this piece of ethnography, they are by no means the only available perspectives. There are a number of equally promising social theories which could provide a similar framework for other studies. What is of import here are not the theories in themselves, but the application of social theory to try to understand the relationship between agency and structure to the process of implementation and public health in general.

I will therefore argue that what is needed is an anthropology of public health and an ethnography of implementation which can offer vital insights for public health, insight into how interventions and health systems function on the ground, how and by what mechanisms outcomes are achieved and how health systems operate. We need an anthropology of public health, to understand how public health, health systems and implementation happen at ground level. Armed with this understanding we can move towards improving interventions.

## 11.2 Public Health Today

Research focusing on front-line health staff, implementation and health systems is not only sorely needed, it also fits in nicely with the currently emerging themes in the international public health discourse. Faced with severe global shortages in

human resources, there is growing interest in gaining a deeper understanding of the working practices of front-line health staff and the importance of implementation studies is growing in recognition. In addition, a growing interest in multi disciplinary studies opens the door for more input from anthropology in terms of theoretical perspectives as well as methodological strategies. Finally, I will argue that research on health systems, such as that carried out by the Health Systems Development Programme, creates the ideal setting for the anthropology of public health, as it recognises and strives to explain the difference between the intentions and outcomes in health policy implementation.

There is growing recognition within public health that, present trends prevailing, the world is unlikely to reach the health related MDGs in time for the 2015 deadline (UN, 2008) and the public health community is now turning its attention back to comprehensive health reforms to address this deficit. The ambitions and aspirations of the Alma Ata declaration are again coming into fashion, 30 years after they were first proposed. Primary health care, and interventions aimed at addressing comprehensive health care, may offer the best hope of reaching the MDG in time for the deadline, but how prepared is the public health community for this shift, and how deep does political commitment to this approach run?

When Dr Margaret Chan was appointed Director of the World Health Organisation in November 2006, she set out a six pronged primary agenda for her directorship, two referring to fundamental health needs, alongside two operational and two primary strategic aims. The two strategic aims were; a) strengthening health systems and b) using evidence to define strategies and measure results. The proposed framework for strengthening health systems highlights six areas of effort;

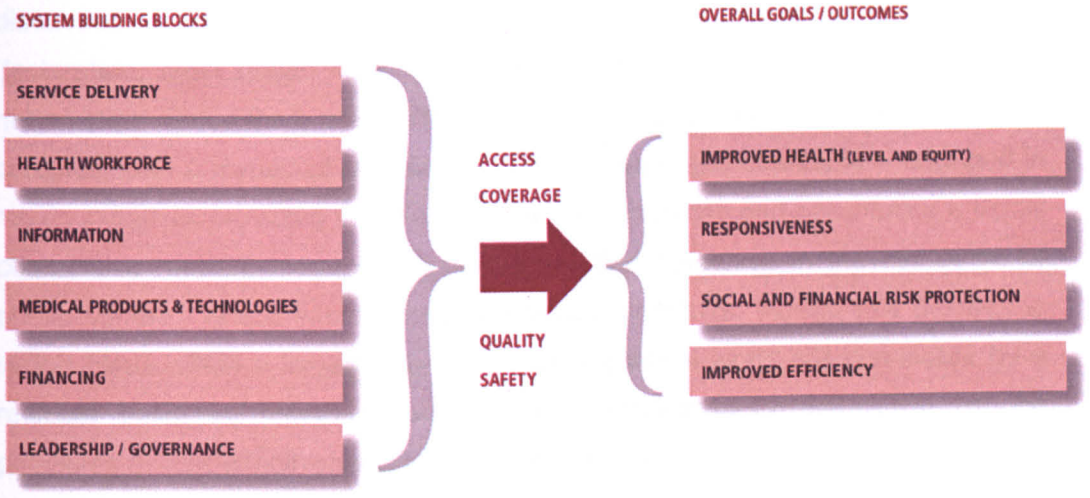



*Figure 17.* Health Systems Framework (WHO, 2000)

The World Health Report of 2006 (WHO, 2006b), 'Working Together for Health', analyses the current crisis in the global health workforce, the deficits in human resources within the health sector and how to address some of this shortfall. Naturally, the role of the community health worker has again been identified as central to solving this staffing crisis. In addition to this, the WHO, under Chan's directorship, has issued several seminal publications related to the human resource shortage within health care in the developing world and advocate task-shifting as a possible means of addressing this crisis (WHO, 2007c). So, this is the political and policy landscape as it looks on a macro level. There is an expressed interest in health systems development, and in training/re-training/retaining health staff as a means by which we can achieve the health MDG by the 2015 deadline.

The second perspective, which is taking on renewed importance in current policy discussions, is the renewed interest in primary health care (PHC). The most recent World Health Report (WHO, 2008) proposes Primary Health Care as an answer to some of the underlying problems plaguing health systems around the world. Primary health care is back on the agenda and the journey back to Alma Ata is being held up as our best hope of reaching the Millennium Development Goals. However, it bears remembering that PHC was the product of a particular time in international development. The world has changed since the 70s. As was

discussed in Chapter 5, at the time of the conceptualisation of the Alma Ata declaration, most health care was directed and implemented through a strong nation state. Since then, the health care provision landscape has grown incredibly complex, with a myriad of providers – public, private and charitable – engaged in mixed initiatives providing a veritable bonanza of services and constituting a highly competitive medical hierarchy. Currently, we find ourselves in the 'discourse of public sphere', where interventions are driven by NGOs, though this process is taking place within a largely neo-conservative political world still dominated by a residual belief in 'market-engendered spontaneous order' structured by the principles of cost-effectiveness. Introducing PHC into this drastically changed world order begs the question of whether we can retain the principles that underpinned the Alma Ata declaration or if primary health care and community health workers merely offer a cheap way of shifting responsibility and accountability for their own health care back onto the most vulnerable populations.

The current trend towards NGOisation of public health could, if applied to PHC, become a means of circumventing state accountability. This has already happened in some regions and for specific public health issues, as problems take on global proportions that go beyond the capabilities of national or regional governments and control is largely given over to international agencies such as the WHO, The Global Fund and similar bodies. If we are to introduce PHC into this setting we must ensure that all the tenets of Alma Ata; equity, inter-sectoral collaboration, community involvement and the use of appropriate technology, are adopted to ensure that the primary health care ethos is imported along with its tools.

In the midst of this, field-level health workers must renegotiate their standing in the wider hierarchy. Primary health casts ground level health workers as crucial elements in the quest to achieve the goals set down at Alma Ata, yet, within the field of public health, there is little in-depth understanding of the role of health workers in implementation. In addition, the role of health workers has changed since Alma Ata and they must now compete for influence within a much more complex health provision landscape. Having uttered the necessary warnings, it is clear that the ambitions of PHC and the ambition to utilise local strategies are born

of the same social outlook and share a desire to work with communities rather than in or for communities.

These are laudable ambitions and might constitute a brave step towards a holistic view of health that embraces both vertical and horizontal strategies as and when they are appropriate. It is also a return to more 'low-tech' solutions to health problems, after decades of focus on vaccine development and new technologies. Though these are sorely needed, they often come too late and at too high a price to reach those that truly need them. Having recognised the intrinsic link between poverty and ill-health, it is one of the most shameful realities of public health that current health systems far too often fail to reach the people who need them the most – the poor and marginalised. By shifting the focus back onto primary health care, ground level staff and strengthening of health systems, an opportunity to address ground level health care provision has opened up in public health discourse. But how appropriate are the frameworks within which we approach and analyse these issues?

### 11.3 Health Systems: What Exactly Is Being 'Strengthened'?

*"The need for sustainability and for strengthening health systems, especially in the poorest countries has almost become a mantra in international policy statements" (Brugha and Walt, 2001:153)*

In the foreword to the WHO's framework for strengthening health systems, Margaret Chan writes that *"the strategic importance of Strengthening Health Systems is absolute. (...) The best measure of a health system's performance is its impact on health outcomes."* (WHO, 2007b:iii) The two pillars in the health systems strengthening framework (see *Figure 18.*) that are of greatest interest in this context, is **Service delivery** (packages; delivery models; infrastructure; management; safety & quality; demand for care) and the **Health workforce** (national workforce policies and investment plans; advocacy; norms, standards and data). As outlined in the document, the discussion around these focuses

predominantly on technical and operational aspects; on training, cost-effectiveness, logistics, operational standards, management of human resources and availability of materials. Though undoubtedly important, this is a very linear approach to health systems, adopting a top-down approach, where health systems are seen as large apparatuses that can be controlled through proper managerial and administrative practices in order to achieve desired outcomes. However, in my view, health systems are far more complex than that.

### *11.3.1 Health System as Process*

All the aspects outlined in the WHO framework are clearly crucial to ensuring quality and efficiency of health services but, as systems approaches, frameworks like this are severally limited by their understanding of health systems as closed and functional systems. To understand health systems solely through their ability to achieve desired outcomes is to neglect their processual nature. Drawing on policy analysis, it is clear that the input of desired policy goals does not equal desired outcomes through a simple linear process (Grindle and Thomas, 1991) but, rather, the creation of outputs through implementation is a multi-faceted and complex process that depends as much on the actors involved in the process as it does on the original intent or input. Applying Comaroff's double dialectic framework, it is clear that discourse is created as much through local 'interfaces' between health providers and service users, in a relationship where both parties contribute to the process and where both parties can be seen to be pursuing their own interests (Long, 1992), as they are by international agendas.

For Julio Frenk, a health system must be understood as a relationship between institutions and populations, a relationship that is not simply reactive but predictive, not episodic but continuous (Frenk, unpublished). If we take this analysis a step further, we can begin to see the health system not as 'a' relationship but as the cumulative of thousands, millions, of individual encounters between health providers and service users at ground level. Arce & Long (2000) investigated how localised practices adapt and change the ideologies imposed on

them by modernising agencies and call for ethnographic studies of how these discourses relate to the "strategies and language games of local people who face new and increasingly global social relations" (Arce and Long, 2000:3). By shifting the focus to the relation between global discourse and local strategies, they demonstrate how global discourse, no matter how hegemonic, must always be played out "in local encounters and through human agency" (Nustad, 2001:486)

There is no getting away from the fact that health systems are, indeed, very large, bureaucratic and administrative apparatuses. However, anthropological analysis allows us to access the extent to which they are also social microcosms, driven by internal power relations and fractional political behaviour and interests. Health systems are not impersonal abstractions or rational 'systems' that can be measured and evaluated purely through quantitative outcome measures, that can be directed and manipulated by omnipotent actors in the guise of policy makers, planners and researchers. Behind the health policy analysis and outcome indicators lies a health systems process, processes that involve a vast array of actors at all levels.

### *11.3.2 Health Systems as Workforce*

Health systems are employers, some on a massive scale (the NHS is believed to be the 3rd largest employer in the world, after the Chinese Army and Indian Rail (TheTimes, 2004)) and it is the cumulative impact of the actions of health system employees that constitutes policy in practice.

There is a general global human resources shortage in the health sector. Health systems all over the world are struggling with worker shortages, skill mix imbalances, misdistribution of human resources, negative work environments and a weak knowledge base. In addition, what work force remains in developing countries has to deal with the impact of HIV/AIDS, out-migration and a legacy of chronic underinvestment in human resources.

Health workers are 'the ultimate resources of health systems' (Chen et al., 2004). So, to strengthen the health system is to strengthen the workforce. Though the density of health workers is clearly important (Anand and Barnighausen, 2004), numbers are not everything. Strategies to strengthen human resources in health systems have too often focused only on availability and distribution of personnel (Hongoro and McPake, 2003). However, "workers are active – not passive – agents of health change. Often commanding two-thirds of health budgets, they glue together the many parts of health systems to spearhead the production of health" (Chen et al., 2004:1984). As such, health provision must be seen to be about the nature of the care provided, as much as the quantity of care, since "outreach services, clinics and hospitals are only as good as the people who staff them. Health workers are the linchpin, the keystone, the pivot of all efforts to overcome health crises and to achieve the MDGs for health" (JLI, 2004:21).

Understanding the role of policy and discourse is crucial but, equally, so is the understanding of implementation, as one does not function without the other. We can no longer see process as a "divided, dichotomous and linear sequence from policy to implementation" (Clay and Schaffer, 1986) or vice versa for that matter. Policy and implementation are inextricably linked, as are agency and structure. Micro level processes are affected by, and in turn affect, macro processes, through a double dialectical relationship.

An in-depth understanding of structure, agency and power is crucial to understanding these processes. Gill Walt's (1994) framework for policy analysis emphasises the importance of understanding the role of actors in the health policy formation process, however, most policy analysis has tended to focus on actors involved in high level policy formulation. Less work has been done to understand the role of actors at ground level, in the meeting between health systems as envisaged by policy makers and health systems as experienced by service users. Implementation studies have tended to look at actors in terms of their individual motivations, as liberators, or, as lackeys. However, to understand the role and impact of ground level health workers, we must see them as simultaneously being

both lackeys and liberators, only then can we see how they are embedded in the system and employ agency within this very framework, all at once.

### *11.3.3 Health System as Interface*

Despite the central position of the work force in health provision, it has not received 'due attention' in the past (Wang et al., 2002). Now there is growing recognition of the importance of mobilising the work force and strengthening health workers' knowledge base, in order to strengthen the health systems they work within (Chen et al., 2004). The focus on health workers is crucial at this juncture in public health but greater emphasis must be placed on understanding health workers as real embedded individuals rather than as a category or cadre to be addressed.

As appreciation for the wider determinants of health grows (CSDH, 2008, Blas et al., 2008), the focus of global public health discourse is shifting towards structural interventions for health (Gupta et al., 2008) that aim to remove upstream barriers in order to aid in the production of the conditions under which people can be healthy (Porter et al., 1999). It is important that we understand how such system changes will impact on the front-line health workers who implement these reforms. Penn-Kekana et al's ethnographic study of maternity health workers in South Africa demonstrated that recent structural and financial reforms of the health sector had unintended detrimental effects on the everyday working practices of the midwives. "It is not the policy principle (...) that leads to the undermining of maternal health services, but the complex nature of the policy processes, in particular the lack of consideration given to implementation processes and the needs of health workers who implement policies" (Penn-Kekana et al., 2004:i72).

As front-line health workers are deeply embedded in the system and wider structures within which they work, interventions or programmes aimed at reforming these systems will necessarily have a profound impact on the nature of the relationship between health workers and service users.

From my own study it is clear that changes in the leprosy policy landscape have affected the health workers' social identity, their policy narrative and their everyday working practices. The impact of these changes is being passed on to services users, for better and for worse. If we understand these mechanisms we can strive to plan and implement better suited policies and interventions in the future. As Buchan (2000) demonstrated in the UK, the most significant impact of reforms are often their effect on the motivation and attitudes of health staff.

Accepting that health systems, as experienced by service users, are the cumulative expression of the interactions between health workers and service users we can come to see health systems as manifestation of this interface. Reforms aimed at structural interventions affect health workers as much as service users, and, as such, changes the nature of the interface between the two.

### *11.3.4 Health System as Intention and Outcome*

To understand how outcomes are achieved at ground level we must go back to basics. Statistical modelling and quantitative analysis are crucial to the evaluation of health provision efficacy. However, they also have severe limitations in that they neglect the processual nature of implementation and the quantitative efforts which go into creating measurable outcomes, as well as ensuring quality of care.

*Figure 18.* Relationship between plan and outcome

Within public health policy there is often a tacit assumption of linear progression from plan to outcome. That, if we plan well and execute our plan correctly and efficiently, we will necessarily achieve the planned outcomes. However, the process of executing a plan is complex and subject to constant adjustment (see

*Figure 18.*) and, by understanding this process, we may be able to plan more efficiently in the future. Understanding the implementation process should also allow us to understand the desired outcomes of our target population and, thereby, to improve future plans by accessing the strengths and capacities of target populations. Focusing on the implementation process can enable us to engage with the reality of local communities' lived experience, in a way that the ground level implementing staff do on a daily basis, thereby forcing a us to refocus our attention from outcome measures to how health workers do 'that thing they do' and how they achieve their goals through applied 'simple complexity'. This work is often dismissed as common sense but, in reality, and as this thesis has attempted to demonstrate, it relies on a subtle skill set that cannot easily be codified in training manuals or policy, but comes with years of experience and extensive networks. By building a better understanding of the implementation process, and the role of health workers on the ground, we can contribute to the creation of more realistic and practicable plans, as well as increase the likelihood of achieving desired outcomes.

