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GUEST EDITOR: PROFESSOR W. CAIRNS S. SMITH

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Editorial

CONSEQUENCES OF LEPROSY AND SOCIO-ECONOMIC REHABILITATION

Leprosy once affected every continent and it has etched a terrifying image in history and human memory of mutilation, rejection and exclusion from society.¹

As we approach the end of the millennium, leprosy is no longer the dreaded disease that it used to be, and leprosy patients face a far better future than ever before. However, the social image of leprosy is not greatly changed in many parts of the world; this is all too well reflected in the attitude of the community, particularly towards individuals disabled due to the disease.²

Even today, social stigmatization is frequent so that affected persons with clear signs of chronic manifestations are often unable to work or to marry, they become dependent for care and financial support, leading to insecurity, shame, isolation and consequent economic loss.³

All the above statements are from annual status reports of the World Health Organisation (WHO), dealing with the progress in reaching the goal of elimination of leprosy as a public health problem. All these documents continue to underline the need for strengthening action against social, economic and psychological consequences of the disease, not only for persons having the disease but also for whole families and communities.⁴

Similar statements and recommendations have been made in all international congresses on leprosy and publications of the Medico-social Commission of the International Federation of anti-leprosy organizations (ILEP) over the past few decades.

The strategies proposed for dealing with these human consequences of leprosy include:

- Disability assessment, prevention and management, using simple cost-effective approaches and integration into a routine leprosy programme, not only for benefit of patients but also for the credibility of the programme. Supportive activities to core activities for reaching the elimination goal include patient and family counselling, community education, adequate referral systems and promotion of social and economic integration.¹
- There will be a continuing need to care for those patients for whom dapsone and MDT came too late, and who accordingly will live out their lives with grievous disabilities.²
- Regarding rehabilitation of persons affected by leprosy, the strategy of choice is community based rehabilitation (CBR).¹
- The strategy for leprosy related disabilities should be elaborated at country level with full participation of the health sector, as well as other sectors, NGOs (non-governmental organizations) and community leaders.³

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Progress made and challenges

In spite of this unanimity about the need for adopting these strategies, so far the progress made has been quite limited.

PREVENTION OF DISABILITIES (POD), PHYSICAL, PSYCHOLOGICAL AND SOCIO-ECONOMIC REHABILITATION ACTIVITIES IN LEPROSY CONTROL PROGRAMMES

Over the last 2 decades, more than 10 million persons have been cured of their infection through MDT. Among them, estimates of persons with physical disabilities at the time of diagnosis vary between 10 and 20%. If we consider the difficulties in collecting such data at national level and the disabilities arising after starting MDT, the numbers are probably much higher. This means that there could be 2–4 million persons with grade 1 and grade 2 leprosy-related disabilities (impairments) in the world. However, this classification does not give any idea of specific rehabilitation needs related to physical impairments and disabilities. Similar information about psychological and socio-economic rehabilitation needs is almost non-existent at national or subnational levels. At national level, hardly any leprosy control programme has a clear strategy for POD and rehabilitation.

Even in many smaller projects managed by NGOs, the last 2 decades have seen a gradual decrease in attention towards rehabilitation activities. The decision-makers in such projects and many supporting organizations are often doctors, which could mean more attention directed towards treatment aspects and less towards rehabilitation activities, especially for socio-economic aspects.

LEPROSY-AFFECTED PERSONS IN OLD LEPROSARIA AND LEPROSY COLONIES

The last 2 decades have seen gradual closing down of old leprosaria and support for such structures is seen increasingly as unproductive and unimportant. Persons living in such structures are usually elderly, from the pre-MDT era. Some recent data from countries such as Vietnam, India and China shows that there are many such existing structures with significant number of persons living there.⁵ National leprosy programmes may not have updated information about these structures and about persons living there.

CBR PROGRAMMES AND LEPROSY-AFFECTED PERSONS

Not all countries have CBR programmes. Where there are, these are not national level CBR programmes and most are limited to a few geographical areas. Even in such limited CBR projects, leprosy-affected persons may not be included automatically. When asked the reasons for this exclusion, the most common reason cited by CBR programme managers is that the leprosy control programme looks after rehabilitation needs of leprosy-affected persons. Sometimes, this may also denote deep-rooted prejudices against leprosy. However, there are some CBR programmes involving leprosy-affected persons as in Ghana, Vietnam and Indonesia.

MAINSTREAMING IN EXISTING REHABILITATION SERVICES AND NETWORKING WITH OTHER EXISTING RESOURCES AND GENERAL DEVELOPMENT PROJECTS

Unfortunately, disabilities and rehabilitation programmes are not seen as a priority in any country. Barely 10% of disabled persons have access to any rehabilitation services.⁶ The access is even less in rural areas, where the majority of leprosy-affected persons live. There have been attempts to introduce rehabilitation as integral part of Primary Health Care (PDC) services, but this remains a challenge for most developing countries.

Other recent developments

Organizations working in the field of disability and development have long been promoting the active involvement of beneficiaries in all aspects of project activities, starting from identification of needs, definition of strategies, activities implementation and their monitoring. Traditionally, projects dealing with rehabilitation of leprosy-affected persons often continue to be managed by professionals with no or limited experience of leprosy-affected persons. This is gradually beginning to change and needs to be further reinforced.

The launching of new associations representing leprosy-affected persons, for example IDEA International and its country organizations, has helped in focussing more attention towards other aspects of leprosy-related issues, including the use of specific terms by leprosy professionals (for example, using the term leprosy-affected person rather than ex-patient, and not using terms like leprosy victim or leprosy sufferer).

The enormous gains made by many leprosy control programmes in eliminating leprosy as a public health problem present special opportunities for existing vertical leprosy staff and infrastructures to promote new activities for physical, psychological and socio-economic rehabilitation for leprosy-affected persons and for persons with disabilities.

Areas of future action

It may not be realistic to expect national leprosy control programmes suddenly to show greater interest and initiatives related to rehabilitation needs of leprosy-affected persons. Though attempts to promote holistic rehabilitation of leprosy-affected persons have had limited impact up to now, there are four specific areas in which leprosy-related projects and organizations can make significant contributions in the coming years:

- Reviewing their existing strategies for POD and socio-economic rehabilitation, including definitions of simple indicators for measuring their impact.
- Defining new strategies of information and capacity building aimed at primary health care personnel for promoting rehabilitation activities.
- Advocacy and awareness creating among CBR programmes and NGOs operating in the field of general development, about the needs of leprosy-affected persons.
- Promoting greater participation of leprosy-affected persons in all activities and strengthening their organizations.

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Editorial

IMPLEMENTING GUIDELINES FOR SOCIO-ECONOMIC REHABILITATION

Social and economic rehabilitation of people affected by leprosy is now a major priority. Social and economic rehabilitation (SER) programmes that benefit people affected by leprosy already exist in many countries around the world. They differ in content and in context. While poverty is a common factor, they face different challenges and opportunities. Can guidelines be of help?

The Guidelines for Socio-economic Rehabilitation reproduced in this issue have sought to identify the broad principles and approaches that have been found to work in existing, successful SER programmes. These guidelines provide individuals and organizations with the information and tools they need to ensure project activities are appropriate and of real benefit to those in need. The guidelines provide sensible help and ideas for those starting a new project as well as for those already involved in SER activities. The guidelines will prove to be practical and effective, since the contents have been distilled from the contributions and experience of those actively involved in the field.

Leprosy control programmes are increasingly recognizing the importance of SER as a vital aspect of leprosy work. There is now the opportunity to develop new areas of expertise. New skills are needed, new approaches have to be tried, and new alliances have to be made. It is important to seize the opportunity and adopt new approaches that benefit those in need and enhance their dignity.

It is important to reflect on the experience of others before applying their conclusions in a new situation. These guidelines bring together a wealth of experience in one document. They will generate new ideas, encourage new approaches and promote the sharing of information among all those involved in the field. They also serve as a source of personal encouragement to all those seeking to bring an improved quality of life to those whose lives have been affected by leprosy.

The development and publication of these guidelines is an important step forward, but it is only the first step. The next steps are the dissemination and implementation of the guidelines, these are two different aspects. Dissemination is a logistical challenge as those who would benefit from them work across the globe and often in remote areas. Follow-up of previous guidelines in leprosy often reveals the field workers at grass roots level have no access to these publications. This can be for a number of reasons; they get held up at some place, there

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are no resources to post them out within countries and they are left on shelves or put in libraries and never used.

However, dissemination is not implementation. Implementation is a further step that requires that the guidelines are read and that they result in appropriate behaviour change. Guidelines have been developed and disseminated for a wide range of health and medical programmes and they all have the same challenge of implementation. There needs to be advocacy by funding organizations, programme managers and opinion leaders for the guidelines to be implemented. This can include workshops and educational seminars, target setting or the requirement that the guidelines are used for programme planning and reporting. The publication of the guidelines in this special issue of *Leprosy Review* along with a series of papers and reports is aimed at promoting the use of these guidelines in field programmes. There also needs to be a felt need, a demand for the guidelines from field staff and those who do not have access to a copy should contact ILEP immediately¹ to request a copy.

The authors of the guidelines on socio-economic rehabilitation are to be congratulated on the development and production of these SER guidelines. However, this is only the first step; the next step is to ensure dissemination of the guidelines to all relevant field staff. Following the dissemination is the implementation of the guidelines to improve the quality and quantity of socio-economic rehabilitation. The final step will be to evaluate their effectiveness.

Reference

¹ The Guidelines on Socio Economic rehabilitation can be obtained free of charge from ILEP. Requests can be sent to ILEP 234 Blythe Road, London W14 OHJ, UK. Tel. +44 (0)20 7602 6925, Fax +44 (0)20 7371 1621, e-mail ilep@ilep.org.uk. Orders can also be made directly from the TALMilep pages of the ILEP Web site www.ilep.org.uk

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SPECIAL ARTICLE

Guidelines for Social and Economic Rehabilitation

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Chapter	Focus	Intended readership
1 Understanding Social and Economic Rehabilitation	Concepts, definitions and general principles; operational principles; how to identify an appropriate programme response	Senior managers, project leaders and managers
2 Managing Social and Economic Rehabilitation	Organizational culture and structure; the project cycle and project planning; monitoring and reporting; recruiting and training staff	Senior managers, project leaders and managers
3 Managing and supporting field activities	Community relations; advocacy and local associations; special needs groups; vocational training centres; local needs; micro-credit programmes	Project leaders and managers, senior field-level staff, rehabilitation officers and social workers
4 Field experience	Transactions between field staff and clients; the selection process; psychological needs and skills assessment; motivation, vocational and other training; interventions; action plans; expanding the work	As above
5 Assessing impact	The role of indicators in assessing change; identifying and using indicators	As above
6 Case studies and discussion material	Case studies and discussion material intended for training purposes or to promote new thinking	Staff at all levels
7 Getting started	Practical application of the guidelines and recommendations for real-life scenarios	Senior managers, project leaders and managers
8 References, resources and resource centres	List of contributors, publications, resource organizations, training centres etc	Senior managers, project leaders and managers

Introduction

Leprosy is one of the oldest diseases of mankind and has a unique social dimension. In both eastern and western cultures, fear of the disease has existed from ancient times. In no other disease have individuals been made to leave their families and communities and forced to live as outcasts in separate colonies or settlements. For many of the men and women affected by leprosy, simply overcoming the infection is not sufficient to allow a straightforward return to their previous life-style. The World Health Organisation estimates there are some 2–3 million people worldwide with significant disability due to leprosy.

Until recently, those abandoned by their families were cared for in institutions which provided care and shelter. Since the treatment lasted for many years, they were kept in the institutions as permanent residents. They were engaged in different occupations like agriculture, animal husbandry, weaving and tailoring. Such an approach was considered 'rehabilitation'. Yet in that system, individuals became totally dependent on the institution for survival. There was no possibility of restoration or reintegration within family or community.

With the advances in treatment procedures and surgery, this institution-based 'rehabilitation' has become outdated. Through social and economic rehabilitation, people cured of leprosy are helped to regain their place in the community. 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. Family and community support the rehabilitation process.

Social and economic rehabilitation is a unique task. The approach may not be duplicated between places or even from one person to another. The guidelines for social and economic rehabilitation have been formulated as a response to the complexities of the work.

Through the experience and knowledge of those involved in the field, it is hoped that interested persons and institutions may recognize the elements of best practice and go on to provide a better service to those in need. The cure for leprosy remains incomplete until the people affected regain the social and economic status that allows a dignified life.

How to use these guidelines

In preparing these guidelines for Social and Economic Rehabilitation, our intention has been to provide information and advice to managers and field staff at all levels and in a wide variety of projects. The earlier sections are intended for senior managers concerned with definitions and strategic issues. The later sections will be of more interest to staff in the field. There are suggestions for group work and training sessions that will make the material accessible to the widest possible range of staff. The material presented here will also be of interest to people involved in Community Based Rehabilitation.

1. Understanding social and economic rehabilitation (SER)

This chapter describes the developments that led to the current interest in the rehabilitation of people affected by leprosy. There is now a clearer understanding of priorities and of

appropriate ways to respond; three general principles are identified. The context for the work is the broader impact of leprosy. The focus must be upon the concerns of people affected by leprosy and their families and communities. The various approaches adopted by current programmes are used to demonstrate operational principles recognized as important in rehabilitation. Issues that need to be considered when developing strategic aims and objectives are identified.

The chapter is intended for the leaders of organizations considering a first involvement in SER or seeking alternative approaches in their existing work.

1.1. UNDERSTANDING THE NEED

Between 1989 and 1999 more than 10 million people were cured of leprosy. Multi-drug therapy (MDT) has ensured that most have avoided impairment, but there remain an estimated 2–3 million people with significant disabilities caused by leprosy. To a greater or lesser extent they have experienced the stigma associated with the disease for centuries, the fearful attempts at concealment, the trauma of increasing impairment. Although many people are resilient enough to cope with the effects of leprosy, others need help if they are to resume their previous way of life. These individuals are the focus of SER programmes.

The scope of the rehabilitation process is now better understood. In his Editorial, Dr Gopal describes the historical approach to rehabilitation. While treatments were largely ineffectual, there was little chance to restore the previous quality of life. The introduction of MDT has had a major impact on all aspects of leprosy work, including rehabilitation. It is now recognized that rehabilitation is possible, but the sheer complexity of the physical, psychological, social and economic impact of leprosy makes the task difficult. People who have relied on welfare for years may have become dependent, unaware that there is an alternative and they might return to an earlier lifestyle.

The challenge to organizations is to find an approach that is caring yet encourages people affected by leprosy to manage their own lives in the community. The attitudes of family and community are a further challenge in formulating an appropriate response. Speaking at the ILA Conference in Beijing in September 1998, Dr Arole, Director of the Jamkhed Project in India,¹⁸ identified the principles upon which that response should be based:

A change of paradigm is needed, recognizing 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's vision of programmes that give priority to the needs and skills of individuals and are at the same time responsive to the views of the community is fundamental to successful rehabilitation and to these guidelines.

The approach to SER should therefore be based on three principles:

1. A recognition of the broad impact of leprosy on the individual; in other words, its physical, psychological, social and economic effects.
2. Responsiveness to the concerns of individuals affected by leprosy. This requires an approach that restores dignity and self-respect; in other words, participation and empowerment.
3. Sensitivity to the concerns of the families and communities affected by leprosy. Members of the family and the community have an important role to play in rehabilitation.

These principles underlie many existing SER programmes, although over the years local

priorities may have evolved in addition. Broadly speaking, the objectives are the restoration of dignity, increased economic independence, the reduction of stigma and the achievement of integration. SER recognizes the importance of the community and the relevance of poverty. It pays attention to groups with special needs, specifically children, older people and women.

The relative weight given to these factors by different projects has resulted in the wide variety of current SER programmes. Yet most projects would agree with this concise statement of aims made by one contributor: 'To live as a useful, self-supporting member of community'. By speaking of social and economic self-reliance and adding the idea of usefulness, this phrase neatly embodies the principles of SER.

1.2. OPERATIONAL PRINCIPLES AND PRACTICE

The wide-ranging impact of leprosy on the individual and the social and economic differences between the communities in which it is found have led to a great diversity of rehabilitation needs. However, it has been possible to identify a number of common principles, six of which will be discussed here:

- The holistic principle
- The participatory principle
- Sustainability
- Integration
- Gender sensitivity
- Sensitivity to special needs

Elements of all six will be present in most SER programmes.

The holistic principle

As used by development workers, 'holistic' means an awareness of, and responsiveness to, every aspect of life. In these guidelines, this means a concern for the physical, psychological, social and economic well-being of people affected by leprosy. Holistic programmes include activities that address each of these aspects, and thus require teamwork by professional staff from a variety of backgrounds. SER activities may be linked to leprosy treatment, prevention of impairment and disability and leprosy control, with arrangements for cross-referral. Immediate access to newly diagnosed cases gives SER workers the chance to minimize the impact of the diagnosis and start rehabilitation at the earliest possible moment. Stigma is tackled either through local education or by advocacy work up to the national level.

Example: In one project in Ethiopia, SER work focuses on the members of self-care groups in villages. It seeks to widen their activities through functional education, and encourages the setting up of small projects that benefit members of the group and the local community.

