

***In combating social exclusion how are interventions on the ‘excluded’ related to interventions on the ‘excluding society’?:***

***A comparative analysis of leprosy rehabilitation and prevention in Bangladesh***

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Abstract

In this paper, the social exclusion framework is applied to explore the impact of leprosy on affected people in Bangladesh, and to investigate the effectiveness of interventions of health education and socio-economic rehabilitation. Leprosy, because of its political, social, economic and cultural implications, provides a useful self-contained micro-study to test the applicability of social exclusion as a working tool. Primary research carried out in two centres in Bangladesh showed that in the lifetime of present patients it is possible to trace marked trajectories of exclusion and inclusion. It is argued that in order to reverse situations of deprivation, it is crucial to investigate these processes at the individual and societal levels.

Consequently, two means of intervention are compared: health education of society and rehabilitation of individual patients. These interventions commonly remain distinct, but it is concluded that only by integrating the two approaches can deep-seated prejudices be removed, facilitating early detection and elimination of leprosy. It was found that processes of inclusion are effective when they involve the same actors that promoted exclusion, and when they create bridges across the rigid divides separating the excluded from the excluding society or group. It is also suggested that lessons learnt in the context of leprosy can be usefully applied to contexts of HIV/AIDS or caste-ism.

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## Acronyms

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AIDS	Acquired Immune Deficiency Syndrome
DBLM	Danish Bangladesh Leprosy Mission (now part of TLM)
GoB	Government of Bangladesh
IILS	International Institute of Labour Studies
ILO	International Labour Organisation
HEED	Health Education Environment Development
HPSP	Health and Population Sector Programme
LNGO	Leprosy Non-Governmental Organisation
MDT	Multi-Drug Therapy
NLEP	National Leprosy Eradication Programme
SER	Socio-Economic Rehabilitation
TLM	The Leprosy Mission
WHO	World Health Organisation

## 1. Introduction

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Leprosy presents an extreme example of social exclusion. From the earliest times leprosy has been a disease set apart from all the others and in a great many communities its sufferers have been rejected by society (Bryceson, 1990; Jopling, 1991; Nicholls, 2000). Even those who are clinically cured still suffer the consequences of their disease (Cornielje et al, 2000; de Stigter, 2000). A WHO report in 1999 stated that even today affected persons with clear signs or chronic manifestations are often unable to work or marry, becoming dependent for care and financial support, leading to insecurity, shame, isolation and consequent economic loss (in Deepak et al, 2000).

The first section of this paper outlines the social exclusion analytical framework, which provides the structure for this study. An overview is then given of leprosy research, with a particular focus on two approaches to intervention: health education and socio-economic rehabilitation. The aim of health education is to change the condition of patients and prevent further disease by educating society as a whole. The aim of rehabilitation is to change the individual's socio-economic status, indirectly changing the surrounding community. In the final section, findings and results from primary research in Bangladesh are presented following the social exclusion framework, and then summarised in table form.

## 2. Social Exclusion: a tool for analysis

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The notion of social exclusion as an analytical concept originated in France in the 1960s and emphasised the risk associated with the breakdown of the social fabric through progressive rupture of the relationships between the individual and society and the ensuing loss of collective values (Bhalla, 1998; IILS, 1996). Gradually debates have widened, in particular to explain the effects of markets, as economic dimensions are now interpreted as both a cause and effect of social exclusion (Gore, 1997; de Haan, 1998). An extensive project by the IILS in the past 5 years has sought to test the concept of social exclusion as a globally relevant paradigm (IILS, 1996).

### *(a) Social exclusion: individual versus society*

Theoretical work by Silver (1995) and Singer (1997) has explored different paradigms of social exclusion.

Social exclusion can denote a situation or process of marginalisation experienced by **individuals**. On the other hand social exclusion can be understood as a **structural** process which occurs in societies as a result of the malfunctioning of their institutions, and which leads

to the breakdown of social cohesion and the fragmentation of social relations. Implicitly there is a core of shared values and rights around which the social order is constructed; a variety of institutions provide the mechanisms for integrating individuals in society, and exclusion reflects their failure (Room, 1995).

Silver's third paradigm, *monopoly*, provides a more complex picture of society with a hierarchy of inclusions and exclusions. Society is hierarchical, with different groups controlling resources. Insiders protect their domains against outsiders by constructing barriers and restricting access, to occupations, cultural resources, to goods and services. At the same time they promote solidarity within the group (Appasamy, 1996).

The different paradigms can be interpreted as analytical approaches rather than as mutually exclusive representations of reality. Social exclusion and inclusion can have both individual and structural causes. The social exclusion framework can help to untangle the different processes at work and then investigate their interrelated effects on each other thus avoiding the risk of emphasising one aspect above another. The framework does not however provide a blueprint for reversing patterns of exclusion as shown by studies on 'adverse incorporation' (Wood, 2000). The terms of inclusion must be worked out in each situation.

*(b) Social Exclusion: the framework for analysis*

The main features of the social exclusion framework are a **focus on process**, in which deprivation is analysed as a result of dynamic causal factors rather than as a measure of outcomes (Bhalla, 1998) and a **focus on the social actors** and power relations involved in the processes of exclusion (and inclusion) (Rodgers, 1995). It provides an interdisciplinary approach provides insight into the cumulative factors that keep people deprived.