When policy based on solid evidence fails to produce the desired effect at the implementation stage, the public health community speaks of the 'implementation gap' and invests time and resources into understanding policy weakness or faults in the mechanisms of implementation. As long as policy produces the desired outcomes, we congratulate ourselves on a job well done and assume that the outcomes are the result of our wisdom and effective planning.

The assumption that the system does not need fixing as long as it produces the desired outcomes presumes that the policy, the system and the intent are the driving forces in the policy process, and that implementation is merely a technical problem, a managerial and administrative task that, if handled properly, will produce the desired results. However, there is also an acknowledgement that implementation gaps can be caused by actors or structures within the system, thereby recognising that the implementation process is as much subject to internal and external influences as the rest of the policy process.

Much as implementation gaps can be caused by actors or structures, so can implementation successes, in which case they cannot straightforwardly be seen to be the result of the policy or the system but rather the product of the process of implementation. I have attempted to demonstrate the extent to which the health workers I worked with exercise agency *through* the system in order to address what they see as shortcoming in the system, thus, ensuring that the desired outcomes are achieved either by compensating for shortcomings in the policy or by expressly 'not' following policy.

Implementation success as the result of such processes comes very close to the Indian concept of Jugaad, and much of the same criticism can be levied at these processes. It is not enough to repeatedly circumvent the system, the system itself needs to be adjusted.

There is considerable creativity within all systems, creativity that can potentially have both negative and positive impacts, creativity that is driven by actors who are simultaneously lackeys and liberators. Just because something appears to be working doesn't mean it doesn't need fixing or that it couldn't be better. People are improving things on the sly all the time and we should aim to utilise this existing creativity to improve systems and future planning pro-actively, rather than to merely fix problems reactively, as and when they arise. In many cases, as was discussed in relation to the field activities of the leprosy health workers, this creativity may actually be what makes the wheels of interventions turn in the first place. It may even be that, without it, it is rather unlikely that policy would produce the desired outcomes.

One way of harnessing creative innovations in order to increase system outputs is through scaling up innovative pilot projects and primary health interventions. However, scaling up without truly understanding what is being done, or how results are being achieved, may fail to create the impact we hope for, as the approach may labour under the false assumption that our data is good; that our policy is good; that our evidence-based interventions work according to plan; and that it is the careful implementation of our plan that brings about the desired results.

Understanding the process, as well as the outcomes, is crucial for the success of any implementation. This is especially true when scaling up, as the conditions for success may not be the same when working on a larger scale. If we do not understand the process, we cannot anticipate the impact of interventions or the ability of health workers to fulfil on these promises in other contexts. We need to understand the "micro-political processes that occur in public services organisations" (Barrett, 2005) and, to achieve this, we need an anthropology of public health.

### 11.4 Looking Under the Hood – What Makes Interventions Tick?

This study set out to form an understanding of health services as a system as well as understanding how interventions are implemented in practice. It set out to take public health and organisations seriously as structuring realities and to understand the role, and potential impact, of health workers within these structures. By looking at how outcomes are achieved, rather than merely what outcomes are achieved, the study facilitates an understanding of the mechanisms through which outcomes are achieved, effectively, what makes interventions tick.

Field-level health workers obviously play a key role in this, as does organisational culture and policy as structuring realities, alongside the local strategies and needs of service users, as these present alternative influences on health workers. The process of implementation is a complex reality with powerful vested interests and numerous actors. It is not merely the question of identifying new 'answers' to implement through an established system but, rather, finding new answers in the mechanisms of the existing systems. The emphasis on the interplay between agency and structure has implication far beyond the theoretical as they represent the interplay between health delivery systems and the actions of those tasked with its implementation, between intentions and action.

Anthropological studies, such as this one, can help us understand how public health outcomes are achieved, as well as understanding the impact of the health

provision context within which services are provided. This ties in thematically with the recent focus on health systems in public health and, in particular, with the work of the Health Systems Development Programme.

### *11.4.1 Dynamic Responses to Health Systems Research*

As argued above, much health systems research is limited by its pragmatic nature. However, there are notable exceptions. The uncertain and complex nature of health systems has been incorporated into a new generation of health systems research, which strives to move beyond policy analysis and outcome measures to look at the 'glue' (Walt, unpublished) that binds health systems together, the processes that constitute the interface between health providers and service users and which create desired or undesired health outcomes.

One notable attempt at building a more inclusive study framework for health systems analysis comes out of the Department For International Development (DFID) funded Health Systems Development Programme (HSD). The approach employs complexity theory to attempt to account for the uncertainty and complexity of health provision that cannot adequately be accounted for through traditional outcome measures, as these are often, despite their stated intention, quantitative in nature (Parkhurst et al., 2005). The framework recognises that health provision is not merely a series of isolated encounters but the product of a mutually constitutive, continuous and dynamic relationship between providers and patients. These encounters take place within a specific cultural, political and social context (Atkinson, 2002, Standing, 1999) and all the elements in the process react to each other, and to external stimuli, in complex and adaptive ways. Therefore, any analysis must aim to identify emergent patterns rather than cause-and-effect sequences. As part of this perspective, the health system is the result of "a series of 'dynamic responses' that sit between the *de jure* health services that are legislated and the *de facto* outcomes that are observed", where the *de jure* health services constitute the intended health system and policy outcomes and the *de facto* health system constitutes health care as experienced by the service users

(Balabanova et al., 2006:7). Implementation of the *de jure* system is necessarily mediated through health workers who respond, react and adapt the system through 'dynamic responses' that are expressed through informal mechanisms such as informal payments or manipulation of resources (Blaauw et al., 2006) (see *Figure 19.*). These 'dynamic responses' may be especially important in low income countries where the health systems are less strictly regulated.

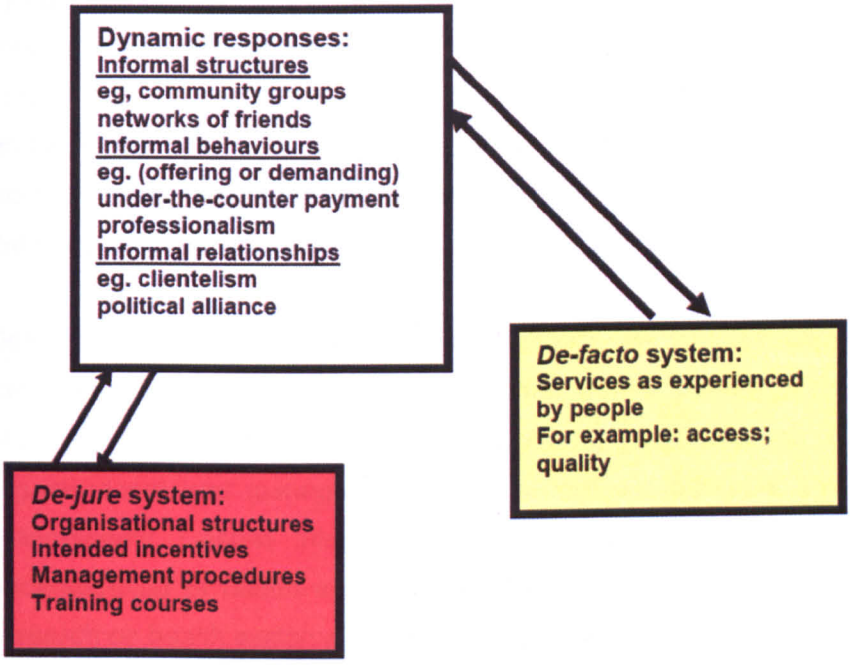



*Figure 19.* A conceptual model for health systems research (McPake et al., 2006:16)

Health workers' responses are complex, in that they are subject to great individual and social variety, and dynamic, in that there is a continuous feedback loop between the formal systems' and the health workers' reaction to these. As a result, there is necessarily a gap between policy intentions and the experiences of service users. Blaauw et al argue that "*de facto* health care systems experienced by users is *compromised*, especially for the poorest – those least able to challenge the practices of health workers or able to find health care outside of the established system" (2006:17 my emphasis). This observation is in direct contrast to my own

experience, where the health workers' actions served to improve access for the poorest through the application of such 'dynamic responses'.

The HSD framework argues that previous research on health systems strengthening has drawn too extensively on experiences from developed countries with less research on and, as a result, less understanding of health systems in developing countries. In addition, much research has been 'preoccupied' with system re-engineering (Martinez and Martineau, 1998). However, "it is clear that reorganising and re-arranging the *de jure* system without paying attention to human resources is unlikely to result in improvements in health system performance (...) [as] it is the reactions and behaviours of health workers, more than their simple availability, that ultimately determine how systems function and the success of health sector reform initiatives" (Blaauw et al., 2006:18)

Despite its ambition to understand behaviour, as well as complex contextual relations and processes, the approach suffers from a 'poverty of theory' (Blaauw et al., 2006) as the framework remains stubbornly pragmatic, with an emphasis on organisational and managerial factors, as well as individual and environmental determinants. Despite this, the HSD and other attempts to build an in-depth understanding of health systems herald exciting new directions in public health research on health systems, implementation and health workers.

### *11.4.2 My Research and Health Systems*

> *"Health sector reform that seriously addresses the 'software' of health systems would differ significantly, in both content and process, from current initiatives. It would focus on priorities such as developing shared goals, promoting organisational values, creating supportive working environments, influencing informal social networks, building trust, and improving organisational learning. These initiatives will probably require new types of bureaucratic organisations and depend on more participative and transformative approaches to management and leadership" (Blaauw et al., 2003:40)*

This study should be read, in its own right, as an in-depth ethnographic account of the everyday working realities, social identities, policy narratives and agency of a specific group of front-line leprosy health workers working in an Indian NGO at a time of drastic changes in the leprosy policy landscape. However, the research must also be understood in relation to the health systems research described above, as an attempt at incorporating anthropological methods and social theory into the study of human resources in health systems and the relationship between policy intentions and the actual experiences of service users. This research is not, however, an attempt at suggesting a framework or a particular social theory. For the purposes of my study, the two French theorists, Bourdieu and Foucault, provided a useful framework for analysis. However, there are a host of social theories that deal with the relationship between agency and structure and that could provide alternative frameworks in other contexts. Which theory is best suited will, to a large extent, depend on the context, the research question and the researcher. It matters less which theory is applied and more that a theory is applied.

There is an urgent need for more data to inform the debate surrounding human resources and health system strengthening (Hongoro and McPake, 2004), but we should question what kind of data we are collecting and with what theoretical parameters this is being analysed. As long as human resources research remains stubbornly pragmatic, health system research cannot move beyond a quantitative paradigm. This is not merely a question of methodology. The move in public health towards recognising health systems as complex social systems driven by 'dynamic responses' call for equally complex and dynamic frameworks for understanding and analysing these systems.

As outlined in the HSD framework, our understanding of health systems must move beyond merely describing the differences between de jure and de facto systems towards forming an understanding of the mechanisms that drive this process. In order to achieve this, we must rely on explanatory models that draw heavily on social theory and the understanding gained through in-depth ethnographic studies of field-level implementation.

However, this does not mean that epidemiologists must now become social scientists (Susser, 1999, Walker, 1997). There are no magic bullets, simple methodologies or predefined frameworks to adopt but, rather, "understanding all the relevant systems factors and how they relate to health workers' behaviour requires a multi-disciplinary approach" (Hongoro et al., 2004:19-20). Differences in paradigms must be bridged, interdisciplinary prejudices must be overcome, the timing and strengths of different disciplines must be localised and, most importantly, we must find practical and achievable ways of co-ordinating this collaboration (Ramalingaswami, 1986). It is imperative that we conceive practical ways in which to construct thriving multidisciplinary partnerships without limiting their creative potential.

The Health Systems Development Programme's emphasis on 'dynamic responses' resonates well with my own research and the conclusions of this thesis. On the one hand, the HSD framework indicates the readiness of public health to engage with social research on a truly multidisciplinary level. On the other hand, my ethnographic study can serve as an example of the potential of in-depth ethnographic studies and the careful application of social theory for furthering the insights of the HSD framework and for developing the framework in the future.

The methodologies of anthropology are already being applied within public health, but the careful application of social theory is what will enable us to build more complex understandings of the mechanisms that drive these 'dynamic responses', rather than producing merely descriptive accounts. Public health researchers may complain that human social behaviour is difficult to explain, quantify or analyse, but I would argue that public health, as a discipline, simply lacks the specific skills and tools to develop and apply such analyses. However, social scientists have spent centuries theorising, devising and perfecting the tools needed to analyse just this kind of complex, dynamic behaviour. "Because health systems are social systems, health system researchers and reformers need to pay much more attention to social theory (...) [and] health systems researchers need to be much more active in using, and contributing to, the substantive body of work in the social sciences" (Blaauw et al., 2003:39).

I believe this piece of research demonstrates the potential for ethnographic studies of implementation to further public health understanding of health systems. I also believe that this study and its findings stand as testament to the importance and plausibility of applying social theories to public health scenarios and that it lays the foundation for a more involved relationship between anthropology and public health.

Hopefully this research can inspire others to carry out similar studies in different cultural, political and health care settings. For when it comes to health systems research and human resources, just as Atkinson notes for studies of decentralisation, there is a need for better local knowledge: "Without a body of work documenting the realities of policy implementation in context, we have no record of what is really being changed, we do not know what we are monitoring through quality indicators and we cannot assess relevance of regional and national experiences from one context to another" (1997:635).

### 11.5 Anthropology of Public Health for Anthropology in Public Health

> *"Anthropological accounts of development institutions are very important, but if we are to locate the most anthropologically significant development encounters, then we should be looking beyond the offices of the UN and USAID. The proposal for a methodological reclamation is thus a call to study development more wholeheartedly at the main sites of its dialectic encounters, and to do so with the goal of producing 'thick' ethnographies (...) through long-term fieldwork and participant observation in localised, grassroots settings." (Friedman, 2006:219-220)*

Though Friedman writes about development studies, his argument has relevance for studies of health systems and health policy, as much of current policy discourse fails to engage with agency or process in a meaningful sense or at an appropriate level. Anthropologists often get absorbed, rather than integrated, into the world of public health but what is needed is multidisciplinarity, not multi-methodology. Studies need to look at field-level implementation to be able to understand the

complex ways in which local 'beneficiaries' or 'service users' "challenge, co-opt and reform" services in line with their interests. This can be seen clearly in the meeting between health workers and community in the field.

As discussed in Chapter 5, if we see discourse not as hegemonic but as doubly dialectic, this opens up to an appreciation of the impact of local agency in the process of discourse creation and the importance of polyvocality. This is not to say that the agency of front-line health workers currently has a drastic impact on global policy trends. However, the recognition that there is more than one discourse that counts, that there are numerous discourses on local and global level, leads to a recognition of the importance of the agency of local front-line workers on several levels. It is important because it influences local discourse; it is important because it has the potential, in the presence of appropriate channels of communication, to influence international policy discourse; and, primarily, it is important because it constitutes the 'face' of the health system as experienced by the service users and, as such, it constitutes the de facto implemented policy. In this context, service users can no longer be understood as passive subjects but should be seen as active actors in the implementation relationship.

Friedman argues that we can only access local agencies and local voices through in-depth anthropological study, through being and doing. By aiming at 'thick' descriptions, we also circumvent the danger of assuming that all local voices are equal (Everett, 1997). If we fail to consider the dialectical nature of local discourse, and the role of power in this process, our endeavour to build on local strategies and capacities might very well translate to supporting, and reinforcing, local inequalities. So, if discourse is understood as the product of the relationship between structure and agency, as argued in previous chapters, the relationship between health workers and local communities, between provider and service user, takes on renewed significance. The discourse created is no longer the product of a reified adopted discourse but, rather, the product of a dynamic interplay between conscious, living acting subjects. Rather than addressing quiescent recipients, interaction becomes collaboration, with agents actively engaged in the creation of discourse (Comaroff, 1985).