The participatory principle

Respect for, and responsiveness to, the voice of the client is central to rehabilitation. You should give special attention to people whose self-esteem has been eroded by leprosy, actively involving them in decisions about improving their quality of life. This leads to 'empowerment': the ability of the client to make decisions and manage the transactions of everyday life. Unless clients are enabled to 'own' the process of rehabilitation, they will not

be fully committed to it. Members of the family and the community can be involved in the process, as may associations of people affected by leprosy (8.1 lists publications on related development issues).

The participatory principle has far-reaching implications. It enables people affected by leprosy to give their own views about project activities and suggest their own outcomes; it also questions traditional assumptions. The organizational implications are discussed in 2.1 and the implications for staff recruitment and training in 2.5. Social audit may be used to assess the organization's responsiveness to clients (see 2.4)

Example: In Ethiopia, staff organized a discussion to find out what a group of women wanted to do. Four of the women decided to start a food processing business. After some early difficulties, they eventually rented a shop and employed a shopkeeper. More women have joined in since then, and now 24 of them are involved and earn a regular income.

Sustainability

This means activities that bring lasting benefit. A community-orientated approach ensures that interventions to help people affected by leprosy are acceptable to the community and benefit other people. Active support from the community may not be essential, but acceptance certainly is. Encouraging support from the client's family makes for a sustained benefit. Direct involvement of family and community members and sharing of benefits further increases sustainability. Responsiveness to environmental, seasonal and market factors is also important.

Example: A regular income can often bring respect and overcome stigma. In India, several projects work through vocational training centres and job placement, helping clients to find permanent paid employment. Where job opportunities are more restricted, some organizations provide employment in their own workshops.

Integration

Rather than creating special services for people affected by leprosy, you should use existing services provided by other organizations for the whole community. You will need to set up referral systems and negotiate access to services. You could also fill gaps in the services provided by others: for example, by providing training courses in fieldwork techniques or in leprosy awareness. This approach makes the best use of available services and resources. National plans for co-ordinating services to people with disabilities may require the integration of all leprosy-related services.

The integrated approach is particularly appropriate in situations where the proportion of people affected by leprosy is low or where health and voluntary services are well developed. It avoids the discriminatory effect of setting up services solely for one group of people and benefits from the expertise in the wider world of disability services, especially community-based rehabilitation (CBR). Publications about CBR are listed under 'Health care' and 'Rehabilitation for people with disabilities' in 8.

Examples: In Nepal, the Release project recognizes a wide range of disabilities and works with other NGOs in the field. In Tanzania, Uganda and Egypt, government programmes and CBR are integrated in a national plan for services to people with disabilities.

Gender sensitivity

To date, little attention has been paid to the need for a gender-sensitive approach to SER, and projects have often been biased in favour of men. In fact, leprosy can have a greater impact on women, as they are more likely to face exclusion from the family or the community. You must ensure that women enjoy equal access to services and participate actively at all stages. Gender sensitivity is also important in the recruitment and training of field staff. In general, projects should pay more attention to the circumstances of women, what they do and what they are.

Example: Workers in Tanzania recognized that leprosy had a quite different psychological impact on women than on men. They therefore improved the gender awareness and responsiveness of their work; one immediate result has been the appointment of more women staff.

Sensitivity to special needs

In addition to women, many other groups, such as children and older people, have special needs. Differences of language, culture, religion or location may be significant. You should identify these needs and the activities that can respond to them.

Example: In 3.4 there is an example that describes the needs of children affected by leprosy, identifies risk factors and suggests a programme response.

These operational principles are neither exclusive nor optional. You must consider whether they are relevant to your own priorities and to local needs.

1.3. DEFINING THE TASK

My education came from the people affected by leprosy themselves . . . it is still continuing.

Contributor to the guidelines

This subsection describes how you can collect and analyse the information needed to prepare a statement of strategic aims and objectives.

There are five main objectives:

1. To discover the number of people affected and the level of individual need.
2. To understand the community and its needs, and to identify the physical, social and other constraints in the local situation.
3. To identify an appropriate response, taking into account any special needs.
4. To estimate the likely requirements for skills, materials and funding.
5. To secure the commitment of donors and local authorities.

You should collect information in an open-minded way, giving priority to the views of people affected by leprosy and their families and communities. Rather than relying on a simple questionnaire, use a range of different methods: for example, observation, comparison and noting the response to pictures and diagrams. For such purposes, development workers prefer to use Participatory Rural Appraisal (PRA); see 5.4.

Careful analysis of this information will provide a secure basis for planning and ensure that activities are appropriate to the local situation.

Estimating the need

The first step is to estimate the number of people who are affected by leprosy and need help with rehabilitation. Figure 1 shows how the WHO terminology can be used to describe the

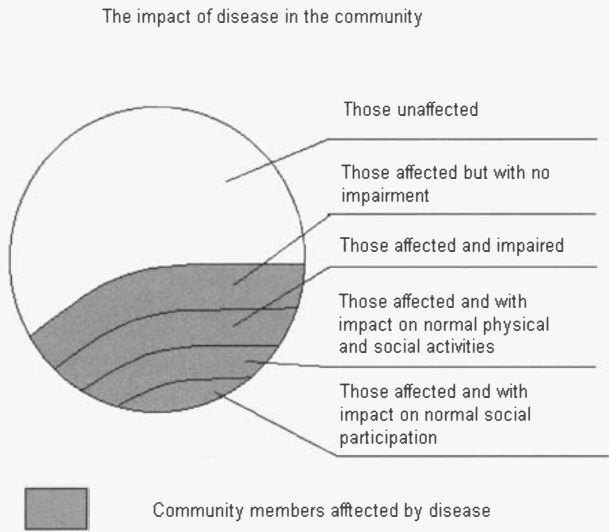


Figure 1. The impact of leprosy.

impact of leprosy and Figure 2 shows that not everyone will need help. Dr Gopal recommends that the people affected be divided into six categories:

1. Those with no physical disability and no social or economic problem.
2. Those with physical disability but no social or economic problem.
3. Those with no physical disability but with social or economic problems.
4. Those with physical disability whose social and economic life are under threat.

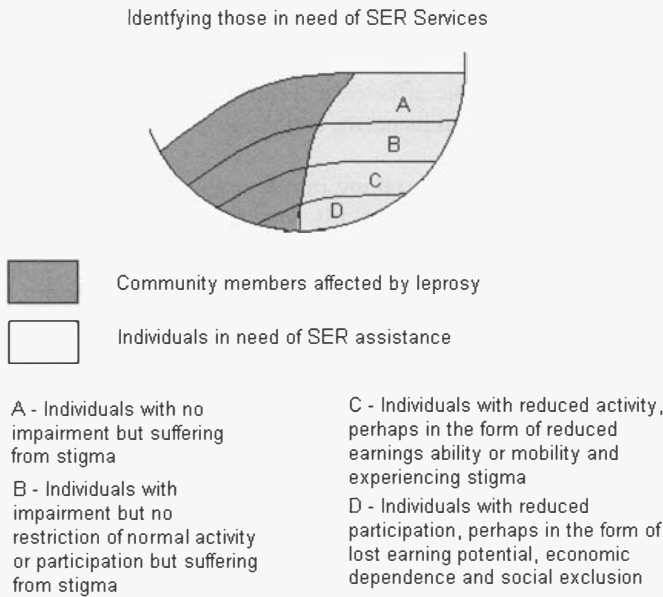


Figure 2. Those in need of SER.

5. Those with physical disability whose social and economic life is already dislocated.
6. Those who are aged, suffering long-term dislocation and in a state of destitution.

People in categories 1 and 2 do not need help with social and economic rehabilitation. Those in category 3 may need counselling and psychological support, and will benefit indirectly from programmes that tackle stigma in the community. Those in category 4 and 5 are the primary targets of SER. You may need to concern yourself with people in category 6 and acknowledge the need for an appropriate welfare programme.

A survey of people affected by leprosy will give some indication of the numbers in each category. Choose a few individuals and talk to them about the impact of leprosy on them and the range of their needs. Use this information to help you identify priorities for the proposed programme.

Community needs and physical and social constraints

The psychological, social and economic effects of leprosy are largely determined by the community's attitudes towards the disease. These attitudes will vary from place to place, so you must talk to key local people who can outline the concerns of the community. Identify any special needs groups. Explore the significance of gender. Find out about the local terms used to describe leprosy: some may have negative connotations while others may be socially acceptable (see 3.1 and 3.2).

Physical constraints on the project will include the distribution of the local population, the nature of the physical environment, and the availability of transport and communications. These are important for access, meetings, follow-up and estimating costs.

Deciding upon the response

If there are large numbers of people affected by leprosy and no existing services, you may be justified in creating an entirely new programme. But if the numbers affected are small and/or health services or services for people with disabilities already exist, you should concentrate on filling gaps and ensuring that people affected by leprosy get access to services.

Decisions must also be taken about the level of participation. You should consider the resource implications of the holistic approach, as well as those of sustainability, gender sensitivity and special needs. The organization will also have its own priorities, preferences and experience to take into account.

Skills and resources

The most important need is for trained staff. Will it be possible to find social workers, project officers, financial controllers and managers willing to work in the area? Local staff may need to be trained; people with experience of other organizations will be particularly valuable. You should compare alternative approaches to the work in terms of the personnel, administration and finance they might need.

Authorization and funding

It is vital to find as early as possible a donor prepared to fund the proposed work. You may need to prepare case studies and outline proposals to persuade a donor to commit resources.

Mission statement

To facilitate physical, psycho-social and economic restoration of people with disabilities or social handicap in partnership with affected people and communities.

Project focus

To provide assistance for people of all ages, races, religions or sexes with different types of disability and to work with the community to create positive attitudes, for the participation of community members in rehabilitation activities and to enable communities to assist their people with disabilities. To maximize physical abilities, to gain access to all services and opportunities available to the general population and to achieve full social integration within their communities.

Figure 3. Examples of mission statement and project focus.

At an early stage you should also seek authorization from local authorities and some indication of the availability of local funding.

Statement of strategic aims and objectives

On the basis of the information you have accumulated, you should now be able to write a statement of your strategic aims and objectives: in other words, a mission statement. In Nepal, this is a statement of principles (see Figure 3) that provides the basis for more detailed planning.

The ILA Congress in Beijing identified five objectives for organizations involved in SER. These move the focus of interventions beyond the individual towards the broader issues of rights, the role of health professionals and the effective use of resources:

1. Equality of rights for people affected by leprosy.
2. Better understanding of the need for rehabilitation.
3. More attention to psychological, social and economic rehabilitation using a holistic approach.
4. More sensitivity among health workers to the need to empower clients.
5. Improved co-ordination between organizations to make best use of scarce resources and skills.

Analysis of the local situation and preparation of a mission statement will allow you to prepare a document that will guide your further planning. The next steps are to consider in detail the implications of the work for your organization, to identify your objectives and prepare a project plan.

1.4. SUMMARY

Understanding the need

- Among people affected by leprosy, those unable to support their families or maintain their former standard of living will be the focus of SER activities.
- The needs of an individual may be physical, psychological, social or economic.

- Responsiveness to the needs and skills of an individual promotes dignity.
- Responses must be sensitive to the views of family and community.

Operational principles and practice

- Six operational principles are recognized: the holistic principle, the participatory principle, sustainability, integration, gender sensitivity and sensitivity to special needs.
- The local situation and organizational constraints will determine the priority you should give to each of these principles.

Defining the task

- Assess the impact of leprosy: the number of people affected and the level of individual need.
- Find out about the community, its social and economic status and its needs.
- Understand the physical, social and other constraints on your action.
- Choose an appropriate form of response.
- Identify the needs for skills, resources, materials and funding.
- At an early stage, ensure that funding is available and your intervention is acceptable to the local authorities.
- Prepare a statement of broad aims and objectives to guide your detailed planning.

2. Managing SER

This chapter is concerned with the organizational implications of SER. It explains the need for an organizational culture based on listening and learning, and the implications this has for leadership and decision making. There is a discussion of planning and the procedures for monitoring and reporting. Finally, there is a subsection on staff recruitment and training.

The chapter focuses on aspects of management relating specifically to interventions in social and economic processes, and hence will be of interest to senior and project managers.

2.1. GETTING ORGANIZED

This subsection shows how SER requires an organizational culture that responds to information from the field and a leadership style based on delegated decision-making and teamwork.

Organizational culture

If the concerns of clients and the views of the community are to carry any weight, there must be good communication between the project, the client and the community. There should also be good communication within the organization and teamwork between staff at all levels.

For these reasons, a ‘listening and learning’ approach will be a recurrent theme in these guidelines. Such an approach requires a reversal of traditional management practices: managers must learn to respect the experiences of clients, field staff and other professionals. Listening must be seen as an essential way of creating understanding and generating knowledge. Learning involves a willingness to change priorities or to

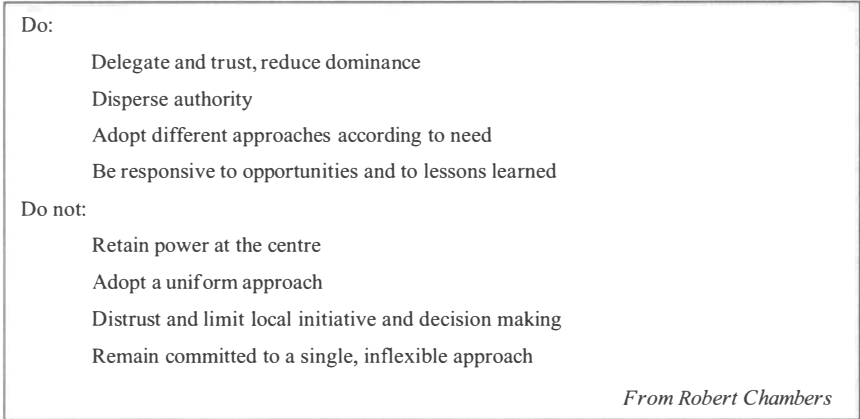


Figure 4. Reversal of priorities.

reconsider long-standing assumptions. In Figure 4 Robert Chambers summarizes aspects of management that need to be reassessed to shift the focus on to the client.

Figure 5 shows the complex flows of information that occur within the Listening and Learning approach. Such communication does not just happen: listening skills need to be developed, particularly in identifying what is important.

An organizational structure that devolves responsibility to field managers is preferable to a strongly hierarchical arrangement. Field managers and social workers monitor the progress of fieldwork, maintain relations with the community and share information with other organizations. Field assistants are directly involved in assessment and motivation, and make referrals to social workers when their help is needed. The work must be based upon mutual respect and upon supportive procedures that provide the necessary control without restricting the flexibility of response. Section 8 lists publications that discuss organizational competence and sustainability.

Leadership

Project managers must have extensive field experience and good qualifications, as these will provide the basis for effective delegation. Those who lack experience may feel threatened and retain power for themselves. A tightly controlled structure stifles initiative and responsiveness in the field. The goal should be an open management style that encourages the development of diverse skills and ideas.

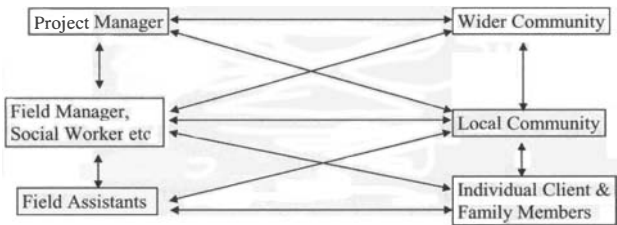


Figure 5. Channels of formal and informal communication.

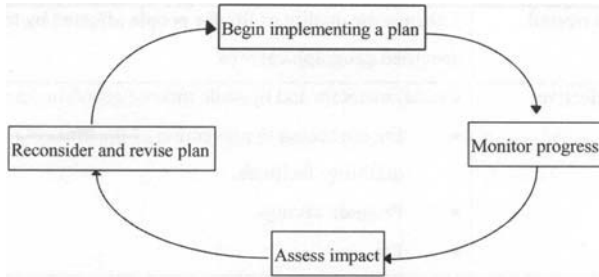


Figure 6. The project cycle.

Project cycle

Adopting a project cycle involves successive rounds of planning, implementing and reviewing which ensures that your organization responds to information from the field. A periodic review gives you the opportunity to discuss recent successes or failures and apply the lessons learned (Figure 6). This enables you to start small and build upon the approaches you find to be successful.

At field level, some organizations review the progress of individual clients at monthly intervals, others do so quarterly. Field managers may look at the effectiveness of different programme elements less frequently, perhaps once or twice a year. Rather than being seen as an ‘add-on’, this cyclical review process should become an integral part of project monitoring (see 2.3).

2.2. MAKING A PLAN

The purpose of a project plan is to provide answers to these questions

- Who is to benefit?
- What should be done?
- How is it to be done?
- When is it to be done?

In general, planning for SER is no different from planning any other programme, except for the following three complications:

- Leprosy has a complex impact on the people affected, requiring multi-disciplinary responses for each individual.
- The attitudes of the local community often mean that affected people are stigmatized (and indeed, often stigmatize themselves). Programmes should address the needs of communities as well as individuals.
- The potential for sudden physical deterioration requires close co-ordination with prevention of impairment and disability activities and careful follow-up.