The multi-dimensionality and processual focus of the social exclusion framework that make it an attractive tool, also pose a considerable challenge to its operationalisation. A framework is necessary in which the actors and areas of exclusion can be integrated, in such a way that allows the including and excluding mechanisms to appear.

De Haan (1998) suggests a checklist of indicators under the three headings of *rights* (human, legal/civic, democratic, psychological), *resources* (health, infrastructure, education, employment, nutrition, income) and *relationships* (family networks, wider support networks, voluntary organisations, the state). These cover the *institutional*, *distributional* and *relational* aspects of social exclusion. I have used these indicators to structure my research and adapted an operational outline developed by de Haan in the table summarising findings (Table 5.1).

**Rights:** Under this heading it is possible to take a closer look at the structural chassis around which exclusionary processes develop. Exclusion from security, justice, representation and citizenship can be explored by considering the institutions and rules, formal and informal, which enable and constrain human interaction (Gore, 1995). Social exclusion is a property of society if racial, sexual and other forms of discrimination are present, if the markets through which people earn a livelihood are segmented, or if public goods, which in theory should be available to everyone, are not so in reality (de Haan, 1998).

**Resources:** Within the SE framework, the approach to resources is analytical rather than descriptive, seeking the mechanisms and connections underlying deprivation. This way of describing disadvantage directs attention to the ability of persons to change their position within an income distribution and social hierarchy, as well as the form of income distribution and hierarchy itself (de Haan, 1998; Sen, 1981).

**Relationships:** People can be excluded in some areas and included in others. Moser (1995) notes how economic analysis commonly focuses on individual or single-function household indicators, whereas a holistic analysis which aims to successfully target beneficiaries needs to recognise the variety of roles, relationships and social functions at individual, household, community and civil society levels.

To summarise, the framework provides a checklist to ensure the multidimensional treatment of exclusion. Within these headings the challenge is to identify the processes that lead to exclusion or inclusion and their compounding effects. The three paradigms of individualism, structuralism and monopoly can be used as heuristic devices to look at the reality of exclusion from different angles, unpacking the societal and individual contributions to exclusion and inclusion and uncovering different layers and causal attributions of exclusion (de Haan, 1998; Nayak, 1995).

### **3. Leprosy**

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#### *(a) Leprosy: the disease*

Leprosy is a chronic communicable disease affecting chiefly the skin and peripheral nerves. It is caused by a bacterium, *M. leprae*, which is transmitted during close and frequent contacts with untreated, infected persons (www.who.int). The normal response to exposure in 90% of the human population is the development of immunity and no clinical manifestations (Mull et al, 1989). Reduced immunity levels, for example through malnutrition, increase susceptibility to leprosy (Opala and Boillott, 1996, Ulrich et al, 1993; Mull et al, 1989).

The clinical evolution of the disease is slow, often extending over many years (Browne, 1985, in Krishnatray, 1998). In almost one third of untreated patients, leprosy results in the occurrence of impairments affecting the extremities and the face (Opala and Boillott, 1996, Navon, 1998).

Hansen discovered the bacterium in 1873 (Opala and Bollott, 1996). The introduction of dapsone in the 1940s and subsequently of multi-drug-therapy in 1980s has caused a drastic reduction in prevalence of leprosy (Rao et al, 1996). This success led WHO in 1991 to set the goal for eliminating leprosy as a public health problem by the year 2000, elimination being defined as a level of prevalence <1 case per 10,000 population (Noorden, 1995) since below this prevalence rate, leprosy should disappear naturally.

### *(b) Social Exclusion and Leprosy*

In much of the relevant literature, leprosy stigma is interpreted as 'the chief cause of the social and economic dislocation that people affected by leprosy experience' (Nicholls, 2000). However, the analysis of leprosy solely through the lens of stigma has caused research to remain quite insulated. This approach has been countered by an increasing number of authors, as the causes of stigma have been found to be context-specific (Biljeveld, 1965; Gussow and Tracy, 1965; Jopling, 1991; Scott, 2000). Consensus has now shifted towards an analysis of patterns of stigma as determined by cumulative historical, economic, cultural, and medical causal components specific to each society (Navon, 1998). In this paper I have considered stigma to be one of many mechanisms that lead to social exclusion.

Descriptions of social exclusion due to leprosy show that it has affected **rights, resources** and **relationships**. At an institutional and legislative level in pre-independence India (and therefore Bangladesh), exclusion of leprosy patients existed at the legal level until recently. For example, the Motor Vehicles Act (1939) prohibited people affected by leprosy from obtaining a driver's license, although only 25% suffer from sensory loss of limbs (Patankar, 1992, in Krishnatray, 1998).

In the medical profession leprosy has often been considered a disease apart and studies from India report cases of doctors refusing to treat leprosy patients (Mishler, 1981; Berreman, 1984; in Scott, 2000). In the past, patients have been unable to obtain medical treatment in mainstream health centres, but only from specific leprosy centres (Jopling, 1990), but this is now changing in Bangladesh.

Many studies have reported how, to a greater or lesser extent, leprosy patients have suffered financially, either directly as a result of their disease, when disability has prevented them from working or from performing household tasks, or indirectly as a result of the stigma experienced

(Kaur and Ramesh, 1991). Economic difficulties felt because of leprosy are frequently in addition to already precarious situations, since leprosy is more prevalent in areas of low economic development (Ulrich et al, 1993). Extreme cases of destitution occur when leprosy patients are deprived of housing and sources of income and are forced into begging. A study in Tanzania found that out of 500 beggars, 60% were leprosy patients (Tibaijuka, 1996).