In my mind, the *"current tendency to define ethnography as merely one of many qualitative methods masks its full potential"* as a means by which we can explain the *"socioculturally situated nature of knowledge and action"* (Huby et al., 2007:193) constitutes a limited application of anthropology. Anthropology has too often been utilised merely as a methodology within public health (Lambert and McKevitt, 2002). The future of anthropological research in the public health field is about more than just methodological impact, particular perspectives or 'cultural' insights. By asking different questions, and seeing things from a different perspective, anthropological insights can be crucial to the success of public health initiatives and to aid in the self-awareness of public health.

The successful realisation of multidisciplinary collaboration is, in part, a question of whether or not anthropology is willing to move beyond merely having a role to play in public health towards truly engaging with public health issues, theory and all. To bring our analysis beyond the identification of trends towards understanding some of the underlying causes of these trends, we must carry out research that combines anthropological method and theory to build an in-depth understanding of public health and health systems.

In recent years, public health discourse has moved away from a strictly bio-medical perspective towards a more ambitious perspective that acknowledges the social determinants of health (Harris, unpublished). Perspectives such as Infectious Disease Policy argue for a shift from reaction to pro-action and towards a public health that aims to create the conditions in which people can be healthy (Porter et al., 1999). With this broadening of the public health remit, there is a need to reconcile micro and macro perspectives. Anthropological studies can help build an understanding of the health system context within which implementations are initiated and how this affects public health outcomes. As demonstrated by this study, discourses and outcomes are the results of the interactions between structural forces and human agency, and this insight has wide implications for how we perceive health systems, implementation and outcomes.

As argued above, this engagement must go beyond the application of anthropological methods to include an endeavour to understand context and causation through the application of social theory. It can be argued that the trend towards specialisation in the scientific endeavour "has propelled man into tunnels of specialized knowledge. With every step forward in scientific knowledge, the less clearly he could see the world as a whole or his own self." (Kundera, 1984:15). Public health methodologies tend to rely on analysable proxies of social reality as means to identifying trends and outcomes, anthropology, on the other hand, takes the whole as its starting point. Trend identification and quantitative outcome measures all tend towards identifying effects. They are premised on the arrogant assumption that we, meaning policy makers, planners, researchers, are familiar with and able to manipulate the vectors by which outcomes are achieved, and that subtle manipulation of these vectors can improve the efficacy of interventions. However, as discussed above, we have imperfect knowledge of the system and the factors which produce these outcomes. The application of social science theory entails the engagement with epistemological dispositions to answer the questions surrounding the process by which outcomes are produced. Importantly, this perspective also opens up new avenues of action for improving health provision or what is popularly known as 'strengthening of health systems' in the literature. The problem starts at the very moment we think of health systems as just that, systems, rather than as a process governed by a myriad of actors. Applying anthropological research to complex entities like health systems is complicated and complex. But only through attempting to build a better understanding of the process of implementation and health provision can we hope to improve interventions. Anthropology is ideally suited to this work due to its processual, embedded, flexible, reflexive and holistic nature.

In order to improve implementation we must first understand implementation, in order to strengthen health systems we must first understand that which we aim to strengthen. By creating an anthropology <u>of</u> public health we can build a better understanding of the health service context and by building a strong tradition of 'ethnography of implementation' we can build an understanding of how agency is played out in this context. There is a difference between stated intention and

practice. Anthropological studies, like this one, have a role to play in building an understanding of how public health interventions and health systems operate on the ground and, through such insights, developing more appropriate interventions to strengthen health systems and improve implementation. It is time that anthropological research in public health extends beyond formative research, cultural insights, appendices and policy analysis, and engages meaningfully with the practice of public health delivery and the mechanisms of service provision. Only when we have an effective anthropology of public health can we truly have effective application of anthropology in public health.

# APPENDICES

## Appendix 1 – The Anthropologist in her Field

The research process is one which encompasses the transformative journey of the researcher and his/her relationship to the research subject. When we emerge on the other side of data collection we are not the same person who originally entered. What we find is not always what we expect to find, who we are is not always who we thought we were, the theoretical frameworks that fitted perfectly from the crisp coolness of our university offices often seem worn and ill-fitting in the face of reality on the ground. We often represent ourselves as fresh faced receptacles, devoid of prejudice, embarking on a journey of discovery where we will venture forth into the wilderness and return with objective truths we gather along the way. Instead, we are in truth world-weary travellers with perhaps more baggage than we would like to admit. This tabula has not been rasa for quite some time. We all have political affiliations, theoretical proclivities and personal stories that influence our understanding of the world. In this lies perhaps our greatest strength as researchers, if we approach this embeddedness in an open and honest manner.

### A.1 Participant Objectivation

The silence surrounding the researcher's place in his/her own research was somewhat addressed with the reflexive turn within anthropology in the late 20th Century yet there remains a debate surrounding the delicate balance between the primacy of the researcher, and the primacy of the subjects of research, within the field of anthropology. Many have argued, and I am inclined to agree to some extent, that an overemphasis on reflexivity has somewhat dulled the critical edge of anthropology. That there has been a tendency to become so engrossed in the process of analysing our chosen discipline that we are in danger of reverting to a mode of anthropology which is more similar to psychoanalysis of the researcher, rather than focusing our efforts on the analysis of the social reality of our subjects (Mascia-Lees et al., 1989). Recognising this conflict, Bourdieu's (2003) notion of participant objectivation offers an approach which retains the valuable insights of reflexive analysis, without ever allowing it to fall back into introspection, by shifting

the focus from the researcher to the intellectual domain that created that researcher. Rather than asking 'who' we are as researchers, Bourdieu urges us to investigate what intellectual traditions prompted us to ask these particular questions at this particular time.

The key to such an approach lies in the constant and honest assessment of one's motives, transparency in one's methods and a thorough understanding of the power relations inherent in any interaction. The need to understand the context and history of a study is now widely accepted in anthropology, as is the practice and principles of reflexivity. Combining these with our understanding of fieldwork we must be honest about ourselves, we must be willing to walk a very fine line between personal disclosure and personal psychoanalysis. Our arena of fieldwork starts when we start thinking about something we would like to study, start playing with ideas and places. It starts with what books we read, how we do our background research, who we contact to help us orientate ourselves, who our supervisors, alma maters or research network are etc... I am not proposing that we should start every monograph with an account of our childhood and an explanation of how this instilled in us certain values which later determined the choices we made, both in terms of study area as well as theoretical approaches. Yet, that is what we do to the subjects of our studies. Bourdieu's notion of the Habitus has gained great popularity in the last decades. We imbue our studies with analysis of the habitus as a means of understanding embodiment and identity, to understand the choices made by societies and individuals. Yet, we rarely subject ourselves to the same kind of scrutiny. At least not publicly.

Taking a page from Bourdieu's book, it is clear that my fieldwork started the day I decided to apply for funding to do a PhD, several years before I first set foot in India. Having completed a BSc in Anthropology and an MSc in the Control of Infectious Diseases, my fieldwork was prompted by a desire to reconcile these two often opposing approaches. Conducting my PhD in a school of public health rather than in an anthropology department was a conscious choice. One of the primary aims of my research was to try to identify ways in which public health interventions and perspectives can draw on anthropological theory and modes of seeing, which

go beyond the more commonly utilised qualitative methodologies, to develop more appropriate and acceptable interventions. It is clear that this desire influenced both my choice of methodology as well as my theoretical framework.

I was raised a socialist and schooled in political economy and the social theories of the power at a time when anthropology was focusing on subaltern voices, the weapons of the weak and new social movements in a backlash against the identity politics of the 1980s-90s. It is clear that this has had a profound effect on all my subsequent research. In addition to this formal education, I have worked in factories and offices, in menial jobs and in middle management, digging holes and shuffling paper. What all these jobs seem to have had in common is a wanton disregard for the knowledge and experience of the ground level workers. Time and time again, I experienced decisions based on petty demarcation of power, the need to be right because to be in a position of superiority means you ought to be right. However, it was also clear how limited the view from the bottom is, how narrow the focus and how fast horizons open up and competing priorities come into play as you ascend the ranks of hierarchy. So the path to my research question was the accumulation of my experiences expressed in the desire to harness the practical skills and experiences of ground level health workers and to try to understand how the wider organisational setting enables or hinders the effective utilisation of these insights. If you want to understand the best way to restock the shelves in the supermarket, you ask the person who does it every day, but you do not expect him/her to be able to advice you on how this might affect delivery schedules and shipping costs.

### A.2 Who Am I to You?

As important as it is to understand oneself and one's relationship to the field and ones informants, is the question of how my informants saw me and my position relative to them.

Was I seen primarily as a foreigner, a student, a woman, a researcher, a spy, a source of funding, an auditor, an ally, a 'resource person', a problem, a burden, an asset, a friend, a colleague?

I suspect I was seen as a burden at first. This strange white woman with short hair that they had to drag everywhere with them, and who asked incessant stupid questions. I will never truly know how they saw me at first, but I do know that our relationship changed as time passed. There is a 'moment' we all hope for, the 'moment' that anthropologists speak of in hushed and reverent voices. The moment when you find that you are no longer just an outsider to the community you are studying, but have become an outsider inside. My experience is perhaps a little unusual in that I can pinpoint the exact time and place this occurred, the culmination of a gradual process. It was a sunny afternoon, the 5th of March, approximately 15:00. Senior members of the UK based organisation that part founds ILO had come to visit the project. At this occasion I made a comment, which appeared trivial to me, but which was perceived very favourably by the health workers. After the meeting ended and the guests had left, the health workers all came over, shook my hand and thanked me for 'bringing positive light to them'. I did not say anything of particular note; it was an instant, a moment, the moment. Before that point I had been a tolerated, if somewhat untested, entity within the project. Who was I to them? A spy, an auditor, a friend, a foreigner? After the 5th of May I was no longer 'untested', I had become 'family', a part of the 'ULP family'.

However, I was to discover that achieving 'the moment' is both a blessing and a curse. Once I became invisible, once I became just another member of the family, the staff at the project no longer felt that they had to jump through hoops for me and I was left much more to my own devices. Which was wonderful and a relief, but it also made things more difficult. As I battled to schedule the last batch of interviews I was deferred, ignored or made to wait. To become invisible I had given up the priority status which meant that I got what I wanted when I wanted it. Now I had to get in line like everyone else.

## A.3 Ethics beyond Consent

Reflexivity is about more than self-awareness, it also a question of gaining clarity about how our presence will affect other people. In that respect we need to consider the ethical implications of our actions in a light beyond technical aspects of forms and committees.

This realisation starts with the acknowledgement that there our informants may have very different ideas about what constitutes research than us. Another issue which influenced my ability to gain 'informed' consent was the diverging ideas about what really constitutes 'research'. Having had all the staff at the project sign consent forms at the start of my project, I used the informal interviews as an opportunity to repeat the process at a stage when the staff where in a better position to actually give 'informed' consent. Since they had at that point experienced me working alongside them and observed my methodology, and we'd had long discussions about the nature of my research and my findings. Still, there were a number of situations where the member of staff I had just been interviewing would pull me aside outside of the room and give me a candid and uncensored version of some of the answers they had provided me with in front of the recorder. I asked them if they understood that I was 'recording' everything in my brain and in my notebook at night and that this was in reality what they had just consented to. They would shrug and say 'yes, yes, but...' and continue their train of thought. The point of contention was the recordings and what could happen if these were to 'fall into the wrong hands'. I explained that a consent sheet is a two way contract, it is as much the researcher's guarantee to them as the other way around and that it is meant to safeguard both parties. However, this raises a very relevant question; to what extent is it unethical to become invisible i.e. to seek consent at the outset, then to hang around for long enough for people to forget why one is there and to start treating you as one of them. To what extent should consent be sought periodically and continuously to remind people of one's intentions. Personally, I found that there was a very fine balance between me being honest about who I was and why I was there, obtaining the consent I needed and constantly reinforcing my position as a potentially threatening outsider. In an attempt to

establish power equilibrium I provided the interviewee with copies of the consent sheet signed by me and the interviewee.

In addition to copies of the consent sheet I provided those who requested it with a CD containing a copy of their own interview, so they would have the opportunity to listen to themselves speak English. Initially I was apprehensive about complying with this request and providing these recordings, without being able to come up with a single good reason not to fulfil the request. I found myself feeling uneasy, exposed somehow and I realised it was because I was being asked to give up my power as a researcher and place myself in the hands of my research subjects. An informal interview is not like a structured survey, there is a lot of the researcher in there. The conversation bounces around from topic to topic and the staff would often challenge me about my own views on a subject. I have never been the subject of this kind of study, never had to give of myself and to hand over control of this material to someone else. Now my subjects where asking me to do exactly this, and it gave me a small taste of the apprehensions they were experiencing. In the end I had to consider whether I was willing to stand by the mutuality of the process as I placed them in the hands of the ULP staff, if I would trust them the way I had asked them to trust me. It was a remarkable process.

Complex as issues of consent are, my ethical dilemma in the field would pose starker challenges. Ethnography is many things – not least of which is a process. A process that is fluid, continuous, intangible and unpredictable, where the researcher is carried along like a cork on a torrent. Preparing for this ride, prior to going into the field, can only ever be a feeble attempt at creating an awareness of how fundamentally unprepared one is and to strive to be prepared to handle this unpreparedness in a structured manner in order to negate some of the potential negative impacts on the research process, on the researcher and on research subjects. As I grew closer to the staff at ULP their plight was to affect me deeply. I came to empathise with their situation, to share their loyalty to their work and, even, to share a very small piece of their social identity. It is the nature of anthropological work that it is slow in the making and even slower in the writing. But as my social relationship with the staff developed, so did my ethical dilemma. I

was taking their love and friendship and converting it into research that would ultimately benefit me, yet my research would not come in time to do anything for the project staff. What was worse, could my research be causing them additional pain, in an already tremendously stressful situation, by dredging up questions about the past, organisational issues and job satisfaction? I had my reward, but was I leave my subjects to pay the piper?

Vividly aware of being manipulated by staff at all levels of the organisation, I decided not to transform myself into an advocate or my research into action research. Had the staff themselves chosen to speak out I would have gladly added my voice to theirs and contributed to the discussion. Even if I resisted the temptation to become their champion, I always attempted to contribute a ground level perspective to any senior management meetings I attended. However, I came to realised that I had more to offer than my voice. Even if I could not ensure the health workers' job security in the project or in the organisation, I could do everything in my power to ensure that they were as 'employable' as possible by equipping them with all the transferable skills in my arsenal, and so was ULP university and Professor Kris born.

**A.4 Methods and frameworks. To see and to see ourselves.**

The impact of our choice of methods and our presence in the field on our research findings are often far more tangible than we realise or like to admit as researchers. Our presence as researchers in our research is not only a theoretical consideration but something which literally colour all collection and analysis. The honest and considered awareness of this impact is crucial to understanding the research process as well as the findings. Therefore I briefly want to discuss a few issues related to my methodology.

### *A.4.1 Learning to Speak more than a Language*

When I first arrived at the project the primary hurdle was to be one of communication but not merely one of language. Having failed to find instruction in Telugu in London it was decided that I would concentrate on learning the language in situ. However, upon arrival I was to find that it was in no way this simple. Hyderabadi discourse is a complex and seemingly haphazard mishmash of Telugu, English, Deccani, Urdu, Hindi and a host of other languages.

As if trying to learn to navigate this complex forest of languages was not confusing enough, the intent behind the words can sometimes be just as slippery for the uninitiated. I had only been in the city a few weeks but was still making poor progress with my Telugu. However, I had learnt that when meeting a person of equal social standing, or whom you consider yourself friendly with, the first question on anyone's lips is always: *'Have you had your food?"*, be it breakfast, lunch or dinner. Utilised in the same way as we, in Europe, would say *"How are you?"* which goes a long way towards emphasising the importance of food in the local culture and its association with wellbeing. So one of the first things I learnt in Telugu was naturally – *Annam Thinara? (అన్నం తినర) (Had your food?)*. However, how limited my understanding was, of even this simplest of sentiments, became clear in a conversation I had with someone at the project early on in my research period:

> "I came back to the project after lunch, and Arjun asked me "*Annam Thinara? (Had your food?)*". Glad to show of my newly found Telugu skills I answered – *"Thinanu (yes I have)"*.
>
> He then asked me: *"Em Kura?"*
>
> Now, this one was new to me so I asked him what it meant:
>
> *Arjun*: *"it means 'what curry'. Ultimately you have rice – annam. So, just ask what curry. Means, what did you have".*
>
> *Me*: *"But I thought annam meant food, or does it mean rice?*
>
> *Arjun*: *"yes"*
>
> *Me*: *"No, I mean does annam mean food or rice?"*

To this Arjun gave me a confused look, and again he said *"yes"*. Clearly, there was something I was not understanding here. So, I decided to approach the matter from a different angle.