Preparing a project plan involves making a clear statement of every aspect of the proposed work. This is not just to meet the requirement of donors or government—it is essential if the project is to work. A comprehensive plan provides the basic information needed to carry out staff recruitment, project activities, monitoring, reporting and evaluation.

A structured approach to planning, paying attention to detail, is preferable to an unstructured approach and donors prefer it. The methods projects can use include the Logical Framework or Goal Oriented Project Planning.

Strategic or overall objective	Enhance the quality of life for people affected by leprosy in a specified geographical area
Specific objectives	Create, maintain and upgrade income generating activities. <ul style="list-style-type: none"> • Ensure access to prevention of impairment and disability facilities. • Promote savings • Etc.
Strategies	Work with organizations providing income generating and CBR services. <ul style="list-style-type: none"> • Form groups and encourage savings. • Provide follow-up service. • Etc.
Activities	Select clients. <ul style="list-style-type: none"> • Provide loans. • Create database for use by clients. • Hold review meetings. • Etc.

Figure 7. A plan for Community Based Rehabilitation activities in Ethiopia.

It is important to understand the meaning of the technical terms used in project planning: Figure 7, which describes a CBR programme in Ethiopia, gives some examples.

The time and effort that goes into preparing a plan can give it an almost sacred status, defying all possibility of revision. But SER projects must be flexible, ready to react to the lessons learned and the opportunities that arise. Plans for such projects should therefore emphasize methodology rather than specific activities and make it clear that priorities can change in response to practical experience. Donors should be kept informed of any significant changes.

2.3. MONITORING PROGRESS AND REPORTING

Monitoring project activities and progress produces information that feeds the review process project cycle described in 2.1 (Figure 6). To be of any value, it must result in decisions and actions. In a well-designed system, information generated at field level should be circulated widely within the organization and also externally.

Monitoring may also be applied to internal processes, such as the selection of clients or the performance of staff. Rather than carrying out monitoring through separate Monitoring and Evaluation Units, you should make it an integral part of field activities, owned by and managed in the field.

The key questions you should ask when assessing the monitoring and reporting requirements of the project are:

- Who needs to know?
- Why do they need to know
- When do they need to know?
- How much do they need to know?

These points are expanded below

Who needs to know? Monitoring systems are too often biased towards the needs of senior managers and donors; field staff do not always see the benefit of collecting data. So when listing the people who need information, do not forget the people within the project—project leaders, field managers and field staff—as well as those outside. Reporting to clients and advocacy organizations shows your respect for their commitment and encourages their involvement.

Why do they need to know? To be of real benefit to the project, monitoring and reporting should be designed to meet the needs of people directly involved in the field. Talk to the field staff and list the type of information they ask for. Traditionally, monitoring has focused on whether the project is carrying out the activities promised in its plan and is managing its budget properly, but you should also monitor the impact of the project on clients: for example, using the impact indicators identified in the Log Frame.

When do they need the information? For internal purposes, the reporting cycle may be monthly or quarterly. For external reporting, the cycle may be 6 monthly or annual (as in the case of ILEP B Questionnaire).

How much do they need to know? The minimum required for effective action: don't collect data for a 50-page report if a four-page report will do!

You will now need to find out where the information is and how you can gain access to it. Much of the data on activities and finance will be contained in the records kept by field staff and accountants, but information on processes such as empowerment and participation may be more difficult to collect. Chapter 5 describes how this can be done.

The information obtained through monitoring should be discussed as part of the review process, first at field level and then in summarized form by management. It should inform field staff about progress and enable them to identify successes and failures. This is essential for planning and for improving the effectiveness of the project.

On whose behalf should monitoring be carried out? In the procedures described above, the interests of the staff and the project have priority, yet the participatory approach to SER insists that the interests of the client be taken into account too. Participatory Monitoring and Evaluation meets this requirement by ensuring that clients are actively involved in the monitoring process and that their view on progress carries weight. The Most Significant Change programme described in 5.2 describes such an approach in Bangladesh.

2.4. EXTERNAL EVALUATIONS

At infrequent intervals—perhaps twice during the funding period—donors and others will wish to review the progress of a project and the effectiveness of the organization implementing it. These evaluations, which may involve project staff, visiting specialists and clients, are intended to serve as a learning process, with the findings shared in full with the project. The donor will be concerned about financial controls, management systems and cost effectiveness, as well as the impact of the work as set out in the Terms of Reference for the evaluation.

A monitoring and reporting procedure as described in 2.3 will provide some of the information needed for an external evaluation. It will allow the organization to demonstrate its responsiveness to lessons learnt in the field and to answer the donor's questions about impact, working relationships and the capabilities of staff.

Some organizations adopt as a strategic aim the recognition of people affected by leprosy

as partners in their work. Social Audit is the method by which an organization assesses its progress towards this objective: it analyses the relative importance attached to the concerns of all the parties involved and assesses how far this enables the voice of the client to be heard first.

2.5. RECRUITING AND TRAINING STAFF

SER demands a wide range of skills from project staff. There are roles for many different professions. Formal qualifications and specialized skills are highly valued. Relevant experience is important. Yet all these will be ineffectual if the member of staff concerned does not know how to be respectful and responsive towards clients. Where staff recruitment is concerned, therefore, selection, induction and ongoing training take on particular importance.

Most organizations prefer to recruit field staff from the local community. They know the local culture and language, and have access to the community. Employing people who are themselves affected by leprosy adds an extra dimension of experience and understanding, enriching the relationship between staff and clients. Supervision can be provided by a small number of professionally-qualified staff who provide training and use their expertise to support the field staff. Irrespective of professional status, certain qualities are needed in all staff:

- Respect for and responsiveness to clients, demonstrated in a willingness to accept their participation.
- Good communication skills.
- Ability to work in a multi-disciplinary team.
- Staff with professional qualifications must be good teachers, willing to share their skills with others.
- Gender sensitivity.
- Ability to make sound decisions in a participatory environment.

These requirements are difficult to meet: many new staff start out with considerable commitment but their enthusiasm falls away as they realize the demands of the work. The following methods of support should help to prevent this:

- An induction process for all staff. This should involve several weeks of training, particularly in listening and communication skills and in the organization's values. Some recruits will drop out during the induction process as they become aware of what the work will be like. Staff may be sent for training at one of the centres listed in 8.3.
- The contents of the training should include: 'how to' information; best practice as defined by the project; gender sensitivity; sensitivity to other special needs; availability of resources, etc. Information about social work in leprosy can be found in the publications listed in 8.
- On-the-job training refreshes existing skills and adds new ones. Suitable training courses or training material may be available locally from organizations outside the leprosy sector.
- Supervision and reporting lines are needed. You should prepare work plans for each staff member and compile a procedures manual; special arrangements may be needed in remote areas where access to field staff is difficult.
- Some organizations carry out a regular performance review of each staff member and set personal goals.
- Overall responsibility for each client must lie with a nominated staff member.

2.6. SUMMARY

Getting organized

- Create a listening and learning organization, one in which the voice of the client is heard and respected.
- Structure the organization to allow for delegated decision.
- Adopt a leadership style that is supportive rather than restrictive, and which encourages local initiative.
- Commit yourself to a regular review of plans and be prepared to respond to lessons learned in the field.

Making a plan

- A formal plan provides the structure needed to describe every aspect of a project in detail.
- Describe objectives and desired outcomes. Identify the activities needed to bring about change. Prepare plans and budgets for each part of the project.
- Plans should emphasize the responsive nature of the work.
- Keep donors informed of significant changes.

Monitoring progress and reporting

- Keep monitoring to the minimum required to meet the need for information.
- Plan monitoring to meet specific internal information needs.
- Ensure that clients participate in monitoring.
- Use the information obtained as the basis of regular reviews, and make sure that these lead to positive action.
- Make information available in summary form for wider circulation.

Recruiting and training staff

- Appoint professionally-qualified staff to key positions.
- In the field, rely on the knowledge and skills of local people specially trained for the task.
- For staff at all levels, a respectful and responsive attitude towards clients is essential.
- Identify local training centres and materials. Be aware of the training offered at internationally recognized centres. Make sure staff receive the initial and on-the-job training they need.

3. Managing and supporting field activities

This chapter looks at project activities in general: that is, those not related to individual clients. You will need to tackle the problem of stigma; this may involve advocacy and the encouragement of local associations. Maintaining good relations with the community helps to create the right environment for work with clients. You should be aware of groups with special needs, such as children affected by leprosy and those in need of re-housing. The chapter discusses resources such as vocational training centres and micro-credit programmes. Project managers must also be aware of local issues—such as religious beliefs, traditional customs and attitudes to co-operative work—and their relevance to rehabilitation.

This chapter will be of interest to staff who manage at field level as well as to senior managers.

3.1. ADDRESSING STIGMA AND INJUSTICE

Stigma is the chief cause of the social and economic dislocation that people affected by leprosy experience. Overcoming such stigma is an essential step towards reintegration in society. Part of the response is to increase the self-confidence of the individual (see Chapter 4). This chapter is about addressing the community's attitudes towards leprosy, particularly those of long standing. Typically, people affected by leprosy are denied access to festivals, markets, employment and the local water supply. Their children may be denied schooling and later, be forbidden to marry. This results in social exclusion and economic dislocation.

In many cases, the people affected by leprosy hold the same traditional prejudices themselves, and dread the impact of the disease on their lives. The same attitudes are evident at national level, with institutional prejudice against leprosy, the barring of access to public services and other such injustices. You will need a full understanding of the nature of stigma before you can plan a strategy to tackle it; the process of 'self-stigmatization' requires particular attention.

Overcoming stigma

Tackling stigma brings benefit to everyone affected by leprosy, whatever their level of impairment, activity or participation. At the local level, you should concentrate on overcoming the ignorance and prejudice that underlie stigma. This can be done by running education campaigns targeted at key individuals or at the whole community. Activities may include exhibitions, leafleting and drama, taking place at local markets, public meeting places, health centres and schools.

Attitudes will also change if the community is involved in helping a person affected by leprosy (Figure 8). The involvement of professional people with a client can have a similar effect. Activities may be aimed at improving the knowledge of health professionals. Many projects organize special events each year to mark World Leprosy Day.

Advocacy

Many projects get involved in publicising the injustices experienced by people affected by leprosy and in working for their rights. You can use the available media and form links with

Acceptance by the community applies particularly to transactions such as buying and selling products and services. In the town where one project operated, the people used to avoid physical contact when they gave alms to people affected by leprosy. Now they can be seen rushing to a particular shop to buy vegetables and fruit that will be consumed raw: tomatoes, lettuces, cucumber, water melon, papaya. The customers know full well that these have been grown by people affected by leprosy -- but the difference is that they, the community, have taken part in the project.

Figure 8. Involving the community: a case study from Ethiopia.

local or national organizations concerned with leprosy and other disabilities. Bringing together people affected by leprosy into small groups or more formal associations has many benefits:

- It provides an opportunity to share experiences, develop new attitudes and acquire new life skills.
- It creates a public voice for the rehabilitation process and encourages participation.
- It develops confidence as individuals 'go public' about the impact of leprosy.
- It provides a powerful voice when confronting officialdom.

Such groups are most effective when the initiative comes from people affected by leprosy and when they reflect special needs: for example, women's associations.

Because of their differing perspectives, there is some potential for tension between such groups and the local project. But there is also the potential for beneficial partnership. The groups may be given training in leadership and money management, and encouraged to assume responsibility for advocacy. In some countries, groups extend membership to people with other forms of disability. Several countries have national organizations or co-ordinators for associations of people affected by leprosy or by other forms of disability.

3.2. THE IMPORTANCE OF COMMUNITY RELATIONS

If you can gain the respect of the community and maintain links with its members, they are more likely to accept your project's interventions.

In these guidelines, the term 'community' refers to households in the neighbourhood of the client that share access to a common resource (such as a water supply) or form part of a recognized unit such as a village. These communities and the client's family provide the context for all dealings between the project and the client (Figure 9). In some cases the client's family, workplace or religious centre (such as a church or a mosque) has an important role to play in rehabilitation.

For this reason, the project must maintain communication at various levels and encourage the maximum family and community support for the rehabilitation process. Even a small amount of community involvement will benefit the client. The project also benefits because it gains access to local knowledge and resources not otherwise available.

You should engage in three specific activities in the community:

1. Learn

- Find out about the community, its knowledge, skills and experience. In particular, try to understand attitudes to change: conservatism, fatalism, traditional beliefs.

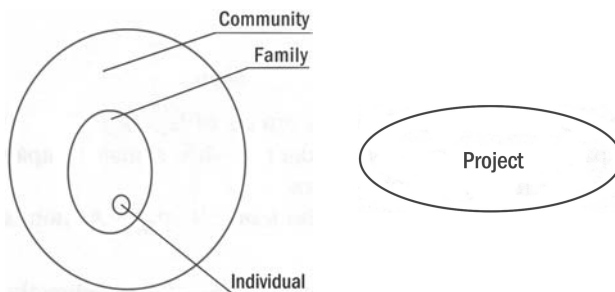


Figure 9. Communications between project, client and community.

- Identify key people—opinion-formers, teachers, religious leaders—within the community and draw upon their knowledge. Ask them about the best ways to reach the community.
 - Listen to the voice of the whole community, not just that of its leaders.
 - Invite suggestions from the community.
 - Monitor changes in public attitudes towards leprosy and the project.
2. Publicise
- Work to increase public awareness of leprosy, emphasizing the importance of reintegration into the community for people affected by the disease.
 - Enlist support for self-help or self-care activities.
 - Encourage communities to let clients take responsibility rather than set out to ‘do things’ for them.
3. Involve
- Involve members of the community in interventions—this ensures that solutions are acceptable and individuals are not excessively empowered.
 - Even if they are not directly supporting your project, keep community leaders and other important local people informed about it.
 - Maintain links with development activities that are addressing the needs of the whole community.

Maintaining good relations with the community is therefore a priority for field managers (see Figure 4). A two-way flow of information demonstrates that the project respects the community and its leaders. Regular public meetings or the distribution of written reports are ways of acknowledging the community’s support.

Community Based Rehabilitation (CBR) addresses the needs of people with disabilities in the setting of their communities, and SER projects should recognize it as a potential source of expertise and resources.

3.3. RESPONDING TO SPECIAL NEEDS

From time to time you will need to help groups of people with special needs. Older people may be particularly at risk. Those with no land or limited resources will be the most vulnerable to seasonal changes and the availability of work. Others may have special needs for improved housing or for resettlement. Others with special needs may include women or the residents of a leprosy colony. This subsection describes a typical response to a group with special needs, using children as an example.

The response consists of three steps:

- Identify specific needs.
- Identify risk factors.
- Identify the principles that must underlie your response.

Children are particularly vulnerable to the effects of leprosy:

- The loss of a parent—temporary or permanent—has a major impact on a child’s life style, role within the family and future prospects.
- Terminated friendships, exclusion from school or self-stigmatization can have a powerful psychological effect.

Needs will vary according to whether the child is directly or indirectly affected. Those at greatest risk include children who:

- Are from the poorest families.
- Have lost one or both parents, or are adopted.
- Are in institutions.
- Have had only limited education.

Plan your response to the special needs of children by:

- Finding out about the significance of children in the community. What is the public attitude towards them?
- Choosing an agreed national or local standard for your intervention: for example, the International Convention on the Rights of the Child or local conventions towards the family and adoption.
- Considering the urgency of the need and the likely effect of delay.
- Finding out which special skills will be required: for example, experience in working with children
- Obtaining access to the people and institutions that will enable you to meet the need: for example, community leaders, schools.

Since children provide future security for parents and elderly relations their needs are a high priority recognized in many cultures. Similar recognition should extend to the special needs of women.

Long-term needs

A variety of different approaches have been adopted to meet the special needs of people with chronic problems relating to leprosy:

- In Nepal, groups of two or three families have been resettled together to provide mutual support. Providing assistance with housing is a common element of many programmes.
- Faced with individuals who have severe disabilities and cannot work, some projects have shifted their attention to the next generations. They have found local schools for the children and provided vocational training for family members able to work. This focus on the family is a useful way of helping those least able to help themselves.
- People who have major disabilities and no family support may require permanent sheltered accommodation or continuing care. This must be seen as the most desirable outcome, although it is sometimes difficult to distinguish between those who really do need continuing care and those who have the potential to support themselves.

3.4. PROVIDING VOCATIONAL TRAINING

Many people affected by leprosy live in extreme poverty and have few opportunities to earn income. Some projects therefore focus on meeting these financial needs by setting up vocational training centres. This has been effective in situations where a regular income is sufficient to overcome stigma and enables an individual to be accepted by the community (the same is true of people whose disabilities have other causes than leprosy).

Access to vocational training and the availability of secure employment are clearly vital to the success of SER. Programme responses include:

- Running a training centre and integral production unit.
- Running a training centre delivering courses that meet local employment opportunities.
- Placing clients for training by the project or outside.
- Placing clients for outside training only

Where there are local training programmes or apprenticeships available the emphasis should be on vocational assessment and placement rather than offering training within the project. The number of clients and the existence of local courses will influence your choice of approach.

If you are proposing to set up a new centre, you should not underestimate the demands it will make upon your project and how dependent it could make you upon continuing funding. Vocational training centres require specialized skills to identify and prepare training courses and select trainees. There are issues of purchasing raw materials and marketing products. The local market needs to be closely monitored to ensure that training keeps up with changes in design, production techniques and raw materials. Financial management experience and strong entrepreneurial skills are essential. If the centre focuses upon training and there is little income from sales, it will need continuing funding.