With regard to relationships, within families and communities, the one fact that is repeated over and over again is the difficulty for unmarried women who have had leprosy, in finding a marriage partner, even if they carry no signs of the disease (Seaton and Collier, 1997; Wilson-Moore, 1997; Valencia, 1983; Kaur and Ramesh, 1994; Rao et al, 1995). According to Van Parijs (1988; in Scott, 2000) one third of leprosy patients suffer desertion by marriage partners. In a more localised and less pervasive way, research has found cases of complete (rare now) or partial segregation of patients from their families (de Stigter, 2000). Typically, people affected by leprosy may be unable to eat or sleep with their families, denied access to festivals, formal and informal gatherings, markets, employment, local water supply and other public facilities. Their children may be denied schooling and later, be forbidden to marry (Nicholls, 2000; Abebe et al, 1992; Croft, 1995; de Stigter, 2000). Studies show enormous variations in the form and intensity of social exclusion.

It is only recently that the differential implications of leprosy according to **gender** have been specifically considered. Women in leprosy-endemic areas of the world, with few exceptions suffer from marked economic and social dependency and inferiority. This condition is heightened by leprosy infection and its consequences (Ulrich et al, 1993). Research in India and Pakistan showed that the social restrictions imposed on women affected by leprosy far exceeded those experienced by men and that women with leprosy face definite social and psychological problems irrespective of their socio-economic status (Mull et al, 1996; Zodpey et al, 2000). Rathgeber and Vlassoff (1993) suggest that the peculiar nature of women's responsibilities at the economic and familial levels has a profound impact on the extent to which they are affected by tropical diseases and the responses they are able to manifest. Women were isolated from their major daily task of cooking food for everyone, they were not allowed to touch others, they were restricted from going out, travelling, attending festivals, going to the worship places, attending marriages and family functions.

#### **4. Reversing the patterns of social exclusion**

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##### *(a) Interventions through health education campaigns*

The previous discussion has shown that there has been a shift from description of social exclusion as a monolithic social response (Albrecht et al, 1982), reflecting the underlying

assumption that stigma is inevitable and chronic, to an analysis of its causes, which leads to the conclusion that stigma can be reversed (Gussow and Tracy, 1970).

A deliberate focus on processes of change and systematic examinations of stigma began in earnest with AIDS and mainly took the form of public health and education campaigns (Jones et al 1984; Pryor et al, 1993). Health Education campaigns are based on the premise that behaviour change can be brought about by the diffusion of knowledge (Bowes, 1997). Health education is considered an essential component of leprosy control, with the aim of 'correcting by dissemination of the truth in simple terms popular conceptions about leprosy and the stigma that these engender' (ILEP, 1982 in Seaton and Collier, 1997).

In the context of differing social exclusion paradigms, the objectives of health education can be seen as attempts to restore the relationship between the individual and society, restoring a core of shared values and rights through the diffusion of knowledge. It can be considered effective if it succeeds in bringing about *structural* change by influencing the actual institutions and norms, formal and informal, embedded in society.

To a large extent, where they have been evaluated, health campaigns have been found to be successful. Several studies have shown a positive relation between increased knowledge and behavioural involvement (Valente et al, in Krishnatray, 1996; Seaton and Collier, 1997). Kaur and Ramesh (1994) found that despite discrimination patients could now mingle freely reflecting the impact of health education through the mass media. Croft (1999) carried out a survey in two areas of Northern Bangladesh to assess and compare the level of knowledge, attitude and practice towards leprosy between two communities. The area with the well conducted health education campaign showed a much higher level of knowledge and more favourable attitudes, but attitudes and behaviour change lagged behind knowledge. Opposite views hold that 'knowledge itself does not remove fear; it may even accentuate it' (Patanjar, 1988). There is some research evidence from leprosy and AIDS-related research to support this (Valencia, 1986; Mutatkar & Tare, 1988)

Some limitations on the desired impact of health campaigns have emerged from their evaluations in various situations. A Survey Education Treatment programme in India showed that levels of behavioural change resulting from information dissemination were highly susceptible to the accuracy and understanding of the information disseminated (Krishnatray, 1998). The changing nature of knowledge itself makes this task difficult, since for example leprosy was once regarded as hereditary among medical experts, also the type and availability of treatment have varied with time (Young, 1981).



A further issue relates to the discrepancy between experts' representation and people's construction of leprosy. Bowes (1997) denoted as superior those health models which recognise the complexity in transmission of media information, and that it is often filtered and promoted through personal influence. This is even more relevant in regions of the developing world where traditional beliefs about illness and healing are prevalent (Opala and Boillott, 1996).

Research into the impact of health education campaigns on AIDS in Northeast Thailand showed that levels of knowledge had risen considerably, but not the perception of risk (Lyttleton, 1994). Because of the stereotyped models of promiscuous behaviour, the mismatch between the moral assumptions underlying the campaign and those of the recipients, the technological transmission of the message (through TV) and certain language barriers, increased exposure to the messages only reinforced the perception that the risk was not locally pertinent, therefore knowledge remained abstract and unrelated to daily practices. If anything this had resulted in an increase of the stigma and isolation felt by sufferers of the disease (Gussow and Tracy, 1970).