*Me*: *"What if I did not have curry, but a samosa instead? What would I say then?"*

*Arjun*: *"Then you would say: Annamu thinaledhu! Samosa thinanu"*

And I laughed and said: *"But does that not mean "I have not had food. I had samosa"*

Arjun waggled his head, smiled contentedly as if to say 'now you're getting it' and answered: *"Yes"*.

Again I laughed and tried to explain to him that for me this basic and everyday piece of pro-forma conversation said a lot, anthropologically, about 'Telugu' society, about the importance of food and in particular rice. The basic assumption being that to have rice = to have food. That the word for food is the same word as for rice. Arjun did not seem very interested in my musings; in fact he seemed a little bemused by them. At this point Manoj comes by and I ask him for clarification: *"Hey, Manoj. Explain this to me. Does annam mean food or does it mean rice?"*

*Manoj*: *"Yes, it means cooked rice"*

Later I checked my dictionary and found that annam (అన్నం) means: 1) cooked grain; 2) cooked rice; 3) food. So my questions obviously created some confusion and merely prompted the answer "*Yes*". For only an outsider could have asked such a stupid question! As Arjun had said: *"Ultimately you have rice"*, i.e. you always have rice, and thus, rice is food.

This conversation made me realize I had a long way to go before I would master this language.

### *A.4.2 Time series. Impact of the researcher's presence in the field*

Overcoming the language barriers I still needed to consider how my presence in the field changed the health workers behaviour. I had wanted to collect data for a time series analysis of the daily work activities of the health workers but realised early on that their daily activities were different when they were with me than when

they were on their own, rendering whatever data I collected useless for a structured time-allocation analysis but yielded valuable insight into how my presence coloured my findings in the field. So, I continued to collect the time series data despite these limitations.

Accepting that my presence as a researcher was an inalienable part of my analysis, I set out to find ways of limiting my impact. After finally convincing the project management that I did not want to be driven around in the project's jeep, either on personal or work related business, I became aware of the fact that the health workers would come halfway across town to pick me up at the project office before heading out to the field on the project motorcycle. Clearly this was not part of their normal activities had I not been there. So, I suggested that I would take the bus (as I was by this point an expert on the bus system) and meet them at an arranged meeting point from where we could head out together. I even made sure that I had a season ticket that covered all the three major bus types so that what bus to take would not be an issue. Then one day, as we had been waiting for the bus in the old city for 45 minutes I asked the health worker I was with at the time how much time he estimated he spent on the bus each day and how he could tolerate all this waiting. And his answer was a revelation: "*Oh, no Madam. Usually I take a service-auto, but you have a bus pass so it would be a waste*". So, my bus pass, that was intended to ensure that my mobility would not be seen as an issue, had come back to haunt me. We jumped on a service-auto and continued on our way, but it was clear that, no matter how prepared I thought I was, my very presence changed our daily routine.

### A.4.2 The written text

"If texts are to be more than literary topoi, scattered shards from which we presume worlds, they have to be anchored in the processes of their production, in the orbits of connection and influence that give them life and force." (Comaroff and Comaroff, 1992:34)

Finally, a word on the end product of this research process in the form of written text. Clearly, all text is ultimately the result of one researcher's perspective. It is the narrowing down of a multitudinous voices and possible perspectives into a defining text. The text is snapshot of reality. What I saw, how I saw it and how I have chosen to represent it to you, the reader, is necessarily a subjective process (Geertz, 1973) but one which lends the analysis strength and validity rather than detracts from it. However, we must not underestimate the power of the written word. Research is created through the complex and creative relationship between the researcher and the research subject. Even if we recognise the dialectic nature of research this comes to an end in the moment of publication, of the submission of text, when the lines that have previously been left fuzzy are suddenly drawn clearly in the sand. The written account states; this is me, the outsider, this is what I have seen of you, the insiders, whilst I was posing as an insider alongside you, and this is my representation and interpretation of what I saw (and thus what you are). Through the act of writing about 'you', or in this case the 'health worker', I come to claim the authoritative account of what was the product of a dialogue and my voice takes on a disparate and disproportionate power, I get the final word.

Though, as communication improves and the world becomes ever more globalised, and as the controversy surrounding the publication of "The Bookseller of Kabul" (Seierstad, 2002) might serve to illustrate, that discourse is no longer as definitive as we academics might like to think. It is therefore vitally important that the final product, if possible and appropriate, be shared with the research subjects so that any objections can be noted and discussed as part of the written product, thereby, attempting to incorporate the research subjects' perspectives as part of the final discourse. This feedback process was centred round the preliminary feedback report I produced for the organisation.

## A.5 Refining the Conceptual Framework

Last, but not least. The framework in which we analyse our data is not accidental or incidental, it must be seen to spring from the researcher as much as it does from the research subject. Acknowledging this enables us to balance the influence of the two, thus avoid sliding into objectivism or romantic subjectivism. Preparing for fieldwork is always a complicated process as there is essentially no way for a researcher to know in advance what we will find once we enter the field (Yanow, 2004). As researchers we prepare as best we can for every eventuality, we get vaccinated and pack first-aid kits, we prepare academically through extensive literature reviews and theoretical analysis, we shape and reshape our research questions, and we read voraciously around our chosen subject area.

Once in the field I soon discovered that my conceptual framework was built around an implicit dichotomous assumption that was not shared by the health workers. This realisation forced me to re-engage with my field without the aid of my books and my journals, to listen not to how the health workers answered my questions, but to listen to what the health workers had to say for themselves. Based on their world view I found that my well researched and well documented conceptual framework was not nearly refined enough to work as an explanatory model for their complex reality and, so, I refined my conceptual framework by introducing social theories which help explain some of this complexity. But firstly, let's look at how I came to focus on the role of health workers in the implementation process as a research topic in the first place.

I had done my literature reviews, carefully constructed my research question, and even made attempts at mapping out my assumptions. My preparations were solid and my research questions backed up by a myriad of supporting studies. For the first few months in the field things seemed to be going pretty much according to plan. My observations of, and participation in, the everyday working life of health workers seemed to back up my assumptions and appeared to yield valuable data on everyday 'reconciliation' by the health workers. Yet, we rarely discussed their view of what they were doing. The field is a hectic place. Working in health clinics

full of screaming children, navigating the menacing traffic, walking round slums conducting group talks, providing ulcer care and counselling is not an arena conducive to philosophical discussions of intent and approach, thus, conversation tended to focus on practical issues and on the health workers teaching me the basics of leprosy control and treatment.

Subsequently, it was not until three months into my research, when I started doing in-depth interviews with the health workers, that I was confronted with the basic fallacy of my assumptions. My conceptual framework was based on the assumption that the health workers experienced the divergent perspectives of the community and the organisations as a 'conflict', much as I did. Clearly there was often a large discrepancy in what the two parties wanted out of the interaction and, more fundamentally, in what they saw as the desired outcome of the interaction. Further, there was no question that the health workers were aware of this discrepancy, as the desires of the community was something that we had discussed on numerous occasions and something that came up daily in our interactions with the community as they approached us with requests in the field, *'we need access to water'* or *'can't you give us occupational training'* etc....The health workers were also acutely aware of the limitations of the organisation's resources/intent and would counter the communities' demands with a *'no, no I am here from the leprosy organisation...'* or *'yes, I understand but you need to ask the MCH about that....'* etc.

So, there was clearly a difference in intent but what I was not prepared for was that this 'difference' might not be experienced as a 'conflict' by the health workers. So, in my first few interviews, and in accordance with my carefully prepared interview guide, I got the health workers talking loosely about community needs and organisational targets before I tried to subtly introduce the topic of how they experienced this conflict. Only to be met with blank stares. Or with answers that focused on the organisation's resource limitations. Initially I assumed my questions were too abstract and 'complicated', and I tried to find simpler ways of asking the same questions. Until it struck me that there was nothing wrong with my questions nor with the health worker's comprehension of English. The basic flaw was in my assumption of a conflict. The health workers did not see a conflict, they might see

material needs that they as representatives of the organisation were not able to meet as it did not fall within their remit, and they might see *'unreasonable'* demands made by the community out to get as much as possible out of the interaction. What they did not see was conflict. This was purely a construct I had carried into the field with me and, which can be seen to be the result of a dichotomising trend within the literature, a construct that was so deeply entrenched in my research as to be part of the proposed title and research question of my thesis. Three months into my research I had discovered that even as a reflexive anthropologist trying to limit the impact of my own schooling and political convictions there were certain things that were so deeply entrenched in my world view that it blinded me to the possibility of other perspectives. In many ways, despite my efforts of participant objectivation, I had adopted a *"contemplative or scholastic stance that cause her to (mis)construe the social world as an interpretive puzzle to be resolved, rather than a mesh of practical tasks to be accomplished in real time and space – which is what it is for social agents" (Wacquant, 2006:273).* In a moment of panic I realised that my primary insights thus far were into myself and my own world view, rather than into the subjects of my research.

However, as things calmed down, I came to see the world increasingly through the eyes of the health workers and came to realized that, painful as it had been, what I had encountered was not a defeat but, rather, a break-through. As I tried to make sense of the health workers' world, to access their categories and ideal models, I began to see a world made up of nothing but shades of grey. I had wanted to paint a picture in black and white in accordance with my dichotomized conceptual framework. I had wanted to find idealists committing acts of resistance in order to 'reconcile' conflicting paradigms to mutual benefit. What I found instead were human beings doing a complex job under difficult circumstances. I found lackeys and liberators, practitioners of social- and bio-medicine, orthodoxy and heterodoxy, obedience and agency all rolled into one wonderfully multifaceted everyday working narrative.

It became clear that to understand how the health workers see the world, and to explain their actions in accordance with their own world view, I would need to learn

to recognise the impact of my own paradigms. Anthropology is an interpretive science, and this is one of its great strengths, but we must always be conscious of the process by which research findings are produced so that we don't fall into the trap of finding only that which we are looking for or reducing complexity to academic quandary.

## Appendix 2 – The L-Word

Findings of review of the use of the term 'leper' over the space of a year in one of the UKs main broadsheets.

Methodology: searched Guardian archives, http://browse.guardian.co.uk/search, for the term 'leper' on the 5th of May 2006.

Findings summarized below:

"Among some people at the CIA she was both pariah and leper, something you didn't want be around, someone who it was unhealthy to be around" ("Plame is quitting CIA over outing, say friends" Suzanne Goldenberg, Washington, Wednesday December 7, 2005, The Guardian.)

"Stevie, on holiday in Totnes, sees an old man with no fingers or toes. Soon he is sucked into a medieval world of lepers, fear, ignorance and violence. The novel is gripping and seriously scary." ("Comedy gets artful", Geraldine Bedell, Sunday December 11, 2005, The Observer)

"The first thing you notice when having lunch with Gerry Adams is that people are prone to stare in the most peculiar way, as if the president of Sinn Féin were part celebrity and part leper." ("Unifying force", James Harkin, Saturday December 17, 2005, The Guardian)

"Families of the 11 British victims killed in last summer's Egyptian terrorist attacks claim that they were treated 'like lepers' by the UK government." ("Egypt bomb families 'feel abandoned", Mark Townsend, legal affairs correspondent, Sunday December 18, 2005, The Observer )

"She knows that mothers will treat a stepmother picking up a stepchild like a leper." ("Love lessens all", Anna Shapiro, Saturday January 14, 2006, The Guardian)

"Sir Robert Mark, who made many internal enemies rooting out corrupt officers before taking the top job in 1972, described his welcome at Scotland Yard: "I felt rather like the representative of a leper colony attending the annual garden party of a colonial governor." ("Allies rally round as Met chief's troubles grow", Rosie Cowan and Hugh Muir, Wednesday February 1, 2006, The Guardian)

"Smokers have got used to being the lepers of the community, mooching around outside "public" buildings, obviously unseen by stay- at-home MPs." ("Smoking - whose right is it anyway?", Richard Jenkins, Thursday February 16, 2006, The Guardian)

"(...)the only cafe which made us feel welcome and not like lepers was McDonald's." ("McDonald's is not the source of all ill", Susan Lumb, Tuesday March 7, 2006, The Guardian)

"Luckily, outside the Queen Mum's building are a number of donated benches where you can smoke, and I joined the leper colony." ("How to light up a check up", George Melly, Thursday April 13, 2006, The Guardian)

"Victims were subjected to significant social problems. Many were treated as lepers. They had their doors daubed with graffiti, they lost their jobs and their children were not allowed to mix with other pupils at school." ("Left to die: the hidden victims of an NHS blunder", Lorna Martin reports, Sunday April 16, 2006, The Observer)

## Appendix 3 – Literature Review. Leprosy AND Urban

Literature review of the topic 'urban leprosy' carried out on the 22nd of November 2005. The databases covered were PubMed, Web of Knowledge (Web of Science & ISI Proceedings), IBSS, Development Database, CABS, PopLine using thesaurus search terms such as e.g. in PubMed ("Leprosy"[MeSH] AND ("Urban Population"[MeSH] OR "Urban Health Services"[MeSH] OR "Urban Health"[MeSH] OR "Urbanization"[MeSH])). All hits for articles published after 1970 were considered.

As the main field of interest is was in social, epidemiological, operational and policy issues – articles pertaining to strictly clinical issues with only incidental mention of urban setting were disregarded. By this method 109 articles were identified, of which 103 could be accessed and reviewed. The articles were analysed for trends in topics, and 6 categories were identified:

| ***Category*** | ***Area Covered*** |
|---|---|
| Control | (elimination; MDT; urban strategy; vaccination) |
| Epidemiology | (prevalence; risk factors; disability; childhood; drop-out) |
| Health system | (integration; KAP; private practitioners; training) |
| Operational | (case detection; case holding; community involvement; compliance; health education; PoD; referral; survey method) |
| Socio-environmental | (housing; migration; urbanisation) |
| Social | (attitudes; stigma; gender; mental health; socio-economic; stratification) |

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## Appendix 4 – Epidemiological Review

### Taking stock of an urban leprosy project. 20 years of ULP. Circumstantial evidence shows worrying trend in leprosy epidemiology.

***Abstract:***

This article aims to provide an epidemiological overview of the last 20 years of leprosy control in a South Indian city, highlighting the tremendous achievements of the Urban Leprosy Programme in reaching the elimination targets and improving the lives of countless leprosy affected persons. Moving with the times and incorporating social and economic rehabilitation and wider aspects of the disease into their programmes and assisting in the integration of leprosy services into the wider general health services.

Despite these considerable achievements, current epidemiological trends indicate that this is no time for complacency. The project is seeing a steady increase in MB rates, high child rates, advanced and highly infectious cases, and a relatively high disability rate. Indicating delayed detection and active transmission in the community. In addition there are some signs that the surveillance system post-integration may be not be working optimally. Taking these factors into consideration it is clear that leprosy control efforts must be continued at this juncture in order for the considerable achievements to be maintained and to prevent any 'resurgence' in the future. This is particularly important as more and more NGOs are pulling out of leprosy control or diversifying their activities and dispersing experienced staff to other priority areas. Following the WHO's declaration that leprosy has been eliminated globally sources of funding are becoming scarce as funds are diverted to other areas.

We hope that this case study will inspire others to publish their project experiences in the field so that we can determine whether these are context specific or generic epidemiological concerns and build a better picture of the situation 'on the ground'.

### *Introduction:*

For the past 20 years leprosy control has been a single minded drive towards elimination, despite the fact that the elimination target itself has been subject to controversy in the leprosy control community itself. Academic dispute aside it is time now, on the eve of its attainment, that we focus on reporting what is happening on the ground in leprosy control and not in the air-conditioned conference rooms of Geneva and London.

Organisations working towards leprosy elimination around the world are sitting on valuable data, often going back decades, and it is time some of this data was brought to the light of day to give us an insight into leprosy epidemiology at sub-national level around the world.