Here are some other important points about vocational training:

- Selection for the centres is usually based upon referrals from local health service providers and may include people affected by other forms of disability. It is assumed that those making the referral will have carried out a vocational assessment.
- A quota system may be used to ensure that people from the wider community have access to the centres.
- Continuing follow-up is vital for success. Support may be provided in the form of loans to buy a house or start a small business. Other members of the family are also a potential source of support.
- The most usual way of assessing the effectiveness of centres is to report the percentage of graduates in settled employment after 1 year. Reputation and recognition of training are other indicators.
- Questions of access and the rights of clients may arise: for example, the issuing of driving licences to people affected by leprosy.
- Centres show a strong preference for local markets, thus avoiding the complexities of export or the need to respond to changes in materials, design or production in distant and poorly understood markets.
- The minimum age of trainees and the completion of their education are important points of good practice.
- Environment, safety, living conditions and security are also important issues, especially for young people.
- Centres provide training in life skills and money management; trainees are encouraged to open savings accounts.

Where clients are provided with work, it is common practice to give them loans for tools and raw materials or to improve their housing. These ‘micro-credit’ schemes are discussed in 3.5.

3.5. PROVIDING LOANS

Since supporting clients so often requires financial outlay, many projects provide loans through a micro-credit scheme: for example, a group may receive a loan to start a goat-rearing project, or an individual starting a small business may be lent the working capital. Although loans of this kind may already be available from local banks or development agencies, they may involve an interest charge or a service charge. Projects are keen to ‘revolve’ their funds:

they encourage borrowers to repay as quickly as possible so that the money can be made available to others.

Although it is common for SER projects to run their own micro-credit schemes, you should not set one up without first considering the implications. Managing a scheme is a demanding task that involves the detailed screening of applications, strict procedures, careful decision-making and the tracking of multiple financial transactions. Reporting requirements are complex. Some specific issues arise:

- Is micro-finance always appropriate? How much debt do applicants already have, and will they be able to repay? There may be better ways to address the financial needs of the poorest people.
- Do existing loan schemes charge a fair rate of interest? Do people affected by leprosy have access to them? What would be the impact of a new scheme or lower interest rates on other loan schemes in the area?
- Can the project handle the scheme? Are there legal restrictions? Does it have the management and financial skills? You should explore the past history of such schemes in the area.
- Is it possible to take a participatory approach towards loans, so ensuring 'ownership'? You can do this if you involve clients in decision making and monitoring.
- Decision making should be sensitive to gender issues and the special needs of other groups, ensuring equal access.

You must decide questions concerning the size of loans, the handling and distributing of funds, the rate of repayment, the encouragement of savings, the role of groups and co-operatives, etc, by reference to best local practice. The subject is discussed in more detail in publications by Oxfam and Intermediate Technology (see 8).

Where funding for loans is limited, assessing the potential impact will enable you to decide between applicants (see Example 2 in 5.4).

3.6. LOCAL ISSUES

In addition to the general themes discussed above, you will need to be aware of specific local issues that may affect rehabilitation.

Urban/rural differences

Where a project covers both urban and rural areas, there may be significant variations in community structures and attitudes to change. Your work must be responsive to local circumstances, particularly where the prioritization of needs and the perceptions of risk are concerned.

Groups or individuals?

In some countries there is general acceptance of the co-operative or group approach to rehabilitation. Elsewhere, experience with groups has been disappointing and the focus is on individuals; however, as programme benefits have gradually been recognized, so levels of participation have increased and the group approach has become more acceptable. The cyclical review process provides an opportunity to compare alternative approaches at each stage of a project.

Religion

Researchers have identified differences between religious groups in their attitude to leprosy. The strength of traditional beliefs in an area, or the openness to new ideas, will affect the rehabilitation process.

3.7. SUMMARY

Addressing stigma and injustice

- Take time to understand the significance and scope of stigma.
- Tackle the problem of stigma in the local community.
- At the national level, target health professionals and engage in advocacy.
- Encourage the formation of advocacy organizations or similar special needs groups.
- Provide training in leadership and money management.

Community relations

- Learn from the community.
- Raise public awareness.
- Involve the community.
- Keep the community informed of progress and aware of how important its contribution has been.

Responding to special needs

- Identify specific needs.
- Identify the risk factors.
- Base your response upon recognized principles.
- Be aware of the special needs of children and women.
- Note that some clients will need continuing care.

Vocational training centres

- Only set up a training centre if appropriate training is not available locally.
- Consider the management implications carefully.
- Set a referral system that includes vocational assessments.

Providing a loan scheme

- Carefully consider the management and legal implications.
- Set up detailed procedures to ensure accountability.
- Ensure equal access through participation in decision making.

Local issues

- Be prepared to tailor your approach to the needs of each community.
- Consider the advantages and disadvantages of working with groups or with individuals. Start by following established local practice.
- Recognize the significance of different religious groupings.

4. Field experience

This chapter looks at the activities at the heart of the rehabilitation process: the transactions between field staff and clients.

The first step is to identify the people who need help with rehabilitation. An initial assessment will provide the basis for setting rehabilitation goals agreed with the client. This is followed by a process of further assessment, motivation and intervention which builds confidence and adds new life skills. It is supported by follow-up and terminates when the agreed goals are met.

Reviewing the effectiveness of this process is an important learning exercise for the project, enabling it to make best use of its time and to extend its services to yet more clients, with the possibility of developing future group-based activities. In this chapter, experience from the field is summarized in a series of principles and action points.

4.1. SCREENING AND INITIAL ASSESSMENT

For each client, rehabilitation starts with screening and initial assessment. Although some projects may have the resources to accept every potential client who applies, most will give priority to those in most need or at most risk. Questions of motivation, basic skills, local priorities, community sensitivity and gender may all be relevant to the screening process. In Colombia clients are classified as :

- Willing and able to participate.
- Willing but not able to participate.
- Able but not willing to participate.
- Not able and not willing to participate.

Another, more participatory way of screening is to ask the potential clients themselves to decide which of their number is in most need and who should benefit first. This approach may avoid conflict and lead to wider acceptance of the selection process.

The initial assessment (Figure 10), will involve social workers or field staff and provide basic information about the client and the impact of leprosy. For cases undergoing treatment the process should include staff responsible for MDT and prevention of impairment and disability activities and result in a comprehensive plan of action for the client. The plan must be agreed between staff and client and allocate responsibilities.

Example: In Pakistan, assessments are followed by the formulating of a plan of action for each client which identifies the services that will be required and their intended outcomes. It describes the responsibilities of each staff member and of the client, and identifies the indicators that will reflect change. Objectives for an individual are stated using terms such as:

- *Restore self-esteem and dignity.*
- *Increase decision-making capability.*
- *Enable them to provide their families with all basic needs.*



Figure 10. Screening and initial assessment.

- | |
|--|
| <p>A. Personal, financial and social status before the disease</p> <ol style="list-style-type: none"> 1. Age, marital status, education and other personal details. 2. Social status, relationships with family and community, involvement in community functions and activities, etc, before the disease. 3. Financial status, including employment history, earnings, assets and liabilities before the disease. 4. Financial status of family members. <p>B. Impact of leprosy and current state</p> <ol style="list-style-type: none"> 1. History of the disease. 2. Social impact of the disease. 3. Psychological impact of the disease. 4. Employment and economic impact of the disease. |
|--|

Figure 11. Outline for an initial assessment form.

It is essential for staff to keep a record of each contact with a client. Assessment forms may be used to record the changes caused by leprosy (Figure 11). These will form the first entry in a record system that will be updated after each meeting or transaction involving the client.

4.2. RESPONDING TO THE CLIENT

Real practical experience comes from the contact with the individual, bearing in mind that he/she is a human being with special needs and suffering from many internal conflicts because of the disease.

Contributor from Egypt

The ultimate goal of rehabilitation is to enable people affected by leprosy to become self-supporting and live a life of dignity in their community. Central to this process is developing a shared understanding of the needs and skills of each individual and their motivation to change. For some clients, this is a simple process. Others may need successive rounds of assessment, motivation and intervention before they acquire the necessary skills and confidence (Figure 12).

Rather than being just a convenient way to manage rehabilitation, this process of repetition is particularly important for staff. Staff contribute most effectively when they fully understand the needs and skills of the client. It is therefore essential that they share in the learning process. The cyclical approach enables them to increase their understanding and give appropriate guidance to the client at each stage.

At as early a stage as possible, you must try to understand the impact of leprosy on the life

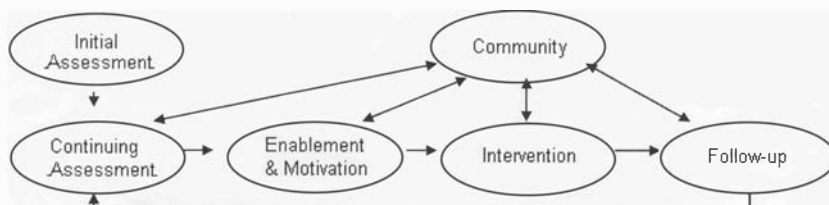


Figure 12. The process of repeated assessment, motivation and intervention.

of the client. This will allow them to talk about the changes in their lives—something that they perhaps have never been able to do before. It helps them to come to terms with the past and prepares them to face the future. These assessments also provide staff with the background information they will need for later, in-depth discussions. Observations from the field, plus the lessons from past interventions, also contribute to the process. Communication with, and support from, the family and the community is vital; some projects encourage this by carrying out assessments in clients' homes. Subsection 4.3 looks at the assessment process in more detail.

Empowering and motivating grow naturally out of assessment; they are simply a change of emphasis. Assessment looks at the past, whereas empowerment and motivation look at what may be achieved in the future. The focus is on activities designed to create self-awareness and confidence, provide new experiences and develop a positive attitude towards change. One contributor to the guidelines described this as:

The process of finding a voice, of developing an understanding, of expressing a need. It addresses the issue of self-esteem and promotes self-confidence. It promotes responsiveness and aims for independence and empowerment. It requires a strong community-orientated approach.

Typically, when projects begin work with clients they are faced with people who have had the confidence to come forward but may have mistaken expectations of what the project can offer. This may lead to a period of confrontation and negotiation, as each party presents their own point of view and begins to understand the other's. Some clients are either not prepared to take risks or lack the support they would need to do so, and so reject any suggestions that fall beyond their experience or 'comfort zone'. Some will become open to change when they see positive change in others. As relationships develop and understanding grows, a supportive environment is created that can empower individuals to take risks and participate in activities to address specific needs (see 4.4). Throughout, the opportunity to learn from people who have already successfully completed the process is a strong motivation.

Personal commitment to an agreed intervention marks a further step in rehabilitation. These interventions may address economic or social needs, and they may involve the family or the community. They are a collaboration between client and field staff, both of whom participate in identifying the problem and seeking solutions. They require the full commitment and ownership of the client (see 4.4).

Follow-up by field staff provides support to the client throughout the process. Their observations and reports are fed back into a further round of assessment, motivation and intervention.

Over time, therefore, there may be a series of interventions with each client. Each successive intervention may increase in complexity as it tackles different needs and develops new skills. Finally, an agreement will be reached that the client requires no further help from the project and he or she will be discharged, providing staff with the opportunity to review and learn from the experience (Figure 13). If clients need continuing support, perhaps to settle into a new community or a new job, staff can provide follow-up.

Scaling-up

In addition to assessing the effectiveness of the various activities carried out with the client, the review should pay special attention to time management. Making the best use of resources is important for organizations that are new to the work and still developing their

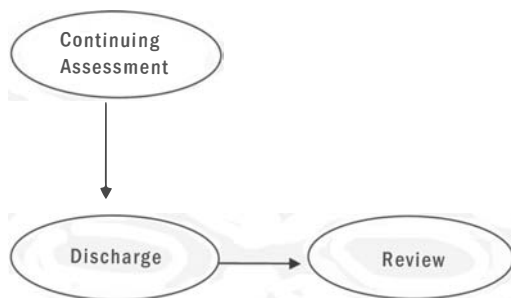


Figure 13. Discharge and review.

understanding of it. The review process enables them to identify factors that can speed up the process and reduce costs:

- It identifies specific skills in which staff can be trained to ensure more effective field work.
- A demonstration that enthusiasm is as important as good training.
- Moving away from a role that involves working *for* the people to one that involves working *with* the people.
- The identification of improved procedures based on a growing understanding.
- Reporting progress to local associations, advocacy organizations or members of the community increases public awareness. This makes the task of motivation and empowerment less onerous, as potential clients can see the benefits reaped by others.
- As larger numbers become involved, so training and other activities can focus on groups rather than individuals.

Some organizations extend the use of assessment forms to describing the impact of project activities on each client and the responsiveness of the organization. This process is closely related to the social audit approach discussed in 2.4.

4.3. ASSESSING NEEDS AND SKILLS

Our lives were such that we could have quietly disappeared from the earth without anyone knowing it.

Assessing the needs and skills of clients is a key aspect of rehabilitation. It provides information about the impact of leprosy and helps clients to come to terms with the changes in their lives. The responsibility for assessment generally lies with field staff, although they will have access to professional staff through a referral arrangement. However, staff at all levels are involved in sharing the learning. This subsection summarizes the factors that bring success when carrying out assessments.

The impact of leprosy

To understand the impact of leprosy, you must first understand the client's normal life-style in the community, which will provide a basis for comparisons with his or her present state. To the outsider, 'normal' life may appear uncomplicated, but the reality may be very different (Figure 14). Understanding what has changed is an essential part of assessment and defines the nature of the rehabilitation process.

In poor communities, people have not one source of income but several. They engage in many different activities. Different members of the family seek and find different sources of food, fuel, cash and support. They operate in different ways in different places at different times of the year. Their living is improvised and sustained through their local knowledge and skills, through their belongings and resources, and through the claims they have on others. Within a community, different social groups can have completely different strategies.

From Robert Chambers

Figure 14. 'Normal' lifestyle.

Assessing self-confidence and psychological state

It is important to be aware of the psychological impact of leprosy, which can take the form of lost self-confidence, reduced self-esteem, fear and anxiety. In most countries there is no access to professional psychologists but staff can use a few simple questions to gain some awareness of psychological needs. This should be done at the earliest possible opportunity after diagnosis. In Colombia there are referral systems in hospitals so that newly-diagnosed individuals can benefit from early assessment.

Example: *Staff in Nepal assess a client's self-esteem by listening out for statements such as the following:*

- *I can't do anything*
- *I'm unable to make decisions*
- *No one listens to what I say*
- *No one treats me like a person*
- *I don't want to be rejected again so I don't make relationships.*

Staff must learn what to listen for and how to encourage clients or their relatives to give full expression to what they are thinking. Mutual trust and respect, and the integrity of the field staff are vital for this process. Section 8 lists publications describing other social work skills. Other aspects of the work include:

- Specialist staff may be consulted: for example, to comment on physical well-being, the risk of further impairment or disability and other special needs.
- The views of members of the family and the local community should be taken into account.
- The assessment should be on-going (a meeting every month, for example) and responsive to changes that occur.
- t must pay attention to detail. For example, when exploring the involvement of family members, staff should try to differentiate between mere tolerance and genuine participation. This will require them to ask 'open' questions that encourage an extended answer rather than 'closed' questions that invite a simple yes or no.

As discussed earlier, staff will collect the basic information about clients at the initial assessment. They now need to use their interviewing techniques and listening skills to understand the client's situation in greater detail. The process involves continuing assessments and depends upon informality and openness. Figure 15 is a suggested form for recording information at each session.

Client's Name:						
Address:						
Meeting date	Participants	Subjects discussed	Agreed actions	Action by	Checked by	Follow-up date

Figure 15. The elements of a form to record contacts with clients.

4.4. EMPOWERING AND MOTIVATING

To get rid of the social stigma we have to have self-confidence first.

Cheng Li Wang, China

Empowerment aims to raise the self-esteem of clients and extend their basic life skills. It changes attitudes so that clients become motivated to change. The key activities for empowerment are increasing the client's awareness through formal and informal education and giving support and encouragement. These will be achieved through the joint efforts of the client and the project staff. Evidence of positive change in other people is also a great motivator: 'It's not just talk, then' is a typical reaction. Restored self-confidence is a major step towards overcoming stigma.

'Awareness' is the level of understanding an individual has of himself, his situation and the society in which he lives. Increasing awareness involves developing new understanding and helping the client to recognize opportunities for change. Contributors summarize their approach as follows:

- Focus on the whole person. Aim to increase self-confidence and develop basic life skills. Encourage self-expression and physical activity. Use informal methods such as drama and music.
- Respond to the fears of clients. Address the specific risk factors. Explore the underlying issues and explain the social and psychological processes at work. To do this, staff need high levels of awareness and good analytical skill; this has implications for training (see 2.5).
- Where clients have formed groups they provide mutual support amongst themselves. This can address emotional needs, self-confidence and self-care to prevent disabilities
- If clients seem to exaggerate their needs, respond with caution and try to develop a better understanding.