All the above examples lead to the conclusion that for behavioural change to occur and be accompanied by destigmatisation, knowledge must not remain abstract, but should be actively generated by regular interaction with the people who form part of one's immediate social world (Krishnatray, 1996; Croft, 1999).

A participatory model of health education also evaluated by Krishnatray (1996) was based on an interactive and social-action based (behaviour) approach. Through the collective investigation of the antecedents and consequences of leprosy it sought to bridge the gap between different constructions of leprosy, also providing a series of health and social activities such as practical demonstrations of ulcer care (DANLEP, 1992). The success of the programme suggests that strategies that address local cultural ideologies, engage patients, community and health workers in dialogue, and incorporate an action component have greater potential of reducing stigma. Krishnatray concludes that the crux of the communication problem is whether public campaigns promote *behavioural involvement* between the so-called 'normals' and the excluded.

*(b) Interventions through socio-economic rehabilitation (SER)*

An alternative response to the social and economic hardships faced by leprosy sufferers is to deal with these at the individual level, making patients the agents of their own socio-economic rehabilitation and integration, since for many men and women affected by leprosy simply overcoming the infection is not sufficient to allow for a straightforward return to their previous lifestyle (Nicholls, 2000). At an ILA conference in Beijing in Sept. 1998 it was stated that:

*'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'.*

This focus on individuals, seen as key players in the process of their own exclusion or inclusion, places the approach in line with Singer's *individualism* paradigm. However, SER schemes do also aim to change the attitudes that prevail in society as a whole and promote the integration of disabled people into society with equal rights and opportunities (Cornielje et al, 2000). This duality of purpose reflects the more complex view of society given by Silver's monopoly paradigm, seeking to break down the barriers surrounding isolated groups and increasing social permeability.

Until recently, 'rehabilitation' occurred in institutions where patients remained as permanent residents and were engaged in different occupations such as agriculture, animal husbandry, weaving and tailoring. This approach is now considered outdated as it allows no possibility of restoration or reintegration within the family or community. Through social and economic rehabilitation people cured of leprosy are helped to regain their place in the community as opportunities are developed to help them find productive employment to contribute to the economy of their family and to live with dignity as useful and self-supporting members of the community (Nicholls, 2000). To achieve these aims some programmes provide interest-free loans to help patients start new trades or occupations, financial assistance to the relatives of patients with severe impairments unable to work, training and placement activities, and subsidise the education of the children of patients (Gershon, 1992).

Evaluations of SER projects on the whole report mixed results with regard to both social and economic status improvement (Palande et al, 2000, Gershon et al, 1992). I have found no studies addressing the impact of socio-economic rehabilitation on levels of knowledge and case detection rates in the local communities of participants.

Cornielje et al (2000) state that vocational training and job placement form a *strong point of entry* for integration into society, providing a mechanism for breaking the 'disability cycle' of isolation, dependence and chronic poverty. Through income generation, people with disabilities become partners in the earning of family income and thereby gain respect, giving them a larger stake in household decision-making processes. Large gains in social role and status in both the family and the community at large empower the individual, who in turn may help other members of the community. The authors also add a note of caution, noting that while the ultimate rehabilitation aim of 'integration into mainstream society' is often achieved

through employment activities, there is a risk in placing too much value on economic activity alone. In order to avoid the stigmatisation of those who cannot become economically active (the elderly, the young and those who have profound /multiple disabilities), rehabilitation should focus on the creation of a supportive environment that stimulates to contribute meaningfully to the lives of their families or communities.

A further issue raised by Cornielje et al (2000) is that focusing on the specific needs of those affected by leprosy continues to make a special case of leprosy. This carries the risk of further stigmatising those involved in such programmes.

### *(c) Comparing SER and HE*

It is striking that the literature concerning health education and that concerning socio-economic rehabilitation have remained quite compartmentalised and separate from each other. This suggests that their implementation has also remained 'un-integrated'. While health education schemes commonly operate on quite a large (regional or national) scale, SER schemes appear to have remained localised. However the discussion in the previous sections highlights the need for complementarity. Studies on health education campaigns have come to recognise the importance of behavioural engagement, linking general knowledge to daily practice of the individual. This is achieved through practical illustrations of contact between people affected by and people not affected by, leprosy. On the other hand, crucial to the success of SER is the recognition that the psychological, social and economic effects of leprosy are largely determined by the community's attitudes towards the disease. Programmes have been found to have limited impact when lacking the community participation and ownership of the programme. Palande (2000) stresses that a strong educational component in the programme is still essential.

Moreover, since many aspects of SER are related to impairment, a strong 'prevention of impairment' component in each project will greatly help in minimising the need for rehabilitation. The availability of SER is limited by its costliness and therefore limited in its coverage. If accompanied by health education for disability prevention, SER programmes will be able to more effectively target those who are most in need of it. Concerning targeting, there seems to be little discussion or planning involved regarding which groups to target and how, apart from some schemes which are limited to women only.

Nicholls (2000) mentions the potential benefits of integrating SER schemes into wider-scale national programmes, and linking people affected by leprosy to existing services rather than creating new stand-alone projects, thus avoiding the risk of further stigmatisation.