This article aims to present the achievements and findings of the last 20 years of one of Indian Leprosy Organisation (ILO) projects in India, the Urban Leprosy Programme (ULP). In addition the article will present 7 factors which constitute indications of a worrying trend that we cannot afford to ignore. Though no one epidemiological indicator is conclusive, when taken together the trend they demonstrate is worrying.

We need to investigate whether the local epidemiological situation can have changed this much in the last two decades or if what we are seeing are the signs of weaknesses in the control programme. Shortcomings which may end up become serious concerns over the next decades if they are ignored at this stage. A tremendous effort has been made and drastic inroads have been achieve against this disease, but the data shows that we still have some way to go and that there is no room for complacency. History has demonstrated the danger of becoming complacent in the final stages of an elimination campaign.

Interpretation of the epidemiological indicators of leprosy is notoriously difficult (Fine, 2006) and we still do not fully understand the modest of transmission (Webber, 1996). What is clear, however, is that these indicators are subject to a host of operational factors (ILEP, 2001). Organisations working towards leprosy elimination around the world are sitting on valuable data as well as the 'operational memory' needed to interpret this data. Especially as more and more organisations are closing their leprosy control programmes or shifting their focus to other pressing problems such as TB, malaria and HIV/AIDS – and with their disappearance from the field we run the risk of losing the very same technical and operational expertise that would allow us to interpret the data and address emergent issues and future dangers.

Though disbanding of vertical programmes and integration of leprosy services into the general health system is both desirable and necessary in low prevalence endemic settings, close attention must be paid to the process and its impact on epidemiological indicators as well as the quality of care offered to the individual. This article argues that NGOs still have a crucial role to play in this post-elimination landscape as they have the capacity to address quality and individual care in a way the public health remit of the national health service cannot accommodate.

Sustained leprosy control efforts are needed if we are to retain the advances made in the last two decades. Continued political, social and financial commitment is paramount to this process, especially at a time when leprosy expertise is being dispersed, responsibility devolved and priority downgraded.

**Background:**

*Nation and State:*
Leprosy was declared eliminated by the Indian government in January 2006. Still 140.000 new cases were registered in India in 2006 and India constitutes more than 70% of the global disease burden (WHO, 2006a). In addition it is estimated that there are 2-3 million leprosy affected persons living with physical disabilities as a result of the disease and millions more suffering social and economic disabilities (TDR, 2002).

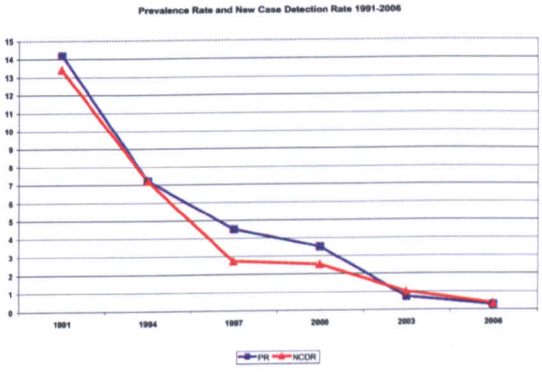
The Indian state of Andhra Pradesh was one of the highly endemic states for leprosy in India. A vertical programme aimed at leprosy elimination has been in operation since 1954. MDT was implemented in the State with a pilot district to begin with in 1983 and was expanded in a phased manner to cover all the 23 districts. The prevalence rate was

124/10,000 at the commencement of MDT, which came down to 0.57/10,000 by end of March 2006.

*Project Background: ULP*

The ULP was established in 1989 in response to the Government of India's National Leprosy Elimination[i] Campaign's (NLEP) drive for greater focus on urban leprosy eradication. It was thus the first direct project of ILO (NLEP, 1983). The project is situated in the Eastern and Southern part of Hyderabad, state capital of Andhra Pradesh. The project provides leprosy services to two thirds of the city covering a population of 21.79.540 in Hyderabad and 2.17.360 in surrounding Ranga Reddy district. The initial phase the project focused on early detection and treatment through mass and school surveys. Since cessation of active case finding in 2001 the focus has shifted to an emphasis on prevention of disabilities, strengthening of community structures, IEC, stigma reduction, SER and particularly vulnerable and hard to reach populations. Since 2002 the project has also been working with tuberculosis, HIV/AIDS and malaria.

At the start of the project the area had a PR of 14.2/10.000 population this has now been brought down to 0.27/10.000 population in 2007 *(see figure)*, with the project area reaching the elimination target of PR >1/10.000 in 2003. The total number of cases registered and treated with MDT over this time period is 13734 with a cure rate of 83%. This is a tremendous achievement in difficult circumstances. The project monitors 26 of the city's Urban Health Posts for NLEP activities, an area with 342 slums in twenty municipal wards and with a slum population of 7,73,573 and 14% of the total population living below the poverty line. There is extensive migration in and out of the city as well as considerable mobility of the population within the city itself.




**Epidemiological Indicators:**

The current accepted way of measuring leprosy elimination is, as per the WHO guidelines, by whether or not the prevalence rate (PR) falls below 1/10.000 population. The project achieved elimination by this standard in 2003.

Leprosy epidemiology is notoriously difficult to interpret due to the long incubation period, the uncertainty over transmission. As a result, many have argued that PR is an unreliable proxy for incidence in leprosy. However, this cannot mean that we should not utilise the data available to us, merely that this data must be interpreted in conjunction with a thorough understanding of the operational and population factors. On a national level this is extremely difficult. However, examining the data from individual projects presents us with a unique opportunity, since these projects have charted their progress over decades and still has the organisational memory and staff available to interpret the data in

reference to operational changes and variables. Though such an analysis will not enable us to make statements about the state of leprosy control in general it can provide us with a valuable insight into the situation on the ground in one particular location and give us valuable indications of what might be going on beneath the surface.

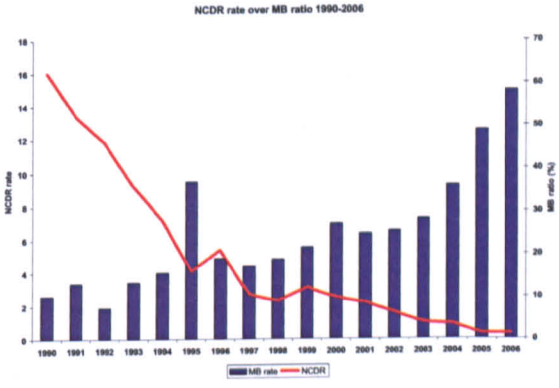
If we look closer at the various epidemiological indicators at our disposal a more nuanced perspective emerges. One which raises some interesting questions regarding what is going on behind the scenes in leprosy control. The long incubation period in leprosy means that it is difficult to determine what is going on at present as the results will not necessarily be seen for another 5 to 10 years. This only makes it all them more important to try to interpret the vague, imperfect and circumstantial indicators we have at our disposal.

By analysing the data from ULP we can identify 7 factors which, when taken together, give some indications of the potential future hurdles we face in leprosy control (ILEP, 2001).

**1. MB rate**

| Year | PR | NCDR | Active | MB |
|---|---|---|---|---|
| 1990 | 14.2 | 16 | 815 | 10.2 |
| 1991 | 14.2 | 13.4 | 979 | 13.1 |
| 1992 | 10.3 | 11.8 | 566 | 7.4 |
| 1993 | 9.2 | 9.2 | 500 | 13.3 |
| 1994 | 7.2 | 7.2 | 458 | 15.6 |
| 1995 | 5.8 | 4.1 | 347 | 36.9 |
| 1996 | 5.2 | 5.4 | 311 | 19 |
| 1997 | 4.5 | 2.7 | 422 | 17.2 |
| 1998 | 3.9 | 2.3 | 246 | 18.8 |
| 1999 | 2 | 3.1 | 290 | 21.5 |
| 2000 | 3.5 | 2.5 | 379 | 27 |
| 2001 | 1.6 | 2.2 | 264 | 24.7 |
| 2002 | 1 | 1.6 | 192 | 25.3 |
| 2003 | 0.7 | 1 | 142 | 28.2 |
| 2004 | 0.5 | 0.9 | 96 | 36 |
| 2005 | 0.34 | 0.33 | 83 | 48.8 |
| 2006 | 0.25 | 0.33 | | 58.3 |

As prevalence rate and new case detection rate (NCDR) have continued falling in the project area the MB rate has been raising alarmingly. The MB proportion can vary considerably from one country to country, and location to location. However, to see this level of natural variance in basic leprosy epidemiology in a specific area is less likely and we must assume that this increase is, at least in part, the result of operational procedures and case detection patterns. MB case are expected to be high at the beginning of projects as there will be a substantial 'backlog' of older cases in the population. Once these have been 'cleared' the MB proportion would be expected to plateau at a lower lever




There are a number of factors which may have contributed to this trend:

*Firstly*, over time the definition of an MB case has changed. The health workers insisted that their definition of MB case has not changed and that this should therefore not compromise the data/ there are no external sources to verify this statement in become less stringent so that more cases are now likely to be diagnosed as MB than earlier. We can indeed see a clear spike in 1995 which could perhaps be explained by new guidelines for diagnosis. However, this does not account for the gradual increase seen over the duration of the project, and in particular the sharp increase in MB

rate since the cessation of active case finding in 2001 (ILEP, 2001).

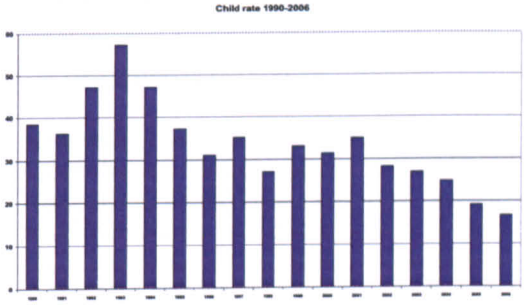
*Secondly*, the MB rate is expected to rise as a control programme changes from active to passive case finding. This is due to the fact a) self-reporting cases are more likely to be MB cases as the symptoms are more severe and noticeable; b) later detection means some PB cases that would have been caught by active case finding may have self-healed; c) and a proportion of PB cases will have developed into MB cases before reaching treatment facility. This is in itself problematic as it could be an indication of later reporting of cases. Late diagnosis of cases could mean increased exposure time for community and family which may in the long run lead to increased transmissions in community as well as disabilities and deformities in the individual patient.

Thirdly, since MB cases are usually less frequent in women and children the proportion of cases will be affected by the age and sex of the targeted population. Therefore the previous focus on school surveys, etc are likely to have brought out more PB cases than would normally have been discovered. This might have contributed to an inflated PB rate in the past.

From an operational and patient perspective a rise in MB proportions is likely to lead to an increase in number of patients presenting with reactions as MB cases are at a higher risk of developing reactions and physical disabilities (Britten and Lockwood, 2004). Such a rise in reaction rates would affect the future service requirements of public facilities as well as place greater demands on the level of skill and experience required in staff. Reactions are often painful, disfiguring and lead to a negative perception of the treatment as the patient experiences this as a worsening of the disease. In such cases careful counselling along with expert treatment and advice is required, something which would most likely only be available at specialist referral centres.

**2. Child rate**

The definition of a child case is relatively stable and few factors will thus influence the validity of the indicator. However operational factors such as active case finding activities and targeted school surveys may still observed child rates.




The rate of new child cases is falling very slowly in the project area. Currently no school surveys are being conducted targeting detection in children as opposed to previous years, an activity which would have boosted numbers in the past. Added to this is the steadily rising MB rate. Children are less likely to have MB than PB leprosy indicating that they may be missed out in the case detection process (Lockwood and Suneetha, 2005).

This trend is especially worrying since children can only relatively recently have acquired the infection and can therefore be an indication of underlying active transmission in the population.

However, it is also worrying because the impact of potential disabilities associated with late detection of leprosy has the potential to have devastating impact on the lives of individuals – both in terms of impact on that individual's quality of life and in terms of QUALYs or DALYs lost on a societal scale.

### 3. Recent detection of highly infectious cases – Histoid cases, ENL reactions, etc

ULP are currently reporting active cases in advanced stages of disease, cases one would not expect at this point in the elimination programme. The presence of such cases could be indicative of late diagnosis and highly active transmission sources still being present in the population. Many of these come from outside project area, however, in a highly mobile urban population this is not unexpected, and the mobility of such cases is in itself worrying as a source of transmission.

These cases are particularly worrying because they are found to be newly diagnosed patients rather than cases of relapse in patients treated with dapsone mono-therapy in the past. ULP are still finding cases with a bacterial index (BI) in excess of +2, and even as high as +4. Cases such as this form a potential reservoir for the disease. (Palit & Inamadar 2007). In the same text, a quote from Ebenezer (1999) says it all:

*"occurrence of such cases reminds us that the road to elimination is not an easy one"*

### 4. Disability rates

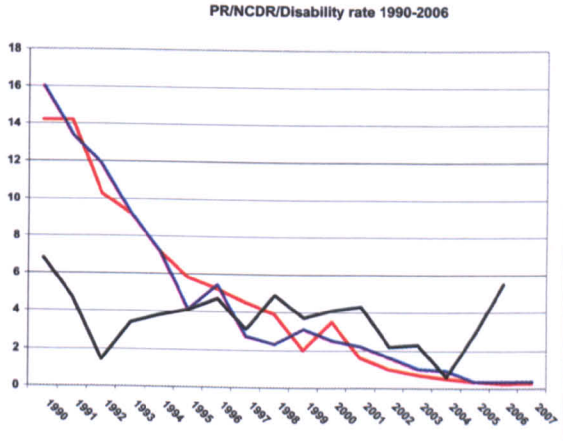
Disability rates can be influenced by operational factors such as different assessment processes between projects and the relative skill of the health workers in carrying out this assessment. However, the health workers at ULP are highly skilled and every member of staff has more than 10 years experience in disability assessment. EHF assessment with microfilaments is carried out every three months from initial diagnosis, 3 year follow up for PB, 5 years for MB. In addition each new disability case is assessed by a trained physiotherapist.

| Year | Cases | Disability |
|---|---|---|
| 1990 | 1954 | 133 |
| 1991 | 1016 | 48 |
| 1992 | 1196 | 17 |
| 1993 | 929 | 32 |
| 1994 | 1059 | 40 |
| 1995 | 655 | 27 |
| 1996 | 565 | 27 |
| 1997 | 601 | 19 |
| 1998 | 641 | 31 |
| 1999 | 677 | 25 |
| 2000 | 510 | 21 |
| 2001 | 400 | 17 |
| 2002 | 295 | 6 |
| 2004 | 152 | 4 |
| 2005 | 171 | 1 |
| 2006 | 135 | 4 |

Disability rates tend to be high in the beginning of projects as the project clears a 'back-log' of old disabled cases. After which the rates should stabilise at a lower level. In fact, active case detection can be expected to slightly decrease the disability rate as it tends to increase the number cases caught in early stages of

the disease, and thus decrease the proportion of disabled cases.

The current disability rate is difficult to interpret as the real numbers are relatively low, thus creating artificially high fluctuations. However, it is presently not as low as one would like at this stage in the project, in addition there has been an increasing trend in the last years, when ideally the rates should be decreasing. Disability rates are important in themselves in terms of the impact on the lives of individuals and the level of care and specialist services required for the duration of their lives. However it may also be an indication of delay before detection, a hypothesis which is further corroborated by the steadily increasing MB rates seen in the project area. Late detection means increased exposure time for community and family which may mean higher transmission rates leading to future cases. Thus might be seen as a canary in the coal mine for the surveillance system, if it is working we should not be seeing an increase in late detections.




Prevention of morbidity
= decreased cost to society

Project currently has ? Grade 1 and ? grade 2 cases on register. All of which will require specialist services and support in the future. A large number of people from around the district also approach ULP for various support services and care as there is no other facility currently available in and around the city. If no NGOs provide these services, and government facilities are few and far between the potential negative impact on individuals could increase leading to more beggars and a treat to the modern Indian states image of itself (Staples, 2007).

**5. Holes in the Surveillance Systems:**

Currently a lot of resources are being invested in integrating leprosy services into the general health system. This is crucial in terms of reducing the stigma of a vertical service and the implied 'otherness' of the disease. It is also a cost effective and necessary step in response to the current low prevalence rates.