Knowledge and skills

Take every opportunity to increase the knowledge of clients:

- Try a variety of approaches, formal and informal, group or individual, in order to identify the most effective way to spread knowledge.
- Improve numeracy and literacy through formal education.
- Provide training that will enable the client to participate effectively in group or family activities. A wide range of subjects may be relevant: local attitudes and beliefs, health and nutrition, local agriculture, civil rights and the development of women. Local development organizations may already have courses tailored to local situations.
- Plan a training syllabus that covers a different theme each month; this enables you to give training in a variety of situations and using a variety of methods.

- Provide training that will enable clients to make good use of a loan and manage their personal or family expenditure more effectively.

Support

This should involve field staff, family and community:

- Be responsive to the growing understanding and initiative shown by the client.
- To encourage positive attitudes and the acceptance of new ideas, share with the client the experiences of other people.
- Involve the family and community in activities.
- Give clients a second chance. If they drop out of the programme but later ask to return, allow them to do so; they will have learned from their experience. The incident should also prompt the organization to think about why the client dropped out in the first place, and whether they should have done anything differently.

Alongside the empowerment of clients, there should also be an empowerment of the staff, the organization and the community:

- Empowering staff. Staff who have inappropriate attitudes towards their work or who operate within a rigidly hierarchical structure will not be able to respond to the initiatives of their clients (see 2.1). The implications of this for recruitment and training are discussed in 2.5.
- Empowering the community. The importance of community relations and community involvement are discussed in 3.2.
- Empowering the organization. Work schedules should allow for an adequate response to each individual. Providing staff with effective procedures, a referral system, careful supervision and on-the-job training will give them the skills and support they need to work to a timetable. Staff must know how much time is appropriate for specific tasks and be able to call for assistance when extra resources are needed (see 2.1).

4.5. INTERVENING

Poverty is a lack of opportunity, not a lack of ability.

Contributor from Ethiopia

This subsection discusses the importance of choosing your intervention carefully and securing the client's full commitment to it. The involvement of the community is one of several factors that will affect the sustainability of the intervention.

Interventions can only start when clients understand their own needs and have found a solution to which they are prepared to commit themselves. The level of disability, existing skills and past work experience of clients will all have some bearing on the success of the intervention, but it is their ownership of the process that will be critical.

Contributors made the following recommendations:

- The client must show initiative and motivation. Encourage decision making and commitment. A positive response from staff increases confidence. You must take the time to consider proposals in detail.
- Recognize that clients may choose an intervention for reasons that are not shared by field staff. Work to develop mutual understanding.

- The client's ownership of the intervention is of primary importance, but field staff have an important role to play in advising and encouraging. Project managers should identify a level of involvement that allows the process to be controlled without restricting its effects or making clients feel they are 'obeying orders'.
- Accommodating the opinions of family and community encourages their members to act as guarantors and reinforces the commitment of the client.
- Every detail and implication of the intervention must be understood and accepted.
- Each intervention needs an action plan specifying outcomes. This should have the status of a contract, listing the responsibilities of the client and the other parties involved and identifying a schedule of activities. Where a small business is being proposed, a business plan will be needed.

Sustainability

The intervention must also be sustainable:

- Use the services of specialists in income generation.
- Use market surveys to assess supply and demand. Seasonal variations may affect production and earnings. Try to avoid undermining the livelihood of other people in the community .
- Vocational assessment establishes the skills and work experience of the client and takes account of the extent of disability; it then identifies potential employment and the training required. The skills of the other people involved should also be taken into account in proposals for job creation or placement.
- Aim to build on the existing skills, experience and knowledge of the client. Avoid work that is completely new.
- Work with known technology
- Provide training in how to monitor and assess progress.
- Arrange for continuous and frequent follow-up, including field visits, home visits and continued contact by social workers
- Review progress and assess the reasons for success or failure. Keep a record of each intervention and learn from it.

Community attitudes

The attitude of the local community is critical to the success of an intervention:

- The local community must be aware of what is being proposed. Its active support may not be needed, but its acceptance will encourage the client.
- Do not provide the client with benefits beyond what is acceptable to the community.
- Extend the proposed benefits to other people in need in the community.

Economic needs

Specific activities address economic needs:

- Encourage saving. Help the client to open a savings account.
- In India and elsewhere, clients may need help to apply for government support for people with disabilities: for example, funds for housing or pensions.

- Provide pre-vocational training that will prepare the client for work. Pay attention to issues such as the risk of new disability, business skills, and informal training in the market.
- Set up a referral system to centres offering vocational training, as this will allow you to make appropriate arrangements for each client.
- If there are opportunities for local employment but no suitable training is available, think about setting up a vocational training centre (see 3.4).

4.6. SUMMARY

Screening and initial assessment

- Where necessary, screening should be based on project policies and local priorities.
- Initial assessments provide an opportunity to draw up an action plan for each client.
- The information collected provides the basis for assessing future change.

Responding to the client

- The repeated process of assessment, motivation and intervention builds the self-esteem and skills of clients.
- Successive interventions encourage clients to assume greater responsibility until they can manage the activities themselves.
- Information from the field feeds back into successive rounds of assessment.
- Projects should give continuing support through a follow-up programme.
- Discharging clients from the programme gives an opportunity to review the performance of the project and apply the lessons learned.

Assessing needs and skills

- Use a needs assessment form as the starting point for collecting information about the impact of leprosy on the client, but encourage open discussion.
- Develop listening skills and encourage clients to express their views
- Involve members of the family and the community.
- Work towards a shared understanding of need.
- Consult specialists when necessary.

Empowering and motivating: summary

- Raise the client's awareness by increasing their understanding of the situation and helping them to recognize opportunities for change.
- Take every opportunity to add to the knowledge of clients through formal and informal education.
- Encouragement from field staff and support from family and community will enhance motivation and empowerment.
- The appropriate organizational culture and procedures will further enhance motivation and empowerment.

Intervening

- The client must own and be responsible for the intervention.
- The family or the community may provide support and reinforce the commitment of the client.
- Develop existing skills and rely on past work experience. Take account of the level of disability.
- Keep the local community informed.

5. Assessing impact

This chapter discusses how to assess the impact of project activities on the client by observing the changes in each client's life. Recognizing and responding to such change is central to project management and planning. Similar methods may be used to assess the organization's progress towards its broader objectives.

Since impact assessment is fundamental to all field activities, the procedures described here will be of interest to staff at all levels.

5.1. UNDERSTANDING IMPACT ASSESSMENT

I don't want to hide my hands. I want to say, 'Look at my hands,' because they are a testimony to my experience, my history, showing that I have conquered every problem I had to overcome.

Yasuji Hirasawa, Japan

All projects need to be efficient and effective. Broadly speaking, efficiency means making good use of resources, particularly funding, and effectiveness means achieving the desired impact. Assessing impact involves finding out what brought changes for the better and what brought changes for the worse (see Figure 4). This subsection will discuss how to decide which changes are important and whose values to apply in describing change.

SER sets out to change lives by reintegrating people into society and restoring their dignity and economic independence. Such changes are the main focus for impact assessment. It is the clients' own assessment of progress that carries most weight, especially in describing change for the better and change for the worse. Where objectives can be stated simply—for example, to increase the client's income—changes can be easily assessed. But where complex processes such as social integration are concerned, there may be no simple way to report progress. Two approaches are possible:

4. Identify the components of complex processes and use indicators, known as 'proxy measures', that demonstrate progress in each part.
5. Adopt one of the methods of Participatory Rural Appraisal (PRA) to identify progress towards objectives such as participation or empowerment (see 5.4).

Example. A group of indicators may be used to describe progress towards a complex objective such as integration. You might describe integration in terms of access to community resources, involvement in local festivals and social events, buying and selling in the market-place, location of housing, shared access to drinking water etc. Taken individually, none of these proxy measures is an adequate measure of integration, but considered together they give an overall picture of the level of integration.

Groups of indicators can be used to describe all aspects of project activities and impact. In many situations, this will mean that you can avoid having to depend on the special skills involved in certain PRA methods (see 5.4 for examples of PRA methods that are simple to use and require little training). Subsection 5.2 now describes how one organization relies on a simple monitoring system using indicators.

5.2. IDENTIFYING CHANGE

The participatory approach is central to most development work and includes participatory involvement in monitoring. One of the larger NGOs involved in development work in Bangladesh has introduced a monitoring system that involves local people (clients) in assessing changes in their own lives. The resulting information is used to review progress throughout the organization. The focus is on the changes that take place under each of four headings:

1. Changes in people's lives
2. Changes in people's participation
3. Changes in the sustainability of their institutions and activities
4. Other changes

These changes are assessed by means of a selective reporting process involving three levels of staff: field workers, project managers and senior managers. Using a simple interview technique and addressing the four headings listed above, field staff encourage local people to describe any changes that have occurred over a 3-month reporting period. Field staff then identify what they consider to be the most significant changes to have taken place under each heading and submit reports to their project manager for local review. In turn, project managers select what they judge to have been the most significant changes across the project and forward the details to senior managers for overall review. At each stage the review process produces information about the impact of the work and what might be done to make it more effective.

A group of indicators is used for each heading. These include the following:

1. Changes in people's lives
 - Financial: saving money regularly, benefiting from loans, improved housing, new sources of income.
 - Health: using sanitary latrines, drinking clean water, eating balanced diet.
 - Personal: home and person neat and clean, sending children to school, acquiring literacy skills.
2. Changes in people's participation
 - Financial: participation in income-generating projects.
 - Social: active participation in groups, progress in solving problems, helping others to solve their problems.
 - Political: participating in local politics, addressing exploitation, injustices and rights issues.
3. Changes in the sustainability of institutions and activities
 - Developing the role of their groups.
 - Developing new skills and new sources of income among members.
 - Opening bank accounts for the group.
 - Saving group funds with a view to using them to support development activities.

Despite the potential for teething problems—such as missed deadlines and an unwillingness to report negative changes—the approach described here has much to offer

projects involved in SER. Monitoring is closely integrated with routine fieldwork. There is a strong participatory element, with field staff reporting changes agreed with their clients. The information is filtered up through the organization so that staff and managers at each level are made aware of what is happening in the field.

5.3. SELECTING INDICATORS

I knew the training as caterers had been successful when two girls returned to the project compound. They politely refused my offer of work within the project. 'We are very sorry, sister, but we have already found work in the city. Please don't be offended.'

Contributor from Ethiopia

Indicators are a way of assessing progress towards objectives. It is clear from the examples given in 5.2 that choosing indicators depends first of all upon common sense and experience. Brainstorming sessions with groups of staff or clients provide those with different expectations, perspectives and values the opportunity to participate in deciding which indicators are to be used and how each should be defined. There are two basic principles to be followed when selecting indicators:

- Principle 1. Begin by considering the project's objectives and choosing indicators that reflect progress. Identify proxy measures and groups of indicators where necessary (see 5.1).
- Principle 2. Wherever possible, adopt the words, phrases and values used by clients. Ask what changes the clients expect. Build upon their understanding and observations. Consult field staff and others.

Example: *The comment from the accountant, 'It was successful because the loan was repaid on time and in full,' must take second place to the assessment of the loan recipient: 'We were able to repay the loan, but we didn't make enough profit to send our daughter to school.'*

Scoring systems

Some indicators will require simple Absent/Present or Yes/No scoring. Others may use a series of graded scores, sometimes referred to as 'markers': for example, to reflect levels of increased understanding or responsiveness. The right scoring system will make it possible to describe simple changes and produce summary statistics in the form of percentages. For these to be useful you should pay special attention to the following:

- Each of the available scores (Absent or Present, Agree/Don't Know/Disagree, etc) must be clearly defined.
- For each indicator each score must be exclusive: that is, only one can apply at a time.

Where you are trying to measure progress towards a complex outcome (for example, participation), you may be unable to identify a satisfactory scoring system. PRA methods can produce the missing information or suggest alternative indicators and scoring systems (see 5.4).

Performance

The monitoring system can only produce useful information if data collection is regular and consistent. Ensure that:

- Indicators are based on data that is available when needed and that staff are trained in procedures to record and process it.

- Data is collected using an agreed form or procedure so that standard reports can be produced on time.

Within the project cycle, it is important to review the performance of each indicator. From time to time it may be necessary to add new indicators or to stop using others. Remember that any changes you make will involve changes in data collection procedures and reporting in the field and will require further staff training.

Basic requirements of an indicator

To be of value, each indicator must meet certain basic requirements, as summarized below. These are described in detail in publications listed in 8.

- **Reliability.** The words and phrases used to define an indicator or its scoring must be clearly understood. It is important that staff working independently produce the same scores when describing the same client or situation.
- **Validity.** Make sure that each indicator does in fact measure what it is intended to measure. Where similar indicators are used, check that changes in one match changes in the others.
- **Simplicity.** Don't confuse field staff by referring to several different factors within a single indicator (see Figure 16).

A meeting with a client identified a series of steps that could be used to report progress towards a new lifestyle: (1) isolated, begging for a living; (2) functioning links with family or project support; (3) good relationship with immediate neighbours; (4) good relationship with surrounding community; (5) accepted in the work force after skills training; (6) fully integrated into society.

The six stages involve a mixture of relationships, employment status and life-style, so assessing progress would be difficult: for example, changes in relationships will not automatically follow on from changes in economic status. The following steps show how functional indicators can be developed:

1. Consider separate indicators looking at (1) housing situation, (2) relationships and (3) employment.
2. Under housing situation, you might identify a series of markers such as (1) living alone, (2) living in community and dependent on begging, and (3) living in wider community.
3. You might describe changes in relationships using (1) no transactions with neighbours, (2) very occasional transactions with neighbours (marginal tolerance), (3) frequent transactions (tolerance), and (4) respected and fully functioning in local community (transactions would need to be defined).
4. Employment might be assessed in terms of (1) begging as only source of income, (2) some earned income but still begging, and (3) all income from employment or self-employment.

Figure 16. Developing indicators.

The listed publications also consider issues of subjectivity, relevance, sensitivity and specificity. The three indicators suggested should make it a straightforward task to assess and report changes. All three use the original terminology.

Making a start with indicators

If you are new to using indicators, do not start by introducing them throughout the project. Instead, begin by identifying a small number of indicators that can be used in clearly defined and limited situations. This will allow you to learn about the processes involved, and later you will be able to extend the practice.

In practice, indicators of economic status are the easiest to identify and use. Alternatively, you could examine the indicators of psychological, social and economic change listed in Figure 17 and further develop them with field staff. Figure 16 may be used as a training exercise in developing indicators.

5.4 QUALITATIVE ENQUIRY

It is important to understand the difference between quantitative and qualitative enquiry. Quantitative methods rely on making measurements against a set scale—for example, measuring income, age or education level—whereas qualitative methods are not limited by measurement or by statistical procedures.

Example of a quantitative method: *Using a survey questionnaire that expects responses in*

Indicators of psychological status

- Self-confidence: for example, the client's dependent on high, medium or low levels of intervention and support from the project.
- Self-acceptance, as reflected in wound care, regularity in MDT, awareness of need to avoid further impairment or disability.
- Capacity to manage a crisis, overcome problems.

Indicators of social status

- Access to drinking water and other community resources.
- Involved in normal buying and selling transactions; able to handle other transactions with community.
- Participation in community activities such as funerals, marriages, rituals, social gatherings, etc.

Indicators of economic status

- Employment status: for example, number of days employed during year, changes in actual income. Income and purchasing power. Increase in savings.
- Housing location and status. Resettlement. Move from rented to purchased property.
- Possession of assets. Better clothing. Ownership of household items. Involvement in buying and selling transactions, especially food.

Figure 17. Examples of indicators from the field.

a standard form—for example, Agree or Disagree—is a quantitative method, because it defines and limits the answers that can be given to each question.

Example of a qualitative method: *Asking open questions in an unstructured interview places no restriction on the questions that can be asked or on the responses that can be given, so this is a qualitative method.*

Qualitative methods are ‘open’, in the sense that they can be used to collect new information and develop new ideas. By contrast, quantitative methods are relatively ‘closed’ since they allow only limited types of response. They tend to be used to describe an individual using existing ideas and terms.

The best-known qualitative methods are those used in Participatory Rural Appraisal, the procedures commonly used in development projects to build understanding shared with, and owned by, the local people themselves. PRA methods include interviews, observation and many other informal activities. The formality of the standard questionnaire favoured by many health programmes contrasts strongly with the openness that is central to many PRA methods (Figure 18).

Which methods should I use?

The interview technique used in the monitoring system described in 5.2 is one PRA method that does not require a high level of expertise. Example Two below describes another method that can be used with limited training; to identify other PRA methods refer to publications such as those listed in 8 that describe the quantitative methods and the circumstances in which they might be used. You should avoid a situation where the use of quantitative methods will generate large amounts of text that cannot be adequately analysed. Instead, identify a small number of manageable priority situations where quantitative methods may be used.

There is great value in using a succession of quantitative and qualitative methods, developing your earlier findings at each step (see Example 1, below).

Qualitative methods in SER

Qualitative methods are preferable in SER, for two important reasons:

1. Since they are not restricted by existing systems of measurement, they can be used to collect a wide range of information and to build understanding of complex situations and processes.