## 5. Findings and analysis

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### *(a) Methodology*

I visited 2 leprosy centres in Bangladesh during July 2001, Danish Bangladesh Leprosy Mission (DBLM) -concerned primarily with leprosy- in the Northern Rajshahi division and Health, Education & Economic Development Bangladesh (HEED Bangladesh) -concerned more generally with health and development- in the Sylhet Division. Both of these organisations are NGOs, which are now accountable to the GoB for leprosy control in their respective project areas. I was based at two NGO in-patient leprosy hospitals (for surgery and more severe cases requiring hospitalisation) and visited GoB hospitals and local clinics with out-patient leprosy/TB clinics staffed by NGO workers.

I collected data using a structured questionnaire, which included questions on personal demographic variables, economic status, disease history and its impact on economic and social aspects of life. 55 individuals were interviewed, all of whom (except one TB and one non-patient on an SER programme) had been diagnosed as having M. Leprae infection. Interviews represent a wide cross-section of affected people, varying by age (range: 12-80 yrs), gender (25 male, 30 female), socio-economic status and experience of disease. Each interview lasted 30-45 minutes and was carried out with the help of a translator. Where possible the patient was interviewed along with their household and community, and where relevant multiple responses were recorded.

Some *focus group discussions* were carried out with groups of patients of similar backgrounds (Beggars Club, Vocational Training Classes) to assess hierarchies of values and of authority (as sources of information) in local communities and perceptions of illness and disease.

*Key informant interviews* were held with a number of medical staff at the leprosy centres and with WHO/GoB health officials in Dhaka. Their opinions were sought on certain issues such as 'What are people's attitudes towards leprosy sufferers?', 'Has health education perceptibly changed local attitudes?', 'Are any HE initiatives particularly effective?', 'What are the main challenges remaining for leprosy eradication?', 'What lessons can be learnt and transferred from the leprosy experience?'

### *(b) Leprosy in Bangladesh*

Bangladesh was one of the signatories to the 1991 World Health Assembly Resolution calling for the elimination of leprosy by the year 2000. WHO statistics for 1998 report Bangladesh as having

13,248 registered cases, a prevalence rate of 1.03 /10,000. This prevalence rate was reduced to less than 1/10,000 by December 1998. Deformity rate among newly-detected cases has declined from 21.9% in 1993 to 7.9 % in 1999. However, there remain regions with much higher prevalence rates. Therefore the current target is the elimination of leprosy at district level (NLEP, 2001).

### *(c) Results and general findings*

In the following discussion under the headings of rights, resources and relationships I have considered only elements of deprivation which result directly from leprosy, since poverty is a widespread phenomenon in the areas studied and may have other causes.

#### Rights

Since 1998 leprosy services are being integrated into the General Health Services, whereas previously the treatment of leprosy occurred outside the mainstream health services. Integration schemes have been piloted for the last 15 years but are now being applied on a national level, with NGOs providing staff and the government supplying premises. The majority of patients are now being treated as out-patients at the treatment centre nearest to their home ([www.stoptb.org](http://www.stoptb.org)). Three government and ten NGO hospitals provide treatment for complications like deformities and ulcers.

Many health workers and health officials spoke very positively of the integration process and suggested that it is an exemplary model for government and NGO co-operation. Patients may now go to a clinic and receive routine diagnosis, treatment and follow-up services without being singled out as leprosy patients. One senior health officer said that he was trying to encourage GoB general hospitals to take in people affected with leprosy for eye surgery as a further step towards integration.

However a considerable number spoke of the poor quality of service received at public hospitals (in general), their lack of medicines and of a certain amount of corruption. Though this did not apply specifically to leprosy treatment it appeared to discourage patients from seeking assistance from GoB complexes. This contrasted with the high levels of esteem

accorded to leprosy health workers. During interviews their commitment and strong relations with patients and their families were very apparent.

No patients spoke of discrimination by medical staff except in the past. NGO health workers and doctors mentioned some resistance they had come across in health officials during training sessions and when introducing leprosy out-patient clinics into general hospitals. On the whole these had been overcome through discussion and practical demonstrations of leprosy care.

Few people spoke of having expectations of the government (for sickness or disability benefits), the widespread feeling was that poverty was so common that they could not expect to be singled out and that the government assumes NGOs will look after leprosy patients. The only active engagement with government officials was spoken of by members of groups, formed either as a result of leprosy or through credit schemes. During my visit a press article reported that the government had created a new settlement in the capital for leprosy patients. Leprosy health workers interpreted this as misplaced goodwill.

Further examples of integration at institutional level were given by DBLM's involvement in advocacy activities (such as participation in World Disability Day) alongside the Social Welfare Department and community leaders (see Table 5.1.A).

### Relationships

20 interviewees reported problems in their **relationships** due to stigma, 12 others stated that they had kept their disease hidden (from neighbours rather than family) in order to avoid stigmatic reactions and 13 others that they had experienced discrimination in the past but things had changed. Among the current problems cited (in decreasing order of importance): fear of inability to marry in unmarried girls, being ignored by villagers, perception of unspoken fear ['they greet me but keep their distance'], only three mentioned instances of segregation or fear within their close family units in addition to three girls whose husbands had divorced them. Three interviewees indicated that they had moved away from their area in response to their disease and the resulting stigma. One settlement in which two interviews were held had originated in proximity to the leprosy centre many years ago with patients who felt unable to return to their own communities, and three women (ex-beggars) were living in sheltered accommodation provided for by the NGO. Three people said that they had experienced isolation in their communities because of poverty, and their stories indicated that their poverty derived from their disease.