However, an integrated service only works if staff is available and have the necessary skills to detect and treat leprosy patients. If the surveillance system is not working as it should cases will go undetected and the benefits of an integrated system will be outweighed by the negative consequences of lapses in detection and treatment. It is thus important that the integration process is monitored closely and that any such gaps are identified and addressed. The data from Hyderabad gives some cause for concern in this regard.

*A) Cases from Outside Project Area:*

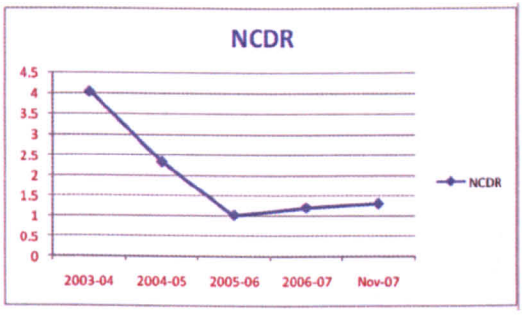
At the projects outpatient clinic as many as 50% of patients diagnosed with leprosy come from outside project area and a large number of these present with MB or disabilities. These patients are not registered with the project but given treatment and referred to their nearest primary health facility. They do not show up in the NCDR of the project, nor should they as this population will not be included in the population denominator. However, the situation is never that clear cut in an urban environment. There is

high migration in and out of the city, which means the base population has a high turnover of individuals, which in turn complicates any calculation. This influx constitutes a very real workload increase, over that reflected in official statistics, for the health workers. It is also worrying that migration in and out of the city often involves the poorest and most vulnerable population, which is the same population suffering from the highest rates of leprosy in the city.

In addition to this, a large number of cases coming from outside the area may be an indication that surveillance systems and treatment is not working as effectively outside of the project area. Siddique's findings in Orissa indicating only 26% of referred cases make it to a PHC. Already the NCDR for the state as a whole show a less optimistic trend than that of the project are.

Though it fell sharply from 4.049 (2003-2004) to 1.01 (2005-2006), just in time to reach the elimination target[ii], the trend has now levelled off and is even showing a slight increase since 2005-2006 to 1.3 in October 2007 raising questions about the validity of the initial drastic decrease.

*"As anyone knows, an effective way to make a disease disappear is to stop looking for it..." (Fine and Wardorpf, 1997)*




*B) Government vs. project area*

Even within the city limits there are grave difference in NCDR. ULP covers 26 UHPs with 8 community health organisers. The government covers the remaining 34 UHPs with the help of 34 assistant paramedical officers. Even with this difference in manpower and in the absence of any active search or contact surveys the fall in new cases registered in the project area was dramatically different from that of the non–project area of Hyderabad district as evident from the below table. There was a 22% decline in the new cases in the project area from the year 2004 to year 2005; whereas the rate of decline for the total district (including ULP area) was 45%. If we take out the ULP portion from the district the decline is alarmingly sharp (80%), raising suspicion about the actual decline of the disease prevalence and the effectiveness of the surveillance system.

With the dismantling of the vertical system and services now integrated into the general health system the PHC/UHP staff is responsible for the detection, treatment and case-holding of leprosy cases. However, this same staff is involved in the implementation of all national programmes as well as attending to the primary health needs of the community. Even with the help of an assistant paramedical officer the above numbers indicate that leprosy is not their main priority and that lack of experience may be leading to holes in the surveillance system and failure to detect new cases. ULP also functions as a resource centre to the Urban Health Posts and private health centres and practitioners in the project area. In the absence of NGO involvement in similar urban settings, the course of leprosy epidemiology becomes highly uncertain.

*C) Rapid Survey*

Findings of rapid survey ordered by Collector in December 2006 to January 2007. covering ???? households in ????slums. identifying ?? new cases. And increase of ??% over the norm.

Indicating that referral and surveillance system is not working quite as it should. And that there are still a considerable number of people going undetected in the community.

| Total New Cases Detected | | | | | | |
|---|---|---|---|---|---|---|
| Comparison of ULP area vs. District | | | | | | |
| Year | ULP (26 UHPs) | ULP annual decline (%) | Out of Project Area (34 UHPs) | OPA annual decline (%) | Total (60 UHPs) | Total annual decline (%) |
| 2000 | 517 | | 297 | | 814 | |
| 2001 | 373 | 28 | 458 | inc | 831 | inc |
| 2002 | 312 | 16 | 354 | 23 | 666 | 20 |
| 2003 | 216 | 31 | 151 | 57 | 367 | 45 |
| 2004 | 173 | 20 | 117 | 23 | 290 | 21 |
| 2005 | 135 | 22 | 24 | 80 | 159 | 45 |

*Summary of A, B and C:*

Taken together, the number and nature of cases attending the projects outpatient clinic from outside of project area, the very different NDCR recorded in two parts of the same city and the findings from the sample rapid survey are all indicative of failings in the surveillance system. A failing which, if not addressed at this point, could have drastic impact on the leprosy epidemiology in the city over the next 10 years.

## 6. NCDR – adjusting for the undetected

However, no surveillance system is without flaws and there are clearly cases missed even within the project area, as demonstrated by the rapid survey.

As PR and NCDR has continued to fall, the MB rate has continued rising. Though some of this may be due to changes in classification and PB cases – other factors such as stop of active search and clearing of the 'backlog' of MB cases in early stage might be argued to have been playing the opposite role. It is thus likely that a large proportion of the cases missed by the surveillance system in the project area are likely to be PB cases. Despite these caveats, it is clear that the steady and drastic rise in MB rates, especially since 2003, is a worrying trend. It is unlikely that the factors discussed above would account for this rise and it would seem likely that there had been a true epidemiological shift in the population over the period. So, despite the fact that MB rate has severe limitations as an indicator, which must be taken into consideration in the interpretation, we cannot afford to completely ignore this indicator when attempting to understand recent case detection trends.

As argued above, there is likely to be a contingent of unidentified, undiagnosed and untreated PB cases in the base population. We need to ask ourselves how large this group might be and what the potential impact on NCDR and elimination targets would be if they were identified and included in prevalence calculations.

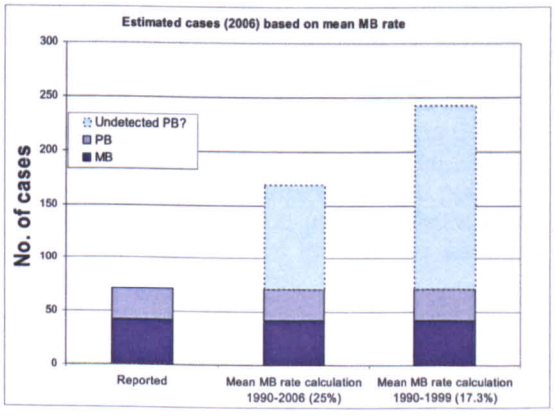
Below follows a highly speculative 'worst-case scenario' of what might be happening behind the scenes. Though I would not argue that this is in any way an indication of what is actually happening in the project area, the hypothetical projects bear thinking about:

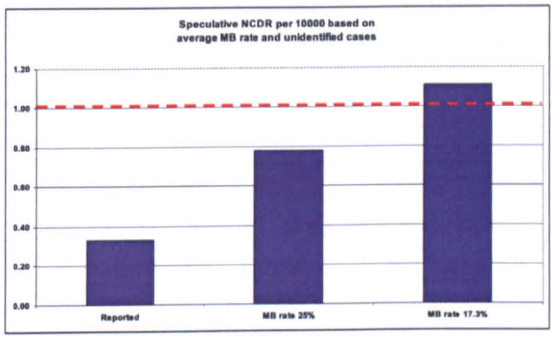
It is impossible to calculate PR for a hypothetical scenario since PR is based on the number of active registered cases at year end and with PB-MDT treatment currently being 6 months it would be difficult to speculate on how these would spread throughout the year. However, NCDR is in many regards a better indicator of the epidemiological situation. Thus, this hypothetical scenario calculates NCDR per 10.000 instead.

Using an estimate of the mean MB rate for the project, one based on rates before recent escalation and one taking mean MB rate since the inception of the project. Mean MB rate from 1990 to 1999 was 17.3% whilst the mean MB rate for the

project as a whole (1990 to 2006) has been 25%. Assuming that the currently existing MB cases constitute this percentage of the 'total' cases in the base population we can calculate the number 'expected' PB cases and compare this number to the actually detected PB cases in 2006. As illustrated in the graph below this would constitute a sizeable number of patients. Of course there is nothing to say that the project has picked up all the MB cases in the population, or to estimate the proportion of PB cases that will have turned into MB cases or will have self healed. Since it is estimated that approximately 22.4% of PB cases self-heal and PB cases in general are thought to be less infectious than MB cases this might not have a great impact in the transmission rates (Daumerie, 2004).

So the actual number means little. However, if we estimate new NCDR's based on these speculations (*see graph below*) we get a very different picture of the situation and advances towards elimination than the actual case load indicates. However, if we are to use NCDR as an imperfect proxy for incidence it is clear that the detection of these cases would have a significant impact on the NCDR and changing the picture of the effectiveness of leprosy control measures.




Now, of course, this does not constitute the 'real' face if the leprosy situation on the ground, for that there are too many ifs, buts and assumptions. But what these rather crude estimations indicate is the vulnerability of the epidemiological indicators, and emphasises the need to keep a close eye on future trends to assess to what extent the NCDR gives an accurate indication of the situation as it experienced on the ground.

### 7. Social and political commitment

Last but not least is the declining social and political commitment to leprosy work. Throughout the world, following WHO's announcement that leprosy has been eliminated as a public health problem and in the face of falling PR, NGOs have been closing projects and re-focusing their activities on other issues such as TB and HIV/AIDS. There is a danger that the technical expertise and commitment to leprosy affected persons is being corroded as more and more organisations are diverting their attention and skilled staff to other priority areas. Integration has been instigated and largely left to itself. If it is to work effectively it will require continued support and commitment. Leprosy workers are being replaced with general health workers with limited experience.
Leprosy control programme has been slowed down and diluted. (Rao and Lakshmi, 205). Across the board it is

difficult to find funders who are willing to invest in leprosy control work despite the fact that it has been demonstrated that 'other diseases', such as leprosy, can be controlled effectively with only a fraction of what is spent on HIV control annually with little measurable success (Molyneux, 2004).

There is a real risk that, despite its assurances, the Indian government will turn their attention to a hoard of more 'pressing' problems facing the health system since announcing the elimination of leprosy from India in January 2006. We have made great advancements in leprosy control. But need funds as well as political and social commitment to make sure these advancements are not squandered at the last hurdle.

There is a growing apathy towards leprosy and this can work against the interests of the persons affected who have "struggled for so long for freedom; now, in the era of multi-drug therapy and the 'horizontal' – as opposed to 'vertical' – model of health care, they have achieved it, but at a cost. The danger they now face is neglect" (Gould, 2005)

On the social side stigma and poverty are still rife in the community and constitute formidable hurdles for those affected by leprosy. Even within the health system stigma is prevalent with frequent reports of doctors and nurses refusing to touch or to provide treatment to leprosy affected persons. One of the strokes of genius in the DOTS strategy for TB was to include political commitment as one of the 5 core pillars of the strategy. It is crucial at this time that we keep leprosy on the political agenda and build on existing social and political commitment in order to sustain leprosy control efforts.

## Conclusion: Connecting the dots

> *"The combination of epidemiological and biological evidence suggests that leprosy cannot be eliminated by multidrug therapy alone. This analysis is supported by recent mathematical modelling of leprosy indicators that suggests leprosy is slowly declining but that the rate of decline remains uncertain and a sustained leprosy control effort is required"* (Lockwood and Suneetha, 2005)

ULP has achieved tremendous results in the city of Hyderabad and the surrounding districts and reached the elimination target as early as 2003. In addition the project successfully supported integration of services into the general health system, built strong networks of public and private medical practitioners and increased awareness of symptoms and treatment in the community. We are in a privileged position to be able to proudly look back and survey our achievements. However, as argued above some of the current epidemiological trends are of concern.

Considered individually none of the indicators seem cause for alarm. But when considered together the rising MB rate, high child and disability rates considered alongside the uncertainty surrounding the reported NCDR and presence of advanced stages of disease in the community there is ample cause to assume that transmission is still active in the community. Seen as a whole they constitute circumstantial evidence that something might be brewing below the surface. And it is important that we have the facilities, commitment and expertise to deal with the situation should the warning signs prove to be more than false alarms. However, the signs of failings in the surveillance system indicate that this might not be the case as the situation stands today, that we may be selling the cow with no thought for tomorrow. Shutting projects and removing expertise. Now is the time to act – whilst we still have an infrastructure. Not in 10 years time when the expertise and experience has been dissipated.

It is important that we acknowledge the great advances made in leprosy control. However, there is no room for

complacency. The desire to eliminate leprosy and the appearance of elimination is not the same thing as effectively bringing the disease under control. Meima et al's (2004b, 2004a) modelling efforts showed that a relaxation of in leprosy control after 'elimination' as a public health problem is unjustified, and argued for a viable long-term strategy.

The broad strokes of national statistics often mask regional specifics and the situation as it is observed NGOs and government workers on the ground. Official records follow bureaucratically defined boarders and distinctions that sometimes disguise the situation as it is perceived on the ground. It is crucial that more projects publish their findings at this time so that we can build a clear picture of what is happening in the field, yielding insight into leprosy epidemiology on a sub-national level. We must be brave enough to be honest about the trends we observe in the ground. We must stop, take stock of the situation – and ask, where do we go from here? Do we need a post-elimination strategy? Are we letting our advances slip though our fingers? What will leprosy epidemiology look like in 10 years time at the current rate?

This is a crucial time for leprosy control. NGO's on the ground are diversifying their operations or shutting their direct projects as their space to manoeuvre and contribute is limited by shortfall in funding for leprosy work and an unclear position within the integrated services. However, NGOs bring something unique and vital to the leprosy control table – as government and international policy makers are necessarily concerned with leprosy as a public health issue it falls to NGOs to care for the individual affected by leprosy and forge close ties with communities. Epidemiological trends aside there is a very real backlog of already existing people affected by leprosy suffering from disabilities and deformities who are in need of the services a project such as HYLEP can offer and which is not offered in existing facilities in the area – government or otherwise. In addition a substantial accumulation of RFT cases which may need further services in the future. As NGOs we must fight to keep the focus on the individual and quality of services offered as well as the public health issue. However, in order to achieve this organisation engaged in leprosy work must rethink their basic operating strategy and include persons affected by leprosy in decision making processes to a much larger extent.

Furthermore, as professionals and academics in this field it is our responsibility to raise the red flag when disturbing patterns begin to emerge. There are political incentives to not asking difficult questions or digging too deep. Thus the task of sounding the warning bell falls to us as public health professionals.

We need to call on other projects to share their experiences and their findings in this forum. Valuable data is sitting in organisational HQ's around the world where they do little good. National statistics tell us little. What we need now is good, solid, long term statistics to assess the situation as it appears in different locations. Need to focus on reporting what is happening on ground level in leprosy control and not in air-conditioned conference rooms in Geneva – on truth not on targets (Fine 2008).

So, where do we go from here?

## Appendix 5. - Whither from Here?
## Leprosy Control beyond Elimination

> "A change in paradigm is needed, recognising people as subjects, not objects, and workers as enablers and not providers. Interventions must be supportive and responsive, empowering rather than diagnostic. They must include addressing the needs and resources of the community and extending its capacity" (Dr. Arole quoted in Nichols and Smith, 2002)

As the old narratives have outplayed their usefulness, one of the major challenges for the future of leprosy policy is to define a future discourse within which to work. The success of future leprosy policy will depend on its ability to create a unified vision of its goals, to involve service users in the planning and implementation of interventions and to shape future policy in a way that capitalises on the strengths and capacities of communities. As argued by Dr. Arole in the quote above, what is needed is a change in paradigm, but what should this new paradigm entail? The leprosy policy for the future must find a way to balance the discourses of the past and delineate a strategy which encompasses the care, control and empowerment aspects of leprosy services. Crucially, any future strategy must strive to ensure that political commitment, and resources, do not disappear with elimination. The danger now is of course that, with the achievement of elimination, resources will be diverted to other diseases, and that those affected by leprosy, yet officially declared cured, will be left without recourse, and extensive knowledge will be lost as vertical programmes are dismantled and non-governmental organisations move on to other concerns. The ultimate concern here is that leprosy might "go underground", leading to a relapse as was seen with TB in New York in the 1990's.