1. Sit down, listen, watch and learn: do not dominate, interview or interrupt.
2. Have an open agenda, allow improvisation and react to the opportunities that arise. Be flexible.
3. Unlearn. Ask for information and advice. Be open to discarding preconceptions. Base judgements on the information presented.
4. Hand over the pencil/chalk/stick. Facilitate. Start the process and then step back, listen and observe without interrupting.
5. Relax. Do not rush. Take time. Enjoy things with people.
6. Embrace error: be positive about mistakes -- recognize, share and learn from them.
7. Respect individuals. Rule 1: Be nice to people. Rule 2: Repeat rule 1. Rule 3: Repeat rule 2.

Based on Principles for assessment by Robert Chambers

Figure 18. The qualitative approach to learning.

2. They can be used to provide the detailed information needed to identify indicators suitable for impact assessment, especially where sensitive issues such as gender, income and debt are concerned.

In each of the following examples, the information obtained from the field would have been written down and summarized in a report. Such reports describe underlying values, knowledge or processes that might result in changes to project priorities and plans.

Example 1

This example, based on a case study in Moris and Copestake, shows the wealth of information you can obtain if you find the right person to talk to.

We decided to conduct some interviews to validate the results of an earlier survey. An old woman asked me if, now that my questions were finished, she could tell me what she knew. She proceeded to give me twenty minutes of detailed information going far beyond the scope of the original survey. She certainly gave every impression of knowing a great deal, and was acknowledged locally as an authority in her subject.

Here the qualitative method—interviews—built on the information gathered through the earlier quantitative method—the survey. The woman interviewed provided a richness of information that went far beyond the simple answers to the survey questionnaire. All that was required was a simple interview technique and a willingness to listen.

Example 2

People who receive loans are often unwilling to reveal the profit they have made. This makes assessing the effectiveness of a loan scheme difficult. An approach based on comparisons can be effective.

I visited a group meeting where each of the women present had received a loan. I asked each to write her name on a piece of paper and then as a group to sort the pieces of paper into an order that matched the financial gain from their loans. A few minutes of animated discussion followed as the slips of paper were ordered and reordered. Finally there was agreement. I asked what those identified with the most gain had in common and how they differed from those with least. For half an hour the women poured out information about the effectiveness of the loans they had received, why some had benefited more than others and what would be done differently next time. Though I still did not know exactly how much profit had been made, I went away from the meeting with a clear understanding of why some women benefited more than others and what needed to be done to make the loan programme more effective.

The method described here depends on making comparisons and is known as ‘Ranking’. Since it is less threatening than direct questions about profit and income, it produced information that answered the interviewer’s questions about the loans scheme. The whole process is controlled by the initial question. This need not be restricted to the subject of money and can extend to questions of social or environmental change. You simply ensure that responses can be sorted in some way. Asking less specific questions requires group members to rely on their own understanding or definitions.

5.5. SUMMARY

Understanding impact assessment

- Impact assessment provides information about the effectiveness of a project: in other words, about quality rather than quantity.
- Indicators may be used to describe progress towards simple objectives.
- Groups of indicators (proxy measures) are used to describe progress towards more complex objectives.
- PRA methods may be needed to provide information that cannot be gathered by other means.

Defining an indicator

- Start from your project's objectives.
- Give priority to the words, phrases and viewpoint of the people most directly affected.
- Identify underlying concepts and the related proxy measures.
- Check reliability and validity.
- Define scoring systems.
- Identify data sources, methods and a schedule for data collection.

6. Case studies and discussion material

The case studies included in the full published Guidelines show how current projects have responded to local needs and opportunities. The discussion points are intended to encourage further analysis as readers draw comparisons with their own experience. This experience can be shared with people who do not have the language skills to read these guidelines: translating the stories and discussion material into the local context and the local language will elicit useful information about the understanding of field staff and their attitudes towards the work. Alternatively, the material may be used for training purposes.

The case studies are drawn from field experience and describe real situations. They raise questions about how decisions were made, how situations were handled and what results were achieved. Not all the answers are given; indeed, the projects themselves may still be looking for better ways to work. The persistence of some loose ends is intended to challenge the reader and stimulate analysis. The discussion questions are designed to extend that process and highlight the issues common to many projects.

7. Getting started

This chapter in the full publication summarizes the Guidelines by giving recommendations for action in response to four real-life scenarios. Each consists of a brief statement of context, some recommended reading and suggested points for action.

1. Introducing SER alongside a control and treatment programme
2. Linking project activities with national (government) programmes, NGOs and others involved in CBR
3. Addressing the causes of stigma
4. Starting impact assessment

8. References, resources and resource centres

The Guidelines identifies the resource organizations and training centres listed here. There is also a reading list of more than 30 publications.

The following publishers and organizations produce materials relevant to SER.

- Healthlink Worldwide (formerly AHRTAG) is committed to strengthening primary health care and community-based rehabilitation in the South; Farringdon Point, 29-35 Farringdon Road, London EC1M 3JB, UK (e-mail info@healthlink.org.uk, Web site <http://www.healthlink.org.uk>).
- ILEP/TALMILEP publishes teaching and learning materials on leprosy; 234 Blythe Road, London W14 0HJ, UK.
- Teaching-aids at Low Cost, PO Box 49, St Albans, Hertfordshire AL1 4AX, UK.
- TLM International (*Partners* magazine for paramedical workers in leprosy).
- Intermediate Technology Publications Ltd, 103-105 Southampton Row, London WC1B 4HH, UK.
- Action Aid India (quarterly newsletter *Disability News*); Web site <http://www/actionaidindia.com/>
- Oxfam Publishing, 274 Banbury Road, Oxford OX2 7DZ, UK.
- Tearfund (*Footsteps*, a quarterly publication on health and related development issues); 100 Church Road, Teddington, Middx TW11 8QE, UK.
- World Health Organisation Publications, 1211 Geneva 27, Switzerland.
- Social Science and Leprosy Network, a Web-based discussion group; to join the group, e-mail Jeanette.Hyland@utas.edu.au
- The Institute of Child Health, CBR Resource Centre, London (Web site <http://www.ich.ucl.ac.uk/library/cbr.htm>).
- World Neighbours (periodic magazine *In Action*).
- INFOLEP

Centres offering training courses in SER or related subjects include the following:

- INF/Release, Nepal, c/o Mr Siegfried Beecken, SER Co-ordinator, INF Release Project, Partnership for Rehabilitation, PO Box 28, Pokhara, Nepal.
- (e-mail pfr@inf.wlink.com.np)
- GLRA, India, c/o Mr Srinivasan, Co-ordinator, GLRA, 4 Gajapathy Street, Shenoy Nagar, Chennai, 600 030, South India. (e-mail glra@md2.vsnl.net.in)
- DBLM, PO Box 3, Nilphamari, Bangladesh
- St Francis Leprosy Centre, Buluba, PO Box 1059, Jinja, Uganda
- Action Aid India. Web site <http://www.actionaidindia.com/>
- COMBRA, PO Box 9744, Kampala, Uganda
- Marie Adelaide Leprosy Centre, PO Box 8666, Karachi 74400, Pakistan

The following organizations involved in advocacy and their representatives are also identified:

- Dr PK Gopal, President, International Relations, IDEA, 58 Selvam Nagar, PO Box No 912, Collectorate PO, Erode, 638 011, India (e-mail: ideaind@vsnl.com).
- Ms Anwei Law, International Project Co-ordinator, IDEA, PO Box 133, Oak Hill, WV 25901, USA. (email: ideausa@inetone.net)

- The International Leprosy Union is a federation of some national agencies directly providing field services in leprosy. Address: International Leprosy Union, Gurutrayeri Building, 1779-1784, Sadashiv Peth, Pune 411 030, India
- National organizations for people with disabilities exist in Japan, Ethiopia, Brazil, Nigeria and elsewhere. Contact details are available from IDEA.

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Socio-economic rehabilitation programmes of LEpra India – methodology, results and application of needs-based socio-economic evaluation

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Summary There is now a better understanding of the scope and process of rehabilitation. The approach recognizes the impact of leprosy on the individual, aims to understand the needs and concerns of those affected, their families and community in the rehabilitation process, and that aims to restore the person to normal social life. LEpra India has undertaken socio-economic rehabilitation (SER) activities in its projects in Andhra Pradesh and Orissa States in India with a holistic approach that has been evolutionary, developmental and participatory. A SER Officer (SERO) was posted to each project. A plan was formulated by the SERO with participation of all project staff. The main emphasis of the programme was on active participation of the affected person in the rehabilitation process. A needs-assessment study was conducted in the target population using a semi-structured questionnaire. Information was elicited about social and economic status, before and after the disease, and the current rehabilitation needs of the persons affected. The next step was meeting the needs through interventions by the SER staff. The impact of the programme on restoration of social and economic status of the affected persons was analysed. The paper stresses the importance of assessing the needs of persons affected by leprosy, structuring a rehabilitation programme with the active participation of the affected person and evaluating the impact of the interventions in restoring normal social and economic life.

Introduction

The objectives of the socio-economic rehabilitation (SER) programme undertaken by LEpra India are:

- Economic empowerment of affected persons by enhancing their productivity.
- Restoration of social status with appropriate socio-economic interventions.
- Restoration of human dignity and improvement in the quality of life of the affected persons through their active participation and empowerment of their communities.
- Networking and partnership with various agencies related to this programme.

The SER programme has been incorporated into seven existing projects by appointing

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SER Officer (SERO) at the project level working with the active involvement of all field staff.

The SEROs were appointed on the basis of the following skills and competencies:

- Skills in identifying the rehabilitation needs of the leprosy affected persons using appropriate tools.
- Intervention skills such as casework, group work and community organization.
- Experience in interview and observation techniques.
- Skills in conducting group discussions, case studies and in participatory micro-level planning.
- Skills in monitoring and evaluation.
- Team management skills.

With the appointment of SEROs in 1997, the SER activity was implemented as a structured activity within the overall context of ongoing leprosy programmes.

Materials and methods

The study was divided into three parts: needs assessment, interventions and evaluation of impact.

NEEDS ASSESSMENT STUDY

To assess the SER needs of persons affected by leprosy and implement interventions acceptable to them and their families, a needs assessment study was conducted initially in three projects.

The study was conducted among persons having grade 1 (G1) and grade 2 (G2) disabilities. There were 2280 persons with G1 and 2667 persons with G2 disabilities. Lists of all these persons were prepared by age and sex. Ten percent were selected for this study by stratified random sampling, 220 with G1 and 258 with G2. A structured interview schedule was devised separately for the G1 and G2 categories of persons to elicit information both qualitatively and quantitatively on the socio-economic consequences of leprosy and rehabilitation needs. A workshop was conducted for staff in each project on SER activities, relevance of needs assessment and methodology of administering the interview.

DEVELOPING SER INTERVENTIONS

Initial and follow-up workshops were conducted for Project Officers (POS) and SEROs by experts in the field of rehabilitation to acquaint them with the methodology of programme implementation, the inputs needed and the importance of sustained follow-up.

Orientation and re-orientation training programmes were conducted for the field staff to explain their role in the SER implementation.

Paramedical workers carried out the initial assessment of needs of affected persons with the help of a structured questionnaire and informal discussions with contacts. These findings were used to prepare lists of persons needing different rehabilitation interventions. These were referred to SEROs who conducted in-depth assessments and prepared proposals in

consultation with Village Rehabilitation Committees (VRC) for review by the Rehabilitation Coordination Committee (RCC) in the project. These committees are constituted at the level of village or at clusters of villages. The committee has 10–15 members drawn from local leaders, informal leaders (members from youth club/women groups), school teachers, Anganwadi workers, village health workers and the clients. The paramedical worker is the convener of the committee which meets once a month, reviews needs of clients, suggests suitable schemes of assistance, monitors regular repayment of loans and explores avenues of procurement of raw material and sale of finished products.

IMPACT ASSESSMENT

A sample of 120 clients who received assistance with SER interventions were administered a structured questionnaire to assess the impact of the intervention in improving the quality of life.

Results

NEEDS ASSESSMENT

The findings of the needs assessment are tabulated in Table 1.

It was observed that discrimination within families was less in persons with G1 disability compared to those with G2 disabilities. Only 6% in G1 reported that they were discriminated against compared to 19% in G2. The discrimination against women in G2 was significantly greater (25%) than against men with the same grade (18%)

The social problems identified were analysed by age and sex. The reported problems included problems at work, in education, in marriage, attendance at family and community functions and behavioural change in contacts.

The following observations can be made:

- Persons with G1 disabilities did not face problems in the work situation, and were

Table 1. Family support and discrimination experienced by persons with grade 1 and 2 disabilities

		Male			Female			Total		
	Grade	16-45	>45	Total	16-45	>45	Total	16-45	>45	Total
<i>Family supports</i>										
	G1	70	63	133	36	38	74	133	74	207
	G2	69	72	141	38	31	69	141	69	210
<i>Family discriminates</i>										
	G1	4	3	7	4	2	6	7	6	13
	G2	14	11	25	17	6	23	25	23	48
<i>Total</i>										
	G1	74	66	140	40	40	80	140	80	220
	G2	83	83	166	55	37	92	166	92	258

accepted in the wider family circles and the community. However, 7% of females with G1 disabilities expressed problems with marriage and education.

- Among persons with G2 disabilities, 7% faced problems in their work situation, 5% in education and marriage, while 8% felt discriminated in community functions and 7% experienced behavioral changes among contacts.
- About 22% of females in G2 grade, who were discriminated within the family, did not have any problems in work situation, marriage and education and acceptance in family and community functions. This needs to be studied further in relation to the extent of disabilities and functional capabilities as it implies that females in G2 category are more discriminated within the family than outside in the community.

It was observed from an analysis of the economic problems of persons in G1 and G2 disabilities that:

- In the G1 category only 10% had adequate income to support their families (2% among females). 64% had marginal income while 25% do not have any income and were dependent on family members. However, only 16% reported a fall in income due to leprosy. The income level of the population was generally low and persons affected by leprosy also had low incomes. Twelve percent of the respondents felt that they needed to change their occupation to prevent damage to their hands and feet.
- In the G2 category, only 7% had adequate income (2% among females), 57% had marginal income, while 36% were dependent on family members. A fall in income was reported by 44% of persons in this category. Thirty-three percent felt that they needed to change their occupation to prevent further damage to their hands and feet.
- In the G1 group, 98% of females were dependent on their family, and in the G2 group 97% were dependent. Women contribute to income by their work in agriculture and other household work, but their work was not considered as income generating and their status was therefore considered as dependent. Thirty-nine percent of the females in the G2 group felt the need to change their traditional occupation for protection of hands and feet.

Preferences for rehabilitation made by the participants were analysed:

- In both the G1 and G2 groups, 30% preferred assistance for small business ventures, 22% preferred assistance for dairy and poultry, while only 2% preferred self-supporting ventures such as sewing machines, weaving and rickshaws. Such occupations were considered to have little market and hence the beneficiaries did not prefer them.
- In the G1 group, 21% desired old-age/widow pensions and 7% desired assistance for housing. In G2, the corresponding data were 25% and 9%.
- The lack of awareness among clients about different schemes of assistance by the Government of India, the absence of an intervening agency to espouse their cause and the lack of initiatives from local leaders to represent their needs were the main reasons why many clients did not show inclination to opt for more self-supporting schemes.

SER INTERVENTIONS

Forty VRCs were formed on an experimental basis to understand how they function. It was found that 20 committees were functioning regularly.

A brief summary of SER interventions developed during a period of 2 years is presented in Table 2.

Table 2. SER interventions and their beneficiaries

Scheme no.	Schemes	Beneficiaries		
		Male	Female	Total
1	Loans from Government	55	9	64
2	Housing (Government)	105	25	130
3	Pensions (OAP/DP/WP) Government	161	150	311
4	Philanthropists	44	23	67
5	Loans from LEPR India	47	10	57
6	Educational support (LEPR India)	3	1	4
7	Service in NGO	1	1	2
8	Total	416	219	635

Over 1300 scheme proposals submitted to the government are being processed for different types of assistance.

A focused approach was adopted for providing assistance to women affected by leprosy, since it was observed in the needs assessment study that over 90% of women affected by leprosy were largely dependent on other members of the family. Apart from the interventions for 219 women beneficiaries, special training programmes were conducted for women in the projects to develop skills to undertake income-generating schemes.

A handloom weaving training centre was established in one of the projects where women are exclusively trained for 10 months in weaving. Ten women completed their training and loans are being processed to help them establish their own cottage units. An electronic watch-assembling unit has been started. Women affected by leprosy but having dexterity of fingers are trained in assembling watches. The scheme is supported by Government. A training programme for ten women has been organized in making incense sticks.

IMPACT ASSESSMENT

Of the 120 interviewed, 53 were restored to initial economic status, 58 reported marginal improvement and nine no improvement. The reasons for lack of improvement in economic status of the nine persons were analysed and found to be: business ran into loss because of credit transactions, death of milk cattle, and addiction of beneficiaries to alcohol. Some of the important reasons for marginal improvement were seasonal business with average yield, gestation period of certain interventions (such as rearing of goats and sheep). These may show improvement in due course.

Of the 120 beneficiaries who were interviewed, it was found that 26 had social problems in addition to economic problems. Of the 26, 18 reported restoration to initial economic status, two marginal improvement and six no improvement. All the six individuals who did not show any improvement in social rehabilitation had significant deformities and were not accepted either by family or society. In the case of marginal improvement, two individuals were accepted by the family but did not have normal acceptance by their community members.