On the whole exclusion appears to have greatly decreased particularly within family units. Eight people said that they had experienced social rejection in the past, but that things have

changed. The overall configuration of stigma remained very unevenly distributed. Furthermore interviews confirmed that the tendency to keep the disease hidden for fear of rejection in various forms still leads many to delay treatment.

### Resources

The economic trajectories affecting patients and their households followed common patterns with ill health leading to financial strains as patients sought a cure, or as they were forced to leave employment or seek different employment due to the constraints caused by their illness. 27 people spoke of economic difficulties resulting from their disease: through employment/domestic work difficulties (unable to work/ unable to carry on same work/ able to work less), due to weakness or disability (24), five had been beggars in the past and two were still working as beggars, four mentioned difficulties in obtaining sufficient food, and one housing, because of lack of employment. Two people mentioned stigma from employers or customers as the cause of difficulties in finding adequate amounts of work [“ he has a small cart but no-one will sit on it”].

Some spoke of difficulties in finding the necessary money for transport and medicine and of economic difficulties inflicted by large bills for traditional/private treatment (unaware of disease and free treatment for leprosy) and the financial burden on families whose members had gone away for treatment. Other responses included difficulties in sending children to school and inability to save.

#### *(d) Processes of exclusion*

The main aim of my study was to detect the causes and processes behind these outcomes and the impact on them of interventions through health education and SER. Due to the one-off nature of my interviews I was only able to collect data on perceptions of change rather than direct measurements of change, which a longitudinal study of processes could make.

I have presented below two of the more complex patterns of exclusion, affecting women and beggars, for whom the social and economic consequences of leprosy are closely interwoven.

### Women

This survey highlighted that the problems experienced by women are more keenly felt, but also different to those experienced by others groups of people. Leprosy is commonly detected later in women because of their more covering clothing, and because of the cost and need of an escort to access health complexes.

A few respondents (male and female) also mentioned that women’s main task is domestic work, which can be severely hampered by leprosy (through weakness/deformity/easy risk of

burns and ulcers in kitchen). However few alternatives to their work exist, whereas for men, if they can't do one job, they can maybe do another and maintain their respect by continuing to earn. The girls on vocational training were strikingly committed to their work, and repeatedly described how through work they would be able to earn money and thus marry.

Only one man stated his fear of being unable to find a marriage partner, compared to almost the complete majority of girls for whom this was the overriding concern. The resignation with which this was repeated seemed to suggest that any history of ill health (especially leprosy) on the part of a woman discounts her validity as a bride probably due to the lack of accessible health care. For a man this can be quantified by decreasing the value of the dowry, but for women this is not possible.

### Beggars

In the case of beggars with visible impairments, leprosy provides both the cause of their social exclusion *and* their means for survival through self-exploitation. Consequently, I was told by the members of an 'ex-beggars club' of their reluctance and fear of changing to a new way of life.

My translator and the health workers spoke of the strong impact of beggars on people's perceptions of leprosy, and some argued that reversing the situations of beggars *before* they 'die out', has a huge potential for conveying the message that even extreme cases of exclusion are reversible. For many health workers the continued presence of beggars with obvious impairments is a pressing concern, as it is a reality in obvious contradiction with the messages transmitted by health education, which appeal against the assumed association of leprosy with impairment and destitution. Focus group discussions showed that there is a common distinction between leprosy with and without (visible) impairment.

While begging has been reduced by forming beggars' groups, some questions arise as to their adverse long-term effects. Evident improvements have occurred in the wellbeing of members and their families, but the possible effects of forming a group whose corporate identity derives from their disease needs to be taken into consideration. One positive development on this front, relating to the beggars group I met, was their recent involvement with Proshika, a development NGO, who were taking over some responsibility from The Leprosy Mission which until now has acted as their sponsor.

### *(e) Processes of inclusion*

### Effects of Health Education interventions



It is not easy to gauge the impact of health education (through TV, loudspeakers, radio, newspapers...), especially in its capacity to change attitudes. The most common indicator used by health workers in assessing the relative effectiveness of different methods is to note the increase in voluntary referrals. This statistic suggests that continued health education is having positive repercussions. The National Leprosy Elimination Campaign in 7-12 February 1999 also reported a positive shift in people's knowledge, practice and health.

When asked what caused people to change their attitudes, 14 respondents answered health education (six mentioned TV) and eight said health workers played a key role in coming to their communities and talking with people on their behalf. Quite a number in Rajshahi division mentioned drama presentation, an innovative programme in which volunteers (including some ex-patients) present health messages in the form of entertainment in local villages. Among the advantages of this method are the personal experiences of the actors, the relevance of the drama to everyday life and the easy access to the events for women.

Religious beliefs about the causes of leprosy have changed in the sense that patients and their communities on the whole say that 'leprosy is not due to God's curse or previous sins, but it is due to germs' (I found little difference between Hindu and Muslim responses). However the way in which this was repeated almost as a cliché and any contrasting opinion was dampened by the community themselves, suggested that it is not clear why one belief denies the other. Education campaigns broadcast knowledge with no clear targeting and seem to have superimposed natural causes over religious/cultural ones, leaving confusion in people's minds.