Currently registered cases constitute only a fraction of the people affected by leprosy. It is estimated that more than 11 million people are directly affected by leprosy and that around 2-3 million of these, who have been officially cured, still suffer physical and social disability as a result of the disease (LEPRA, 2006). If one includes the family and wider social network of people affected by leprosy, as these are often subject to social discrimination as a result of their association with a person known to have (or have had) leprosy, this number grows exponentially. As the prevalence rate falls, and leprosy services increasingly become a question

of chronic disease management, it is important that the affected yet cured are not forgotten in policy formulation.

As Carcianiga & Herselman (1999) point out, the symptoms of leprosy, the characteristic loss of peripheral body parts, nerve reactions, and trauma to anaesthetic limbs does not go away with time. As bio-medically oriented public health interventions have focused on curing the disease and eliminating leprosy, the experience of the person affected by leprosy has often been lost in this process. As the main manifestation of their disease as experienced by the sufferer is the 'side-effects', rather than the bacterial load, the notion of being cured yet suffering from disabilities, painful reactions, and complications is as real an illness to the sufferer as the presence of the bacteria in their body is to the physician. Moreover, the community views these symptoms as evidence of presence of the disease and, thus, it would be difficult to engage meaningfully in social and economic rehabilitation projects without addressing these perspectives. In addition, for those affected by the disease, their illness is only one of a whole host of challenges faced in their daily lives, and it is not always the most important one. If leprosy policy is to move forward it must move toward bridging the gap between policy intention and service user priorities, by building an understanding of the everyday lives, needs and resources of people affected by leprosy.

Care needs will not disappear over night. There is still a desperate need for control, monitoring and evaluation of an 'elimination' which presently stands untested and unproven. In addition, a whole host of new skills and approaches will be required to enable a shift towards empowerment and community care. Clearly the future of leprosy policy must encompass the wisdom of all three discourses.

Care has been, and will remain, of major concern when it comes to leprosy policy. Even with the shift from segregation and care in the absence of a biomedical cure to an emphasis on control, expressed through the SET programmes, with the advent of MDT, care was never absent. The shift from care to control could have resulted in the neglect of patient care as a result of its drive to expedite case-handling through the system, especially after the elimination target was introduced,

as governments and organisations faced the pressure to 'get patients off the books'. Fortunately, a continuum of care was ensured through the engagement of the very same leprosy organisations, departments and staff that had been responsible for the provision of care in the absence of a cure, thus ensuring that the care of the patient was still very much at the forefront of the provider's concerns. Currently there is an underlying fear that further integration of services into the general health system will result in the loss of this 'care aspect', as leprosy becomes just another disease with treatment protocols and standardized records, especially since there is still a rather extensive problem of stigma among health professionals in the general health system.

As we rejoice in the achievement of the global elimination goal it is worth remembering that control will continue to be paramount in the years to come, to ensure that the achievements of the past decades are not squandered. The global leprosy elimination campaign focused on reaching a prevalence rate below 1 per 10,000 population, at which point it was postulated that the disease would die out naturally. However, there is considerable controversy surrounding this assumption, both from an epidemiological and an operational perspective. With poor and inconsistent data, long incubation periods and target driven reporting, it is uncertain what is really happening on the ground. Countless column inches and forums have been dedicated to debating this issue; with the leprosy field polarised into optimistic and pessimistic outlooks. One side argues that the drop in prevalence rate is really occurring, and that the high levels seen in previous years were the result of overreporting and a large back-log of cases in the system, whilst the other side argues that the drop in prevalence rates is due to the recent cessation of active case finding and the current dismantling of leprosy services. Only time and good data will tell what is really going on behind national statistics. Considering the controversy surrounding the elimination target as an indicator, the debate might ultimately, prove to be chimeric. Clearly, there will be a role for control in the form of careful monitoring and evaluation in the future too.

Controversy over the WHO's elimination target aside, there is still a significant number of 'cured' but 'socially disabled' leprosy affected persons in need of an

effective policy post-elimination. Porter (2004) has argued for the importance of remembering the individual, as well as the prevalence rate, in developing a strategy for post-elimination control of leprosy. The challenge of incorporating more 'rights based' approaches, which emphasize empowerment, participation and partnerships, will most likely define leprosy policy in the years to come. The challenge now is to try to find an approach that will enable increased involvement of affected persons in the decision making process, perhaps one integrated with other disability movements. This shift was already evident in some of the presentations made at the 17th International Leprosy conference in Hyderabad.

It can be argued that a shift in perspective, from that of a traditional infectious disease programme towards chronic disease and disabilities strategies, is an epidemiological and political imperative in order to bring leprosy policy into line with current trends in international development discourse. A similar shift could be seen in the HIV/AIDS field with the advent of Highly Active Antiretroviral Therapy (HAART) and the need to reformulate public health responses and operational protocols. However, what was present in the HIV/AIDS field, which is largely lacking in the leprosy field, was a strong engagement by civil society and patient pressure groups, etc. Patient perspectives have been a part of the formulation of HIV/AIDS policy since its inception in the US in the late 1980's. In recognition of the need for participation and empowerment to become part of future interventions, and under pressure from civil society groups such as IDEA (Integration Dignity and Economic Advancement) and ILEP (International Leprosy Elimination Program), the leprosy policy community have started to look to strategies like the WHO's Innovative Care for Chronic Conditions (ICCC) (WHO, 2002) framework for inspiration for future directions of interventions.

This is a difficult tight rope to walk. On the one hand, integration of leprosy services is a great step towards changing views of leprosy as a 'disease apart' and reducing stigma. Yet, on the other hand, there is little capacity for handling issues such as social and economic rehabilitation within the general health system. Therefore, many leprosy organisations have attempted to change their focus to issues surrounding rehabilitation. Guidelines have been prepared by ILEP (Nichols et al.,

1999) on how to organise and provide services for social and economic rehabilitation, and rehabilitation has been included as one of the main strategies for the WHO's Global Leprosy Elimination Strategy for 2006-2010 (WHO, 2005). Though the guidelines advocate integrating rehabilitation services for people affected by leprosy with those provided for people with other forms of disabilities, it remains uncertain to what extent this is happening in practice. Unless there is real integration with other services, such policies risk setting leprosy apart and adding to the stigma of the disease. However, it is not merely the policies that have developed; the actors have also been transformed. Recognising the shift in leprosy policy and the diversified activities of leprosy organisation it becomes clear that what were simply 'leprosy organisations' are now something very different in essence.

Whatever the future of leprosy policy, for it to be successful, it must take care to recognise the importance of local agency as well as international discourses. Leprosy policies are abstract entities discussed within organisations and departments. In order to understand how recent changes in policy have affected the working life and social identity of health workers we must look beyond discourses and narratives to the concrete impact of these changes on the health workers everyday working practices, as well as how they see themselves and their role vis-à-vis the organisation and the wider community.

## Appendix 6 – Job Description, Targets and Monthly Reports

# ULP Monthly Report

### EC Project monthly report

| Sl. No | Activities | Target | No.of Programmes | Achievement | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | M | F | MC | FC | TO | Achievement % |
| 1 | **Capacity Building and Community awareness:** To increase access to early diagnosis of TB, malaria, leprosy, HIV/AIDS by communities' through various IEC programs within 26 UHPs of the project area by 2007. | | | | | | | | |
| 1.1 | Plan and conduct Advocacy on TB,malaria,leprosy,HIV/AIDS issues | - | | | | | | | |
| 1.2 | Sensitization on leprosy,malaria,TB,HIV/AIDS to community member by volunteers / clients | 1 | | | | | | | |
| 1.3 | Training to Nursing students on TB/Leprosy/HIV/AIDS and Malaria | - | | | | | | | |
| 1.4 | Sensitisation to AWWs on SER / TB / Malaria / Leprosy / HIV/AIDS | 1 | | | | | | | |
| 1.5 | Review meetings and strengthen Health Forums | 4 | | | | | | | |
| 1.6 | Conduct general Health camps | 1 | | | | | | | |
| 1.7 | Organize film shows on Leprosy, TB,HIV/AIDS Malaria | 6 | | | | | | | |
| 1.8 | Conduct exhibitions at market/schools / slums and on special events | 3 | | | | | | | |
| 1.9 | Conduct group talks in the slums | 250 | | | | | | | |
| | **Staff Development** | | | | | | | | |
| | Senior staff meeting | 1 | | | | | | | |
| | Zonal meeting | 1 | | | | | | | |
| | Monthly review meetings | 1 | | | | | | | |

**Events**

1 PRAJA PATHAM' programme continued up to 12/05/07. Health programmes also conducted during the programme at UHP level.

2 A training programme for Nursing students conducted at 'Geetha Nursing Home' Chilkalguda area on 17/05/07. Totally 59 students were participated. Pre-test and Post-test conducted to them.

3 On 20/05/07 'Candle Memorial Day' celebrated at DLO urban office. ULP staff and Avahan staff were attended to this rally.

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 2 | **Control of Tuberculosis:** To increase reach and quality of diagnosis of tuberculosis in 5 microscopy centers and one treatment by achieving 70% new smear positive case detection and 85 % cure rate among them by the end of 2007 | | | | | | | | |
| 2.1 | Identify the symptomatic cases and refer them to Project / Government MCs in the project area (From DMCs) | 100 | | | | | | | |
| | From field activity | | | | | | | | |
| 2.2 | Conduct Sputum examination to Symptomatic cases reported at LEPRA direct projects- 5 DMCs | 200 | | | | | | | |
| | From field activity | | | | | | | | |
| 2.3 | Verify the address of confirmed TB Cases in the field and initiate DOTS - DMCs | 65 | | | | | | | |
| | From field activity | | | | | | | | |
| 2.4 | Educate the patients and family members about treatment and Compliance | 65 | | | | | | | |
| | Field activity | | | | | | | | |

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|---|---|---|---|---|---|---|---|---|---|
| 2.5 | identify and provide INH prophylaxis to children | 5 | | | | | | | |
| 2.6 | Surveillance of positive cases for new contacts - DMCs | 41 | | | | | | | |
| | Field activity | | | | | | | | |
| 2.7 | To check external quality assessment of microscopy services in 5 MCs - CHS (STLS) | 2 | | | | | | | |
| 2.8 | Provide/refer TB/HIV co-infections cases for treatment | 3 | | | | | | | |
| 2.9 | Interaction with PMPs about TB/HIV co-infection – under MASS – PPM study | | | | | | | | |
| 2.10 | Organize Anti TB week | | | | | | | | |
| 2.11 | Organize World TB day | | | | | | | | |
| 2.12 | conduct Monthly review with Lab Staff | 1 | | | | | | | |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 3 | **Control of Malaria: Malaria incidence and mortality rates have decreased.**<br>**Increased involvement of community in implementing the selected vector control measures in villages** | | | | | | | | |
| 3.1 | Refer symptomatic cases to PHCs / UHPs | 50 | | | | | | | |
| 3.2 | Support the fever depots for successful functioning | 10 | | | | | | | |
| 3.3 | Group discussions with Youth, SHG and opinion leaders to increase awareness on preventive measures | - | | | | | | | |
| 3.4 | Diagnoses (Examination of Blood Smears) and treatment (at project clinic) | 5 | | | | | | | |
| 3.5 | Plan and implement vector Control Programme in Project area | 1 | | | | | | | |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 4 | **Leprosy Elimination:** Leprosy prevalence remain under control and increase referral services in the project area by 2007 | | | | | | | | |
| 4.1 | Referral of difficult and complicated cases | 5 | | | | | | | |
| 4.2 | Referral of suspects from UHPs | 12 | | | | | | | |
| 4.3 | Carryout clinical diagnosis of suspected cases – confirmed | 6 | | | | | | | |
| 4.4 | Provide treatment and Management of complicated cases (new & follow up) | 17 | | | | | | | |
| 4.5 | Attend weekly clinics to support PHC (10 CHO X12 months X 4 times) | 40 | | | | | | | |
| 4.6 | Attend monthly review meetings & SIS implementation at UHP (26 UHPs X 12 months) | 26 | | | | | | | |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 5 | **POD / POWD: To reduce the impairments and nerve damage among the leprosy affected persons by 2007** | | | | | | | | |
| 5.1 | Conduct Disability Management Clinic | 5 | | | | | | | |
| 5.2 | Assess the nerve function of Leprosy affected persons | 60 | | | | | | | |
| 5.3 | Provide Ulcer care management services | 62 | | | | | | | |
| 5.4 | Refer cases for Reconstructive Surgeries | 1 | | | | | | | |
| | **Foot wear supply** | | | | | | | | |
| 5.5 | Monitor and supply of MCR Foot wear to G I patients | 16 | | | | | | | |
| 5.6 | Monitor and supply of MCR Foot wear to G II patients | 40 | | | | | | | |
| | Self care trainied | | | | | | | | |

**General Physiotheraphy - May 2007**

| | | |
|---|---|---|
| | No of cllients | |
| | Stimmulation | |
| | Ultra sound | |
| | Infra red | |
| | POP splints | |
| | Quadracips | |
| | Shoulder weel | |
| | Tens | |
| | Adductor bands/dy splints | |
| | vibrator | |
| | SWD | |
| | Goggles | |
| | Counselling | |
| | Cruches | |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 6 | **Social Economic Integration: To increase Socio economic Integration of 240 leprosy affected persons in the peoject area by 2007** | | | | | | | | |
| 6.1 | Screening / Need Assessment of (old & New) Leprosy , TB, Malaria & HIV/AIDS | 20 | | | | | | | |
| 6.2 | Conduct In-depth assessment of client, and prioritisation | 10 | | | | | | | |
| 6.3 | Finalise rehabilitation plans | - | | | | | | | |
| 6.4 | Sensitise the clients/family members/community on Govt. schemes & utilisation of LEPRA services (Emp) | 5 | | | | | | | |
| 6.5 | Support from LS revolving funds | 1 | | | | | | | |
| 6.6 | Networking and Mobilising support from govt. sources | 1 | | | | | | | |
| 6.7 | Mobilize local resources & support from Philanthropists | - | | | | | | | |
| 6.8 | Regular follow up of beneficiaries | 8 | | | | | | | |
| 6.9 | Provide Counselling services to stigmatised and discriminated persons | 10 | | | | | | | |
| 6.10 | Meeting district program heads and apprising the proposals and program | 1 | | | | | | | |
| 6.11 | Follow up visits to meet district welfare dept heads | - | | | | | | | |

**1 Client Empowerment programme**

**a** Client Empowerment programme conducted at Santosh Nagar, Hayath Nagar Mandal on 16/05/07. Total 41 (M-22, F-19) patients were attended.

**b** Another client empowerment programme conducted at Moula Ali leprosy colony on 22/05/07. Total 26 clients were attended.

**c** 4 DCCs conducted at UHP premises covering all sector area clients. Total clients attended 40 (M-28, F-12)

**Networking**

**1** Contacted to the 'Sweekar Upkar' office in connection with knows of rehabilitation facilities at their for blind. clients.

**2** Contacted to the Pragathi NGO staff Mr.Mahesh Sharma inconnection with educational assistance and employment to the TB & HIV co infection cases at King Kothi DMC.(M-1, MC-2, FC-3). For world vision MC-1, leprosy cured case referred for educational assistance. Reffered for ration card purpose F-1 Praja Patham.