Discussion

Several constraints are faced in the implementation of the SER programme. The main issues were:

- There is lack of awareness among people about various schemes of assistance available from different government departments. The SER teams have to first acquaint the people about these schemes and explain the benefits before they can decide to accept them.
- The procedures for economic assistance that are offered by the system result in delay in extending the assistance required by the clients.
- The apathy and lack of participation by the community in the process of rehabilitation of persons affected by leprosy. This requires a good deal of persuasive and motivational efforts from the SER teams.
- Some of the projects included in this presentation were located in very difficult to reach tribal areas, which imposes limitations on access to the enablers and the beneficiaries in tapping the resources, utilization and marketing the finished produce.
- Since the SER programme has been introduced recently in ongoing leprosy projects, there is a backlog of persons affected by leprosy in need of different socio-economic interventions.

Since many aspects of SER are related to the disability, a strong prevention of disability component in each project will help greatly in minimizing the need for rehabilitation.

For strengthening community participation and ownership of the programme, the concept of formation of VRCs, which has been initiated, needs to be incorporated and expanded. The community has to assume the responsibility of sustaining the schemes of assistance provided to the beneficiaries.

SER activity has to be considered as an integral part of the overall strategy of each leprosy project. The programme can deliver results only if every member of the team participates in it from the initial stage of needs assessment to reintegration of the beneficiary into the normal environment.

A strong educational component in the programme, whether in the current vertical set-up or in the ensuing integrated set-up, is still essential. Correct attitudes and practices about leprosy in all sections of the society are essential to prevent the process of 'dehabilitation' and extend the required support to those in need of rehabilitation. Leprosy elimination is envisaged within a short span of time but the persons affected by the disease are considerable in numbers and need to be assisted to lead a life with dignity.

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Making sense of rehabilitation projects: classification by objectives

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Summary Rehabilitation of disabled persons can take many different forms according to the socio-cultural and political context in which it is undertaken. Some approaches have emphasized the restoration of the physical function of the client, while others have looked beyond to psychological and social well-being. Some have built on the expertise of professionals while others have emphasized the caring capacity available in the family and the community and sought to reinforce it. Besides providing a wide range of possible services to disabled persons, rehabilitation seeks 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. This paper reviews a range of models and approaches which have been put forward in the international debate on rehabilitation. Furthermore, four dimensions are described which can be used to characterize and define classes of rehabilitation projects based on the objectives that are defined for them. Thus types of rehabilitation projects can be distinguished. Management, evaluation and technical support for rehabilitation projects need to take these essential characteristics into account.

Introduction

With the introduction of new multi-drug treatment in 1982, substantial progress has been made towards ridding the world of leprosy. However, there remain many millions of people who are clinically cured but still suffer the consequences of the disease. Greater priority is now given to their physical, psychological, economic and social needs as reflected in the variety of rehabilitation programmes in countries around the world. This change of emphasis is a feature of the work of the Leprosy Mission International (TLMI). The present paper arises

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from the need of TLMI to evaluate the success of such programmes and to ensure that lessons learned are shared and applied for the future benefit of all those involved.

The rehabilitation of people affected by leprosy is concerned first of all with people and secondly with the variety of forms of disablement related to leprosy. While there is a parallel with the development of Community-based Rehabilitation (CBR) that took place over the past 2 decades, people with disabilities due to leprosy are more strongly stigmatized than most people with disabilities. The present paper therefore discusses historical and current models of CBR and considers their applicability to the field of leprosy. This results in the identification of a number of basic dimensions or objectives of CBR which may be used to classify projects, identify priorities and focus evaluations.

Towards a working definition of CBR

In 1994, UN agencies including WHO and ILO issued a joint statement, based on the early work in the 1980s of WHO and ILO in field testing CBR. This UN document was a consensus document which emerged after years of debate between the two UN organizations about what had to be considered as CBR. CBR was defined as a strategy within community development for the rehabilitation, equalization of opportunities and social integration of people with disabilities¹. It is achieved through the combined efforts of people with disabilities, their families, and communities and the appropriate health, education, vocational and social services. For present purposes we will adopt the UN statement of the three-fold aims of CBR¹ as our starting point:

- Improvement of physical, social and psychological function of the person with a disability.
- Solidarity with those who are denied their rights and working for the adaptation of society.
- Working for integration and equality of rights of those with disabilities within the mainstream of community life.

We would like to emphasize that integration and equality of rights should be made operational to such an extent that people have equal enjoyment of rights within the confines of the socio-economic, cultural and political context. We would like to bring out two principles that are implicit in the above definition:

- Rehabilitation should where possible be part of community development.
- Rehabilitation is achieved through multisectoral collaboration.

These basic elements of CBR are supported by and continue to evolve through an extensive body of research and professional publications, which report field experience, define elements of best practice and discuss models and issues. There is no single pattern of service delivery that can fit all areas,² so applications of the CBR philosophy are very diverse and reflect the variety of cultures and levels of development throughout the world.³ The diversity of programmes has given rise to rhetoric and claims that have contributed to a considerable amount of confusion over what CBR is. Some people go as far as saying that 'CBR is what people say it is'.⁴ Wolffers and Finkenflugel are, however, convinced that the different interpretations refer mainly to conflicts of interest and therefore conclude that CBR is not 'what people say', but rather is an *approach and an attitude* towards rehabilitation whereby people with disabilities and caregivers define their own needs and negotiate with rehabilitation workers and policymakers to improve their living circumstances and to play their full part in society.⁴

Defining disablement

The World Health Organisation, in its International Classification of Impairments, Activities and Participation,⁵ describes the impact of a disease on an individual in terms of impairment, activity or participation. In the context of leprosy these may be understood as follows:

- **Impairment.** A primary impairment may take the form of nerve damage, eye damage, facial deformity or personality disorder. Ulcers, bone loss and contractions are secondary impairments.
- **Activity.** An activity is the nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality (ICIDH2).
- **Participation.** Participation is the nature and extent of a person's involvement in life situations in relation to Impairment, Activities, Health Conditions and contextual factors. Participation may be restricted in nature, duration and quality (ICIDH2).

Thus impairment may lead to limited activity and/or limited participation. In many countries, the diagnosis of leprosy alone may restrict participation, even where there is no impairment. In the present document and in the context of leprosy, the term disablement or disability may refer to any level of impairment or any level of reduced activity or participation.

Issues in CBR development

A number of issues in CBR classification arising from the reviewed literature are discussed under the following headings.

PRIORITY

In developing countries the provision of services for those with disabilities is always of lower priority than education, water supply and employment. Services to those with disabilities living in rural areas and urban slums are largely the responsibility of the private or voluntary sector and generally receive little attention of governments.

KNOWLEDGE AND ATTITUDES TO DISABILITY IN THE COMMUNITY

The most realistic and frequently achieved form of participation in the rehabilitation process is the involvement of the close relatives of those with disabilities.⁶ The WHO statement has been criticised for not placing enough emphasis on this point. Others have commented that it is not realistic to expect the entire community to become involved in rehabilitation activities.⁷ This is why some CBR programmes try to get influential people with close experience of disability, either in themselves or in a close relative, involved in their programmes, since these key activists are the most likely persons to bring about substantial change in resource allocation and public attitudes. Closely linked to the issue of community participation is the claimed integration of people with disabilities into society.

FEASIBILITY

CBR has been proposed over the past 2 decades as the best and only way to meet the needs of people with disabilities in lesser-developed countries. It is seen as the best way to integrate

people with disabilities into mainstream social life. It is regarded as the most cost-effective rehabilitation approach given shortages of qualified rehabilitation personnel and other resources. While it has been criticised as a second rate service for the poor living on the fringes of society, there are many situations in which it must be recognized as the only practical way to meet needs in a different and hopefully more favourable way than the coping mechanisms.

MANAGEMENT

Sony Gill⁸ identifies primary elements of CBR, three of which match those quoted above. He adds a fourth element, which recognizes the vital role at national, regional, district and community level of planning, managing, and monitoring CBR programmes. Recognizing the contribution of managers and the importance of monitoring systems embraces the project cycle approach and the need for projects to pay attention and respond to information coming from the field.

HUMAN RIGHTS

At the 1998 Harare Conference, Miles⁹ referred to a number of issues that need to be considered when developing models of disability service delivery. With its western bias the Disability Movement tries to portray disability as a rights issue and uses slogans derived from the individualizing societies of educated, urban Northerners. Miles warns that the rhetoric of CBR tries to appeal to 'traditional community spirit', however weak or failing, to support and include people with disabilities. He points out that the now well-known slogan 'Nothing about us without us'¹⁰ is misleading, since most modern life involves trusting strangers to play their part. Similarly, the contribution of specialists who are not themselves disabled should not be discarded off-hand. In many of the countries in which TLMI works rights issues are concerned with issues of access and equality of opportunity. These are the emphases that will in many situations provide an entry point for new programmes and activities.

GLOBALIZATION AND UNIFORMITY

Current trends towards the globalization of ideas, information and the media contrast with practical respect for differences of culture and concepts of disability related to them. Miles⁹ has described the continuing struggle between the search for uniformity, for example in the form of mass-directed 'best packages' as recommended by WHO or UNESCO, and an approach which is strongly local, small scale, which allows choice, takes risks and allows mistakes.¹¹ The value of the local is recognized, though it must be workable and have credibility in the eyes of those in authority.

Many of the issues that we raise here refer to rehabilitation policy and planning, in which various stakeholders with different agendas and ideas defend their interests. It seems that quite often policy debates concentrate around issues such as power and control. The various CBR models signify a need for strengthening community components. This can only be achieved by organizing people with disabilities, and the communities in which they live, focusing on felt needs and fostering active involvement in negotiation and shared decision-making⁵ as an essential characteristic of CBR development.

Models of CBR

There has been a tendency to address rehabilitation needs through the delivery of professional services, for example, combinations of medical, educational, economic (vocational), or community development activities.¹² The limitations and failures led people to develop alternative approaches, involving relatives of disabled people (Helander)¹³ or disabled persons themselves (Werner)¹⁴ as service providers. As opportunities have arisen and new programmes have been launched, alternative frameworks for understanding CBR have been formulated. The following headings provide a brief description of some of these.

HISTORICAL DEVELOPMENT

Miles¹⁵ recognizes an historical evolution of five models for CBR, each with access to, or making use of, different levels and kinds of 'information' and each with its own unique strengths and weaknesses. *Traditional* rehabilitation is the established response to disability in the community, rooted in local religion, ideology and economy and often stigmatizing. Local healers, holy persons, people with disabilities and their relatives are the actors. By recognizing this traditional model, Miles emphasizes that nobody is starting from scratch. The planning of a new programme must acknowledge and build on the context of traditional knowledge, local skills and the coping mechanisms that have existed for thousand of years. Between 1950 and 1980, there was a large expansion of technological innovation. Capital-intensive treatment methods were concentrated in medical institutions, hence *Institution-based* rehabilitation. From 1970 onwards, a new emphasis developed on consumer self-advocacy, self-help, integration, normalization and de-mystification. Activities took place in the local community and in the homes of people with disabilities – *community-based* rehabilitation. In the 1980s and 1990s, the *resource centre* provided a middle way between the institution and the home, where people with disabilities and their families can meet and obtain services they cannot use at home. *Information-based* rehabilitation came up in the 1990s, which is described by Miles as an analytical tool for examining different strategies and building an understanding of what is going on and how more resources may be brought into play. As such, it is not in competition with other approaches.

PHILOSOPHY

The philosophies underlying current rehabilitation programmes vary. *Individual, service or medical* models usually aim to 'cure' the existing impairment and/or to 'care' for the disability. These models have the advantage of offering what families, communities and many people with disabilities actually want and ask for. By contrast, in *social* models the focus is on empowerment and enabling. The staff in such programmes have a facilitating function, building partnerships with people with disabilities. They impart skills and knowledge, which enable people with disabilities to become responsible for their own development. The existing power base is changed so that people with disabilities are able to exert influence over their own affairs. *Inter-sectoral* programmes can also be found with links to primary health care and community development and having characteristics of both the individual and the social model. Murthy and Gopalan¹⁶ identify specific aims such as medical interventions, educational components such as the transfer of skills and knowledge, awareness raising and prevention, economic, vocational, advocacy, issues of legal restrictions, social aspects and technology.

STRUCTURE

Peat and Boyce,¹⁶ Miles⁹ and others refer to different contexts or structures in which CBR takes place:

- *Institution-based*: rehabilitation which takes place within specialized centres, designed and controlled by professionals in which resources, technology and interventions are delivered at a high price to usually few people.¹⁷ Professional staff and 'clients' are the actors. Activities take place in urban rehabilitation centres and special schools. While historical institution-based rehabilitation is currently seen as contrary to contemporary notions of rehabilitation needs, there is an awareness of the potential of appropriate and complementary institution-based services.
- *Networking*: the model emphasizes the co-ordination of services and programmes and looks to optimize the use of available resources, ensure access to services and the avoidance of duplication and of competition for scarce resources.
- *Outreach*: provision of therapeutic and/or medical services at clinics, community centres and the homes of people with disabilities.⁹ In such programmes strong emphasis is placed on accessibility and contextualization of the given intervention.
- *Non-service programmes*: those that facilitate CBR but may not themselves offer direct clinical services – manpower training, awareness raising and community mobilization programmes; preventive and promotive activities, vocational training programmes of people with disabilities, strengthening of support groups.
- *Resource-centre based*^{15,18}: an approach that acknowledges the importance of user-friendly community-centred or community-based institutions.¹⁹ People with disabilities and their families and skilled persons are the actors. Werner in Proyecto Projimo in Mexico mobilized local people, many of them disabled, to start a – now famous – villager-run rehabilitation programme for children with disabilities in the western part of Mexico.¹⁴
- *Home-based rehabilitation*: emphasizing that rehabilitation starts and takes place in the individual's home and within the community. Traditionally, women already provide care to their disabled relatives regardless of any CBR scheme. The challenge of home-based rehabilitation is to offer knowledge and skills to enhance the effectiveness of what they (already) do, and perhaps to remove the necessity for them to do most of it. Financial and economic implications are not well documented and raise questions as to sustainability of this model in lesser-developed countries.

ORGANIZATIONAL AND PROGRAMME ISSUES

- *Principles*: the fundamental principles incorporated in the mission statement or constitution of the organization will have a direct bearing on the project. The manner in which these principles are applied in daily activities needs to be scrutinized and their impact on programmes understood.
- *Human resources*: Periquet²⁰ describes CBR in terms of human resources and the roles of non-professional, semi-professional and professional workers. Effective decision making, accountability, responsibility and control are directly related to the human resource base available within the project.
- *Origin*: Kisanji²¹ classified CBR according to the origin of the programme, whether it is a national or regional government programme, a programme developed by a non-governmental organization whether national or international, or a community or individual

(grassroots, persons with disabilities). Community-owned programmes can have an empowering aim and role, though this is not exclusively the domain of such programmes. NGOs may follow the aims and activities set by national government rehabilitation policies. There is always a risk that successful local initiatives will lose important aspects of CBR (community participation and ownership) in the process of scaling-up through community-based organizations or NGOs.

- *Geography*: another way of classifying CBR could be by viewing the geographical situation in which CBR takes place. Urban CBR programmes require different approaches than rural or semi-rural ones. Some CBR programmes are implemented in slum areas with mobile populations constantly in search for work and shelter, where maintaining contacts with individuals is difficult.
- *Target group*: some programmes address special needs, such as children with disabilities or restrict their scope to people with specific disabilities, such as visual disabilities, children with mental handicaps, those affected by leprosy etc.

TOWARDS A MULTIDIMENSIONAL CONCEPT OF CBR

It is clear from the preceding brief discussion of issues and models that CBR is a diverse and complex subject. Peat³ attempted to identify different project types and recognized a total of 20 CBR models. McColl and Paterson²² describe the shortcomings of unidimensional conceptualizations of CBR and suggest a multidimensional framework for CBR classification. On the basis of qualitative information obtained from key informants, they identify six thematic descriptors of CBR programmes, divided in two sets: those that define programmes (aims, beneficiaries and strategies), and those that support programmes (human resources, structural resources and attitudes). These six dimensions (each with individual and community oriented aspects) are then used to define two, three-dimensional spaces, in which CBR programmes may be plotted and compared: the Defining Model and the Support Model. Miles,⁹ though recognizing the merits of this cuboid classification, states that the complexity of this multidimensional model illustrates the difficulty of constructing a convincing classification. He argues that the information based approach leaves ample space for valuing each model in the context of history, culture and development.

In our view, a continuum exists on which distinct CBR models can be positioned on the basis of their philosophical starting points and subsequent approaches: at one end the *individual model* and at the other end the *social model*. These two 'contrasting' models will provide us with insight into a number of characteristics, which in turn will be essential in determining broad categories of CBR models. It should be noted that although the social model is nowadays viewed by many – mainly western academics – as the most desirable and optimal model of CBR, the various mixed models and the individual model have significant value as well. In fact, within the social model several characteristics/principles of the individual model should be incorporated if it is to have any serious meaning for people with disabilities. We recognize, therefore, an element of complementarity within the apparently 'contrasting' models and a development from one to the other.