*Insert Table 5.1(A/B/C) here*

Table 5.1 illustrates the processes at work which lead to the exclusion of leprosy patients. The table highlights mechanisms of exclusion and inclusion and the related actors. Sources of 'inclusionary' information are shown to be mostly different to those which contribute to the exclusion of patients. This allows contradictory beliefs to co-exist side by side. For example, people may see no contradiction between going to traditional healers and medical practitioners at the same time.

Health workers mentioned that the training of certain groups of people such as general health practitioners, traditional healers (table 5.1B) and imams (table 5.1 A) had brought positive results, introducing information through recognised channels of authority (see table 5.1A). In this way, unhelpful practices and beliefs were not abolished but 'redirected', inclusion does not collide with exclusion, but through education transforms previous customs.

Health education efforts have undoubtedly benefited from the structural changes that have occurred through the integration of leprosy care into GoB health complexes (Table 5.1A/B). This demonstrates the complementary effects of transforming formal (organisational structure) and informal institutions (customs and norms). In this case it *is* the actual institutions which previously 'promoted' exclusion which are now actively reversing the process (Table 5.1A/B/C), mechanisms of inclusion are directly engaging those of exclusion.

Furthermore, the process of integration is building bridges across the excluded/'normal' divide. Leprosy patients are now being treated alongside other patients in mainstream clinics, medical staff are starting to treat and operate on leprosy patients as a disease like any other. This is important since inclusive processes could simply attempt to reverse negative activities but remain limited to the excluded group of patients. For example the government provision of housing to a group of destitute leprosy patients reversed their economic situation but did not engage them with non-leprosy people and reinforced their identity as a separate group.

#### Effects of SER interventions

SER schemes target individual situations of social and economic exclusion. 11 interviewees had taken training courses and received loans to start up businesses. No one reported negative experiences, only one said his economic situation remained unchanged. I was told of two people whose spouses had returned as a result of socio-economic rehabilitation and who had experienced a complete reversal of situations of social rejection. Among my interviewees, there were no such extreme cases, though one man did say that receiving a loan changed his mental attitude and restored his confidence to interact with his family and community. Men and women on VT courses (sewing, tailoring, water pump maintenance) were confident that being able to work on their return home would improve their status in the communities, and for the women increase their chances of marriage. One man commented that he felt much more part of the community since he had started working again, because of the social interaction with his customers.

I found that many patients had been referred to leprosy clinics by family members, and that those patients who are open about their disease are active in seeking out other patients. They stated that people's attitudes had changed as a result of their own experience of cure and economic rehabilitation. The impact of personal contact referral is amplified by leprosy's clustered pattern of distribution.

Some constraints on the success of SER programmes emerged from responses given. When the ideal model of community participation is reduced to simple hand-outs of grants or loans, the selection of an occupation and provision of training may be superfluous assets to the community: one man affected by leprosy had received training as bicycle mechanic yet had

reverted to another occupation due to lack of demand, a woman trained in weaving had stopped her work and switched to sewing when her loom broke down, one tailor said he had insufficient work due to the large number of tailors, a shoemaker trained to make shoes for leprosy patients affected by ulcers was made redundant when the hospital no longer needed him. A couple others were unable to continue their work due to a worsening health condition. One health worker said that one difficulty was finding appropriate jobs for people, that would not favour ulcers to develop. Negative attitudes in society towards certain jobs like hairdressing or sweeping are a major hindrance, making patients reluctant to take them up. He underlined that without community support and consultation, programmes were less likely to succeed.

Some centre-based training schemes take family members away from their households for up to nine months and two households commented on difficulties experienced due to their absence (financial, childminding and so on). Community based apprenticeships in some cases had been used to address these problems.

SER schemes owe their success, at least partially, to the fact that the respect accorded to wealth and financial solvency countermands the stigma associated with leprosy. Four people even commented 'it is not because of leprosy that we are stigmatised but because of poverty' though for three of them their poverty resulted from their disease. The respect accorded to wealth seems to reflect changing attitudes, since younger respondents gave money a much higher importance than older respondents for whom family and neighbours rated much more highly on a scale of values

### Comparing SER and HE

Lastly, what are the effects of HE and SER on each other? Perhaps one of the greatest strengths of both DBLM and of HEED Bangladesh was their simultaneous involvement in both HE and SER activities. Health workers are engaged both in individual support and coordination of education programmes in the communities, recognising the complementarity of these activities. Radio and television were considered good for creating awareness and lending authority to the health terms, and interpersonal means of communication and practical demonstrations the most effective way of transmitting the message. One health worker said that he always takes patients with him when doing health education programmes (slide shows etc) or training courses for professionals.

While it has been shown that stigma still remains and contradictory opinions are still present within some communities, the examples reported do suggest that whilst health education alone could remain abstract and SER schemes could promote 'positive segregation', their cumulative effects reinforce each other. The more interventions at the individual level connect with those

at the societal level through established channels of authority (health workers, imams, patients, local leaders, traditional healers) and the more they connect knowledge to everyday practice, the more definite and unambiguous the transformation will become.

It is not sufficient that both HE and SER should occur, they should be interlinked and planned concurrently to mutual benefit. The drama programme successfully did this by setting health information into the context of local beliefs and practices, through actors whose own experience has been one of rehabilitation and reintegration.