**3** SBI ladies club members were visited to the Hylep office inconnection with educational assistance to the clients.

| Care & Support | | | | | |
|---|---|---|---|---|---|
| Foot wear | | | | | |
| medical certificates | | | | | |
| Disability certificate | | | | | |
| pensions | | | | | |
| Bus pass / Railway pass | | | | | |
| Educational assistance | | | | | |
| any other (referred for welfare) | | | | | |
| **Total** | | | | | |

| 7 | **HIV/AIDS; To provide counselling services for 1596 persons to learn and accept their HIV status in a confidential environment in three VCCTCs of the project area** | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 7.1 | Pre & post test counselling for HIV/AIDS | 250 | | | | | | | |
| 7.2 | Treatment for opportunistic infections | 167 | | | | | | | |
| 7.3 | Partners notification/counselling | 8 | | | | | | | |
| 7.4 | Condom promotion (demonstration) | 200 | | | | | | | |
| 7.5 | Condom distribution | 1667 | | | | | | | |
| 7.6 | Refer TB suspects for diagnosis at MCs | 5 | | | | | | | |
| 7.7 | Provide treatment for STI cases | 10 | | | | | | | |
| 7.8 | Exit interview to users by proj. Staff | 10 | | | | | | | |
| 7.9 | Establish Condom outlets | 1 | | | | | | | |
| 7.10 | Monthly meetings with PLHA | 1 | | | | | | | |
| 7.11 | Refer HIV positive cases to care & support centres | 1 | | | | | | | |

| 8 | **EYE CARE :To offer primary eye care services and reduce blindness among 800 persons belongs to slum areas and disease** | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | **Vision Centre activities** | | | | | | | | |
| 8.1 | Screen the persons for eye problems at vision care centre | 33 | | | | | | | |
| 8.2 | Identify refractive errors & prescribe glasses to the needy | 10 | | | | | | | |
| 8.3 | Identify and referral of cataracts for surgery | 1 | | | | | | | |
| 8.4 | Follow up of operated cataract cases in field | 3 | | | | | | | |
| 8.5 | Provide First aid service | - | | | | | | | |
| | **Community level** | | | | | | | | |
| 8.6 | Cataract screening camps at slums | - | | | | | | | |
| 8.7 | Identify and refer cataracts for surgery | 1 | | | | | | | |
| 8.8 | School screening camps | - | | | | | | | |
| 8.9 | Sensitize mother groups about vitamin A and nutrition | 1 | | | | | | | |
| 8.10 | Sensitize the target groups about vision care | 1 | | | | | | | |

Job description of Community Health Supervisor (CHS)

| Title | Community Health Supervisor (CHS) |
|---|---|
| Reports to | Project officer |
| Location of the job | Rural/tribal/urban slums [placement of work] |
| Responsible for | 4-6 PHCs and concerned staff |
| Job Summary | To plan and implement the project activities of the area by building the capacities of community, partners, health staff and monitor the progress through networking and liaison with local institutions to achieve the project objectives. |
| Job Responsibilities | |

Implementation of the project activities:

- Implementing the project activities in his/her area through community participation by identifying the community groups and informing them about health issues / available facilities to achieve the project objectives

Capacity Building:

- Carry out capacity building on leprosy/TB/HIV/STDs/Malaria diseases to the identified target groups by involving PHC staff as per plan to promote knowledge and skills and encourage participation and to improve the quality of services.

Networking with Govt and NGOs/CBOs/Partners

- Visit the identified local NGOs/GOs/CBOs/Partners, organize meetings /discussions, and negotiate to involve in program activities for better coverage of area by developing coordination and promote the organizational image.

Ensure referral of suspects

- Facilitate case finding activities by the local health staff and community groups/partners to reduce the quantum of infection and disabling consequences of leprosy/TB/HIV/STDs/Malaria

Rehabilitation and prevention of disabilities:

- Identify the available resources in government/NGOs and facilitate mobilization of resources to improve the physical, socio economic conditions of the needy person and their families

Motivation of staff:

- Review the skills, knowledge, personal issues and attitudes of the team members, consider their ideas/suggestions/wishes for better motivation of the staff, and identify the strengths and weakness for the development.

Maintenance and safe guard the assets:

- Ensure periodical servicing, payment of insurance, tax renewals and maintain them in working conditions of the assets provided by the project to prevent the trouble shoots and smooth implementation of activities.

Documentation and Monitoring:

- To prepare the tour plans and maintain the daily dairy, vehicle log book, collection and compilation of periodical reports and timely submission to concerned person.analyse the reports and submit findings, lessons learned, recommendations, success and failures.
- Review the activities of the team members during the field visits, review meetings to identify the shortfalls, find out the reasons and possible solutions in participatory way, and provide necessary support and guidance.
- Verify the weekend reports of the team members and submit the findings of the visit to monitor the progress.

Job description of Community Health Worker (CHW)

| Title | Community Health Worker (CHW) |
|---|---|
| Reports to | Community Health Supervisor |
| Location of the job | Rural/tribal/urban slums [placement of work] |
| Responsible for | Area of PHC/Block PHC/Mandal |
| Job Summary | To enable people of a defined geographical area in participatory approach by involving community, CBOs to understand common health problems and issues related to development which are relevant to his/her area so that appropriate and timely measures are taken by the people/community to improve the quality of life with particular reference to health. |
| Job Responsibilities | |

Support Leprosy Integration:

- Support the health staff in the process of integration of leprosy activities in PHCs and Sub Centers by attending weekly clinics/meetings to assist in diagnosis and treatment, ensuring availability of MDT, support in case finding and identification of complications, documentation, generation of reports and records, planning and implementation to achieve effective integration of leprosy services by sharing responsibilities.

Need identification for capacity building:

- To identify the target groups and their training needs by visiting/sharing/discussing to help the community health organizer in planning capacity building activity on leprosy/TB/HIV/STDs/Malaria diseases

Be acquainted with Govt and NGOs/CBOs/Partners for networking

- Identify the Govt and NGOs/CBOs/Partners by routine field visits to help NMS in planning and organizing the program activities for better coverage of community.

Ensure referral of suspects to health facilities:

- Identify and involve the village volunteers, community groups/partners to assist the health staff through IEC activities in leprosy/TB/HIV/STDs/Malaria

Identification and assessment disability and socio economic rehabilitation needs

- Identify the available resources in government/NGOs/community and facilitate mobilization of resources to improve the socio economic conditions of the needy persons and their families
- Identify/assess the disability needs through assessments during village/urban visits, PHC/health facilities visits, and disability camps and ensure that the needs are provided to prevent/restore functions of disabilities.

Documentation and Monitoring:

- To prepare the tour plans and maintain the daily dairy, weekend reports, generation of periodical reports and timely submission to concerned person. Submit the case study reports, with findings, lessons learned, recommendations, success and failures with details of the activities carried out to monitor the progress.
- Participate in review meetings/discussions and illustrate/consult/discuss during the field visits of Community Health Organizer to identify the shortfalls, find out the reasons and possible solutions in participatory way, and ensure necessary support and guidance.

## ULP Time series Category descriptions and break-down

| Sl.No | Activity | | |
|---|---|---|---|
| 1 | Staff capacity building | Training Programmes for staff | |
| 2 | Community capacity building | Contact to the community leaders | |
| | | Group Talks & Group meetings | |
| | | Capacity building | |
| 3 | IEC | IEC activities | |
| | | School HE programmes | |
| | | IEC Van shows | |
| | | Exhibitions | |
| | | Special Events | |
| 4 | POD/POWD | POD follow up | |
| | | DMC at weekly clinics | |
| | | Refer to Surgery | |
| | | Podiatry | |
| | | Ulcer follow up | |
| 5 | Detection & Treatment | Self | Contact Survey |
| | | | Bood smear for Malaria |
| | | | Skin smear |
| | | | MDT treatment, |
| | | | Health Camps |
| | | | School survey |
| | | | case detection |
| | | | Sputum collection |
| | | | Eye care |
| | | MC activities | TB cases follow up |
| | | | New cases treatement |
| | | | Sputum collection |
| | | | Staining & Examination |
| | | For Government | Help to nurses to diognsis of leprosy & STD cases |
| | | | Janma Bhoomi Programmes |
| | | | Pulse Polio |
| | | | Support to Govt Programmes |
| 6 | Validation | Leprosy cases | |
| | | Malria cases | |
| 7 | Motivation &Counseling | Counselling | |
| | | PMPs visits | |
| | | Motiation to Patients | |
| | | Net working with other NGOs | |
| 8 | SER | SER activitis | |
| | | Loans recovery | |
| | | Need Assesments | |
| 9 | Documentation | Self | Maintance of records |
| | | | Various reports |
| | | | Communiyt data collection |
| | | Govt | UHP reports collection |
| 10 | Govt. Meetings | DLO/DTCO/DMO/DM&HO meetings | |
| 11 | Monitoring & Review meetings | Referral cases TB/HIV/AIDS | |
| | | UHP visits | |
| | | Monitoring programmes funded by Organisation | |
| 12 | Others | General Physiotherapy | |
| | | Adult Education | |
| | | Spport to BPRC in Reasearch work | |

## Appendix 7 – Required Documentation

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Date: October 2006

**Study Title: Leprosy - Reconciling organisational intent and local strategies in an urban setting.**

**Interview Guide Senior Staff Interviews**

1. Read date, location, participants for the tape

2. Work Narrative:
   a. How long have you worked with leprosy? What did you do prior to this?
   b. How did you get into working with leprosy? What motivated your choice?
   c. What were your earliest experiences?
   d. When did you take up a managerial role? How did you experience this transition?
   e. What are your primary functions now at [redacted]?

3. Policy Narrative:
   a. Tell me about how things have changed since you first started working with leprosy?
   b. Policy change, organisational response, daily work practices, prevalence rates, etc...
   c. How do you feel about these developments? Where do you see this going in the future?

4. Community Health Organisers:
   a. What is the primary function of CHO's? What should be their main priorities?
   b. How has their role changed over time? Do you feel that their relationship to the community changed a s a result?
   c. What new challenges and strengths have these changes given rise to? Both in terms of their job role, community responses, and from a managerial point of view?
   d. I often hear the statement – "it is hard for health workers to bring clients together unless they can find an advantage for them" – political parties have spoilt the community, urban communities have no sense of community – etc... Do you agree with these statements? If so, how do CHO's deal with this challenge, when it comes to health forums etc? Do they have other 'things' to offer, if so, what?

5. Finally – where should the project go from here, where should leprosy policy go from here?

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**Study Title: Leprosy - Reconciling organisational intent and local strategies in an urban setting.**

**Interview Guide Community Health Organiser Interviews**

**1. Work Narrative:** Tell me briefly about your background and what motivated you to start working with leprosy.

- What is your native place? Why did you come to Hyderabad? How long have you been working with leprosy/ [redacted]?
- How did you first start working with / get interested in leprosy? What training?
- Tell me about how things were when you first started working with leprosy?
- What did you think of this system? Strengths and weaknesses? Was time well spent? Were your talents well utilised?

**2. Policy narrative:** How have things changed since you started working with leprosy and how you experienced these changes.

- How have things changed since you started working with leprosy? Policy, people, atmosphere, routines?
- Why do you think things changed?
- How did you experience these changes? Your colleagues? Fear, optimism?

**3. Everyday work narrative:** I would like you to tell me about your everyday work as a CHO. I have been going around with you for a few months now, so I have seen much of what you do – but I am interested to learn more about how you experience your work.

*I. What do you think is the most important part of your work?*

- Is this how you spend the majority of your time?
- What else takes a lot of your time? Do you think this is a problem?

*II. Tell me about your relationship with the community you serve?*

- Now more focus on awareness raising, health forums, empowerment etc. Do you feel this change in policy has affected your relationship with the community? If so, how?
- Do you think your relationship to the community is helpful to your work? In what way?
- What do you feel is the key to your good relationship with the community?
- I often hear statements such as "it is hard for health workers to bring clients together unless they can find an advantage for them". What do you think about this statement, what do you think/feel you can offer?

*III. When you are in the community, do you feel you get an understanding of their needs/desires?*

- Do you feel that the services you provide, that [redacted] provides, address the needs/desires of the community?
- Do you think the current strategies address the needs of the community more effectively than previous policy? What about the needs of people affected by leprosy?
- Do you think [redacted] should design its services after what the community wants? Why, Why not?
- How do you reconcile community requests with organisational targets set by [redacted]

*IV. What about your supervisor – no longer in the field with you, working alone a lot of the time.*

- Do you feel he understands the nature of your work in the field and support you in carrying it out?
- Where is support best, where could it be better?

**4. The future:**

- What are your thoughts for the future? Leprosy policy [redacted], your own?
- Is passive case finding working? Elimination or just not looking for cases?
- How would you change leprosy policy? What should be [redacted]'s priority area in the future?

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Date: October 2006

**Study Title: Leprosy - Reconciling organisational intent and local strategies in an urban setting.**

**Information sheet for study on**

**LEPROSY AND HEALTH WORKERS**

Leprosy policy, service and organisations are currently undergoing important changes and it is important to understand how these changes are experienced by the people involved in service delivery at all levels as well as by the people affected by leprosy.

I wish to undertake a study of the everyday working life of Hyderabad Leprosy Project ([redacted]) leprosy field workers in Hyderabad. The study is carried out in collaboration with [redacted] and [redacted] Society – and will be collecting data by observing and asking questions of Community Health Organisers, interviewing managers within the project and the organisation as well as conducting participant observation studies of the daily field activities of the organisation.

Participation in the study is completely voluntary and participants may pull out at any time without giving a reason. All data collected will be kept anonymous and confidential, if comments you have made to the researcher during the research process are to be used, either in full or in part, in the final text the researcher will make sure that you cannot be identified as the source of these comments. If you have any questions at all please do not hesitate to ask. The researcher can be contacted through the [redacted] offices or on above e-mail address and I will be happy to answer any of your questions.

Should you chose to participate in this study, I thank you in advance for all your help.

With best wishes
Yours sincerely

Kristine Harris
Research Student

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Date:

# Consent Form – Staff Interviews

Leprosy and Health Worker Study

1. I confirm that I have read the information sheet dated October 2006 for the above study and I have understood the content of this said information sheet and I have had the opportunity to ask questions. YES ☐ NO ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. YES ☐ NO ☐

3. I consent to this interaction being audio-taped and that written notes of my comments may also be recorded. YES ☐ NO ☐

4. I understand that all comments will be kept anonymous and confidential by the researcher. I agree to verbal statement and photographs being used in this study as long as confidentiality is maintained. YES ☐ NO ☐

5. I agree to take part in the above study YES ☐ NO ☐

- *Staff Member*

Name (please print) : _____ Date: _____

Signature: _____

- *Researcher*

Name (please print): _____ Date: _____

Signature: _____

7th Ethics 02.05.08

[redacted]

**Minutes of the 7th Institutional Ethics Committee meeting**

Date & Time : May 2, 2008 at 10 am
Venue : LSHO Conference Hall

**Members Present:**

S. Dabaralenamukhi

1. [redacted]
2. [redacted]
3. [redacted]
4. [redacted]
5. [redacted]
6. [redacted]
7. [redacted]

**Invitees:**

8. [redacted]
9. [redacted]
10. [redacted]

**7.1. Welcome:**

Prof. [redacted], Director/Convener welcomed all the members of Institutional Ethics Committee (IEC). She informed the committee about the death of Mrs. [redacted] on March 20, 2008 and her services to the committee were gratefully acknowledged.

**7.2. Agenda**: The provisional agenda tabled in the meeting was unanimously approved

**7.3. Minutes of the 6th IEC meeting:** The minutes were unanimously approved.

**7.4. Action Taken Report**: The general recommendations of the committee on consent form were incorporated in the new generic consent form.

**7.5. Project Proposals**

7.5.1. Proposal No.: 1/2008
Self Help Group Intervention
Investigator: [redacted]

The Ethical Committee considers the proposal to be purely for social intervention for programe development and implementation and not intended for research purpose.

1

7.5.7. Proposal No.: 15/2007
Reconciling organizational intent and local strategies –health workers and client perspectives in an urban leprosy project in India conducted at [redacted]
Investigator: Ms. Kristine Harris, Dr. John Porter, Mr. Vijay Krishnan

approved

**7.6. Any other business:**

The forms in local language were also presented for approval

**7.7. Closing remarks:**

The Convener thanked all the members for their valuable assistance. The meeting was adjourned with thanks to the Chair.

[redacted] (Retd.) 2.5.08
**Chairman**

[redacted]
**Convener**

**Members:**

[redacted]

— absent.

[redacted]

**LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE**

**ETHICS COMMITTEE**

**APPROVAL FORM**
**Application number:** 5023

| | |
|---|---|
| Name of Principal Investigator | **Kristine Harris** |
| Department | **Public Health & Policy** |
| Head of Department | **Anne Mills** |

**Title:** **Leprosy: Reconciling local strategies and organizational intent in an urban landscape**

Approval of this study is granted by the Committee.

**Chair** T.W. Meade
**Professor Tom Meade**

Date 28 September 2006

**Approval is dependent on local ethical approval having been received.**

**Any subsequent changes to the consent form must be re-submitted to the Committee.**

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