Health workers and officials commented on the tension rather than cooperation at management level over the allocation of human and financial resources to health education and individual-focused schemes. One doctor very persuasively argued that SER programmes, which he saw as a form of safety net, should not be included under the medical umbrella, but perhaps be taken over by separate social entities, in order to avoid the association between leprosy patients and the need for special schemes, particularly when a cure is available. A compromise between these positions might be a national integrated programme in which SER schemes are centrally planned in conjunction with health education programmes, but then farmed out to non-leprosy NGOs.

Increased coordination between different interventions could also improve targeting within SER programmes. There seemed little attempt in the two programmes I visited, to identify and target groups that would benefit most from training, grants and loans, except the implied preference to provide training to younger people, at the beginning of their earning career. SER programmes could be more attentively targeted to reach groups who remain less affected by the process of gradual change through continued health education (e.g. those who are geographically isolated or those unable to access state education).

Finally, referring back to Silver's three paradigms, these considerations on SER and HE, summarised in Table 5.1, point to a complex pattern of influences and actors affecting the lives of people affected by leprosy. NGOs, the medical elites, government planners, health officials, health workers, religious leaders, local communities, families, patients themselves have all been mentioned for their various roles in creating a hierarchy of inclusions and exclusions. The picture that emerges is one of overlapping layers of exclusion, most closely represented by Silver's *monopoly* paradigm. Processes set in motion by leprosy infection engage with those of poverty, disability, education, gender, tradition and so on. To be effective HE and SER interventions must take into account the intricate pattern they are weaving into.

## 6. Conclusions

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Social exclusion has been used in this dissertation as a leading framework of analysis. The value of the concept lies in its focus on the multidimensionality and on the processes and social relations that underlie deprivation. Drawing on work by de Haan, I have developed a practical framework of analysis. Under the general headings of rights, resources and relationships the framework identifies processes of exclusion and inclusion along with the social actors involved.

The framework has been applied to explain the experiences of people affected by leprosy and shows how different groups (such as women and beggars) are affected in different ways, experiencing different processes of exclusion and outcomes of deprivation. Primary research confirmed that people affected by leprosy in Bangladesh still suffer from economic and social disadvantages as a result of leprosy. Despite the availability of a cure, the reduction in prevalence is not as complete as one would expect and levels of knowledge are not matched by changes in attitude and behaviour. While the testimonies of rejection are far less extreme now, the shadow cast over young women in particular by infection with leprosy, jeopardising their chances of marriage, seems hard to uproot.

For men, the loss of employment emerged as a frequent trigger towards social exclusion, and vocational training and subsequent employment as correspondingly important triggers towards inclusion for *both* men and women. This is obviously only relevant for those who are able to work and must therefore not be promoted as the only means to inclusion, since this would exclude the severely impaired, the elderly and children.

Work by Singer and Silver shows that social exclusion can be interpreted from the perspective of the individual or of society with radically different policy implications. By reviewing the literature on health education campaigns and socio-economic rehabilitation programmes in connection with leprosy, and drawing on fieldwork in Bangladesh, I have shown how both are necessary and that each draws on the other to effectively achieve its aims. The relevant literature remains compartmentalized, but in the centres I visited these two approaches were being pursued concurrently, though not always in a coordinated fashion. Taken independently, health education can remain abstract and removed from daily experience, changing what people say, not what they think. Also taken alone, the inherent targeting in socio-economic rehabilitation schemes may reinforce existing prejudices and an 'us and them' mentality. It is the integrated planning of the interventions that allows one intervention to reinforce the other.

By extrapolation of this point, this dissertation illustrates the importance of understanding exclusionary and inclusionary processes at work at both individual and societal levels and the

interplay between them. The social exclusion framework provides a useful structure within which to do this.

By mapping out the actors and processes of exclusion and inclusion side-by-side (Table 5.1) I concluded that inclusion mechanisms are most effective when:

- ☞ they are set in motion by the same actors as those who were responsible for the exclusion, since exclusion and inclusion may co-exist if the one does not engage with the other. In the case of health education this meant that sources of information could not be limited to TV and radio, since these are not associated in people's minds with the sources of leprosy stigma, but should also be transmitted through the recognized channels of religious and local leaders and traditional health providers.
  
- ☞ they create bridges between the excluded and the 'included', substituting previously rigid boundaries with permeable ones. The integration of leprosy out-patient clinics into the mainstream GoB health system is a clear example of this and has been noted as an exemplary case of partnership between government and NGOs.

Finally, what are the applications of this dissertation and of similar studies? The experience gathered by leprosy researchers and practitioners could have a substantial input into the issue of AIDS. The analysis of the incidence of leprosy prior to and following the introduction of a cure, and the investigations into the reasons for its delayed and reduced impact might well provide short-cuts for the diffusion of the AIDS treatment when it is found and distributed widely. The parallel experiences of stigma associated with health conditions and related patterns of social exclusion could also provide useful insights into how they can best be addressed.

A similar study to this one, mapping dynamic mechanisms and hierarchies of exclusion and inclusion could perhaps be usefully applied to situations of assumed irreversibility such as that of the 'untouchable' caste in Nepal, where discriminatory laws were recently repealed. This would aid the design of institutional and educational efforts required to bring about attitudinal change and to make fluid those barriers that were previously considered insurmountable.

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