CBR amongst people affected by leprosy

In the past, the emphasis in dealing with people affected by leprosy was on shelter and segregation – feeding and caring for people with leprosy, but protecting society from them.

Any serious rehabilitative effort came comparatively recently. The availability of an effective treatment has moved the focus for rehabilitation activities away from institutions and into the community. Programmes now recognize the need to match treatment and control activities with appropriate rehabilitation interventions.

The impact of leprosy is such that, even after discharge from treatment, those affected are at continuing risk of impairment and resulting disability. Programme managers are therefore concerned with the continuing prevention of disabilities of hands, feet, and eyes, as well as overcoming negative attitudes on the part of the community and working for the psychological, social and economic rehabilitation of those affected. Typical rehabilitation programmes include vocational training, placement in mainstream employment and the facilitation of micro-enterprises. Such activities fall very much within ILO's mandate of CBR development,²³ which includes a strong focus on socio-economic rehabilitation.

Vocational training and job placement form a strong entry point for integration into society. They provide a mechanism for breaking the 'disability cycle' of isolation, dependence and profound poverty.²⁴ Through income generation, people with disabilities become partners in the earning of family income and thereby gain respect, giving them a larger stake in family decision making processes. Large gains in social role and status in both the family and the community at large are expected to take place. The effects of this process on personality will open ways to become more self-determined. Thus empowered, the person needing help may now be able to help others in the community.

While the ultimate rehabilitation aim 'integration into mainstream society' is often achieved through employment activities, there is a risk within such a model that too much value is placed on economic activity alone. Rehabilitation efforts should focus on the creation of a supportive environment that stimulates people with disabilities to be whole persons whose lives are not solely determined by their disability but who can also enjoy relationships and contribute meaningfully to the lives of their families or communities. Such an approach avoids the continuing stigmatization of those who cannot become economically active, the elderly, the young and those who have such profound/multiple disabilities.

CBR focusing on the specific needs of those affected by leprosy is faced with an anomaly in that it continues to make a special case of leprosy. This carries the risk of further stigmatizing those involved in such programmes. This is one reason why TLMI seeks to address the needs of people affected by leprosy as well as their communities. The emergence of national programmes defining the nature of services to those with disabilities will increase pressure to address the issue of integration further.

A working classification

Our present purpose is to identify common themes and underlying dimensions which may be used to focus programme evaluations and identify families of indicators which will support the evaluation process. We have identified the following dimensions or principles which are central to CBR (cf. Figure 1).

OBJECTIVE 1: CONTINUUM RESTORATION OF QUALITY OF LIFE: 'FROM NORMALIZATION OF FUNCTION TO EQUAL OPPORTUNITIES'

Projects on the left side of the continuum refer to 'normal' functioning within the community and the process of rehabilitation is geared towards normalization of physical function.

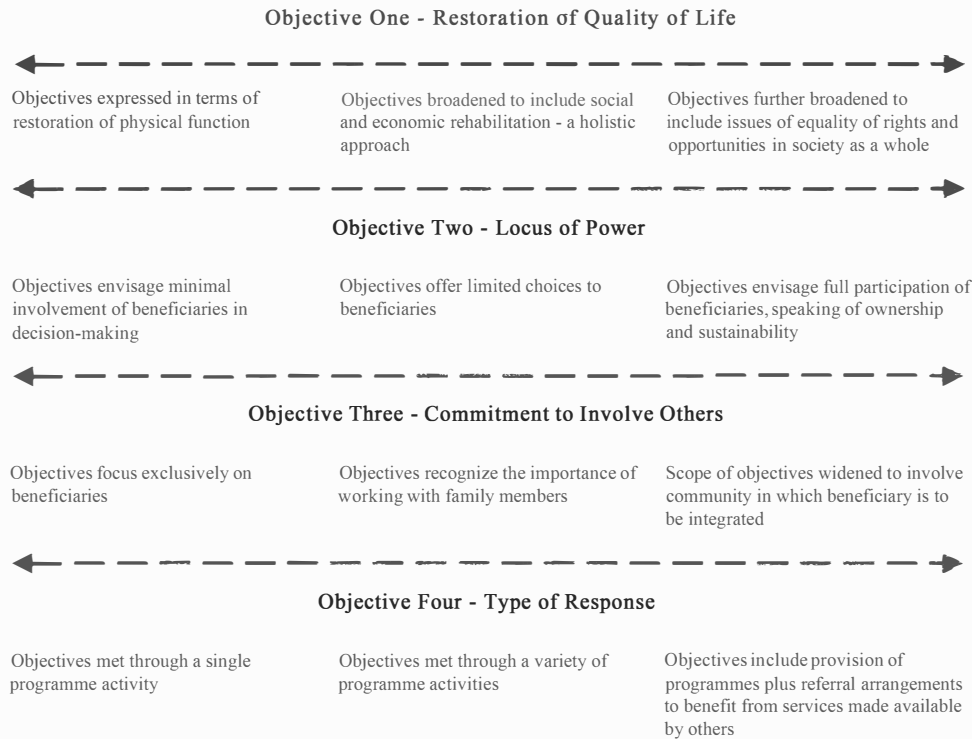


Figure 1. Four dimensions characterizing rehabilitation projects according to their objectives

Restoration of impaired function is seen as the end-product of rehabilitation (e.g. surgical intervention). The focus of interventions is on the alleviation of the restriction of activity or inability rather than on the need to focus on social consequences of impairment and restriction of activities. The full dimension of development in both the process and the outcome of rehabilitation is missing.

Another class of projects refer to social and/or economic rehabilitation and to physical and psychological well-being; they enable beneficiaries to overcome the impact of their disability and stimulate/facilitate the return to an earlier or develop a new, appropriate lifestyle within the community. Recognizing the importance of a full range of life skills is an aspect of holistic programmes, which work for an overall wholeness of life.

On the far right side of the continuum are projects which go beyond the care for the disabled person and address society as a whole, speaking out for the rights and acceptance of people with disabilities (advocacy) and seeking to address knowledge, attitudes and behaviour towards them. It may extend to issues of rights, legal constraints and access of public facilities. Equalization of opportunity is seen as an outcome.

OBJECTIVE 2: CONTINUUM *LOCUS OF POWER*: 'FROM COMPLIANCE TO EMPOWERMENT/SELF DIRECTION'

Within the individual model the professional dominates decision making about rehabilitation objectives, plans and interventions and requires from the beneficiary compliance. The

beneficiary is told what to do or not do and receives protocol-like instructions. The WHO statement, however, refers to self-reliance and self-sufficiency. Effective empowerment requires that clients participate in all aspects of the process so that ownership is achieved and benefits are sustainable, providing solutions that are manageable and affordable. Equality of access to local resources and services is a common objective. In many instances empowerment is realized through (in-)formal education, (vocational) training and paid employment, but may equally take place through participation in self-help groups, community based organizations and through processes of active participation in the development of co-operatives.²⁵

OBJECTIVE 3: CONTINUUM *COMMITMENT TO INVOLVE OTHERS*: 'FROM INDIVIDUAL FOCUS VIA FAMILY INVOLVEMENT TO COMMUNITY PARTICIPATION'

Within the rehabilitation process relatives of people with disabilities will be involved in the process of rehabilitation. However, in individual models there is the risk that relatives become only 'the extra pair of hands' of rehabilitation personnel. It is not uncommon that motivation of relatives to become even more involved in the life of their disabled family member is lacking. Expectations of professionals in this regard are often too high and unrealistic given that in fact not only the person with a disability, but the whole family should be seen as disabled: the burden of caring for the disabled family member should not unnecessarily be increased. On the other hand, as stated earlier, the family forms a powerful resource if rightfully involved in the rehabilitation process.

Integrating previously stigmatized or excluded individuals in the community demands a level of community involvement, though this may vary from acknowledgement or mere tolerance through to active encouragement, participation and ownership. Community participation is seen as indispensable to empowerment since only through community participation social, economic and political changes will take place; changes which are imperative in the process of enabling people with disabilities to become integrated into mainstream society.

OBJECTIVE 4: CONTINUUM *TYPE OF RESONSE*: 'FROM PROVISION OF A SINGLE RESOURCE OR SERVICE VIA MULTIPLE SERVICES TO INFORMATION SHARING'

At one end of this scale, projects offer one particular form of rehabilitation such as physiotherapy, a computer course, or an interest-free loan. Other projects offer a range of services within their own organization, while yet another approach is to act as a broker, assisting clients to find what they need in other existing (development) programmes, resources and facilities within the community that are not necessarily explicitly focussed on the rehabilitation of people with disabilities (multisectoral collaboration).

Within the individual model the focus of rehabilitation is usually only on specific disabling conditions that require (specific forms of) rehabilitation, e.g. the improvement of locomotion through physical therapy, or the prevention of disabilities by making appropriate footwear available. In the social model the focus is more on the person as an individual with specific needs and demands: on individuals who live in society and want to live a life in dignity.

Applications

Having proposed these four dimensions of CBR, the focus moves to describe how these may be used to develop a typology of projects. Projects may be classified by assessing their objectives against each of the four dimensions using an agreed scoring or marking system. This involves assessing the level of emphasis placed on the characteristics described in the available project documentation. For each characteristic the scoring system needs to allow three scores, for example 1, 2 and 3. Besides purely individual models (e.g. score up to 6) or entirely social models (e.g. score 10–12), there are various mixed models which will be labelled as such when they score between 7 and 9.

Application of such a scoring procedure to a set of project documents will in theory produce 81 types of similar projects based on the four dimensions described here. In addition, we expect to identify outliers, projects that differ from all others, and non-existent groups, i.e. potential project types where no such projects exist. Each of these outcomes will be of interest. The existence of some groups may be predicted and confirmed. The absence of certain project types may raise questions of policy and funding decisions. The presence of some unexpected types may lead to analysis of local priorities and decision-making.

The following case studies illustrate the result of applying this scoring method to selected CBR projects:

1. *Project amongst disabled children of the Winterveld community, South Africa.* Project aims are to assess the extent of the problem, build the capacity of those providing care (mothers) and enable carers to fulfil a leadership role in providing advocacy in the community on behalf of those with disabilities. Also to work directly for the development of appropriate facilities for severely disabled children. Scoring for this project is as follows:

Dimension	Comment from project outline	Score
Restoration of quality of life	Advocacy . . . for rights	3
Locus of power	Limited mention of shared decision-making	2
Commitment to involve others	Focus on mothers of disabled children	2
Type of response	Work with mothers, plus direct advocacy role	2

2. *CBR in 45 villages of Tamil Nadu, India.* Project addresses needs of children and adults with many different forms of disability in 45 villages, providing appliances and aids, scholarships for schooling and vocational training.²⁷ This results in the following scores:

Dimension	Comment from project outline	Score
Restoration of quality of life	Provide aids and appliances, health education and vocational training	2
Locus of power	Some involvement in planning of activities	2
Commitment to involve others	Focus on disabled children and their parents but as beneficiaries rather than partners	1
Type of response	Variety of activities targeted at people with a variety of disabilities	3

3. *CBR in five rural areas of Bangladesh*. Project²⁸ aims to make the disabled independent, to create awareness in the community, the transfer rehabilitation skills to the community, to raise level of community participation and to mobilize all available resources. Scores can be assigned as follows:

Dimension	Comment from project outline	Score
Restoration of quality of life	To make disabled independent and self-reliant	2
Locus of power	To provide services with intention to raise levels of community participation	2
Commitment to involve others	To transfer rehabilitation skills to community and withdraw services subsequently	3
Type of response	To provide required services, to make programme sustainable	2

From these three case studies some interesting contrasts emerge. For example:

- Only the Winterveld project has a specifically stated objective of advocacy.
- None of the projects put the decision making power firmly in the hands of the beneficiaries.
- The three projects are all different in their commitment to involve others.
- Though the Indian and Bangladeshi projects both define the desired outcome in social and economic terms and agree that a variety of services should be made available, the Bangladesh project appears to have the stronger community dimension.

Application of the proposed CBR model in the context of leprosy

The following section presents an example of a CBR project focusing on the needs of people affected by leprosy and further illustrates the use of the proposed classification method.

In India, TLM is planning to open a series of information centres for people with disabilities, to be known as New Life Centres. The centres will act as meeting places and resource centres for people with any form of disability. Activities will include family or community support, an information centre, occupational therapy and physiotherapy, counselling and vocational guidance, job and training placements. There will also be an advocacy role.

Dimension	Comment from project outline	Score
Restoration of quality of life	counselling, building self-confidence, vocational guidance, some advocacy	2–3
Locus of power	offering options, making information available; interaction between beneficiaries	2
Commitment to involve others	limited community outreach	2–3
Type of response	information about and referral to other services	3

The focus is the centre where beneficiaries meet and are stimulated to make use of the wide range of possibilities presented to them. The involvement of the community is limited but may grow from this work as it becomes more firmly established.

Discussion

We have presented four dimensions that in our opinion permit a characterization of rehabilitation projects based on their objectives. First, we considered whether the desired outcome of project interventions for the beneficiaries was defined in terms of physical function, social integration or in terms of the acceptance of disabled people in society. Second, we asked how power was distributed between providers and beneficiaries. Third, we considered whether target groups were limited to disabled persons themselves or widened to include relatives and/or the community. Finally, we asked what range of services was offered to the beneficiaries, as an indication to what extent solutions could be tailored to their needs.

We believe this method is a useful tool to analyse rehabilitation projects and discuss its strengths and weaknesses. It may be used to help define policy or to guide debates in the project planning stage. For us, it provides a starting point for evaluation of projects as it will guide the formulation of questions relevant to the type of project that is being evaluated.

It is clear that more detailed work is needed on definitions and in describing the criteria used in classifying projects. The reliability and validity of this classification system will eventually need to be checked by arranging for an independent assessment of a set of project proposals and other supporting documents.

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The psychosocial needs of leprosy patients

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In the world of today one finds that between 11 and 12 million people have suffered from leprosy.¹ Much research has been conducted on the medical aspects of leprosy, but there is a need in various parts of the world for specialized studies of the psychosocial aspects of leprosy.² This need relates to the fact that comparatively little research on the psychosocial needs of leprosy patients has been done. In South Africa, a total of 10,812 patients were registered in 1984.¹ It cannot be assumed that patients in South Africa will manifest the same psychosocial needs as leprosy patients in other parts of the world. Judged by research done mainly in other parts of the world, it can be inferred that the psychosocial needs of leprosy patients are dissimilar. Their needs appear to be three-fold: the need for self, societal and community acceptance. Self-stigmatization after diagnosis is not only true of leprosy sufferers,³ and is often of a permanent nature.⁴ Some leprosy sufferers never accept the disease.⁵ A specific need of self-acceptance is required in a sufferer. Many patients are rejected by their families on account of the latter's fear of leprosy. They may even request the patient to leave home.⁶ According to Van Parijs,⁷ one-third of leprosy patients suffer desertion by marriage partners. When a divorce follows after a diagnosis of leprosy, the emotional consequence are even more devastating. Often, leprosy sufferers are treated very unsympathetically.⁸ Leprosy has become symbolic of highly stigmatized and feared circumstances. The rejection of leprosy patients is illustrated by the fact that many lose their work. At the root of the act of rejection lies an employer's fear that the leprosy sufferer may transmit the disease. Leprosy patients may not be sympathetically treated in medical instances; in India, cases have been reported of doctors refusing to treat leprosy patients.^{9,10} Leprosy sufferers have a strong desire to be accepted in the community, especially in the labour market.

There is limited understanding of the psychological needs of leprosy sufferers in South Africa. The purpose of this study is to answer the following questions:

- What is the nature and intensity of the emotional perceptions of the diagnosis of the disease by leprosy sufferers?
- Why do some leprosy patients consult a Sangoma (traditional healer) before consulting a medical doctor?
- Are leprosy sufferers generally satisfied with medical treatment that they receive?
- Is the divorce rate in leprosy sufferers in Southern Africa as high as the rest of the world?

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- How does leprosy affect the family life of the leprosy sufferer?
- Is there any discrimination against leprosy sufferers in the labour market?

Materials and methods

SUBJECTS

The study group ($n = 30$) consisted of 15 black male and 15 black female patients between the ages of 41 and 60 years, selected at random from the leprosy population. The ethnic derivation of the sample is shown in Table 1.

STUDY DESIGN

This study used semi-structured interviews with the aid of an interview schedule with respondents.

PROCEDURE

Biographical information that included medical and psychosocial history was collected from each respondent. Questions concerning the interview schedule were formulated in the respondent's own idiom. Psychosocial needs identified in the literature served as background for the compilation of open as well as closed questions. Questions were asked about the emotional experience, the influence that leprosy had on their married and family life, their subjective perception of hospitalization and how they experienced community rejection. The interviews were restricted to 1 h. The interviewer was a Master's student in Counselling Psychology; a woman who had command of four regional languages in addition to Afrikaans and English served as interpreter. The interviews were conducted at two locations. Interviews were held with 21 institutionalized patients at Westfort Hospital and nine subjects were interviewed in their own environment.

Results

RESPONSE TO DIAGNOSIS OF LEPROSY

During the interview, the respondents had to explain the nature and intensity of a variety of

Table 1. Ethnic derivation of respondents

Ethnic derivation	<i>n</i>
Sotho	7
Swazi	7
Zulu	6
Ndebele	3
Tswana	3
Xhosa	2
Shangan	2

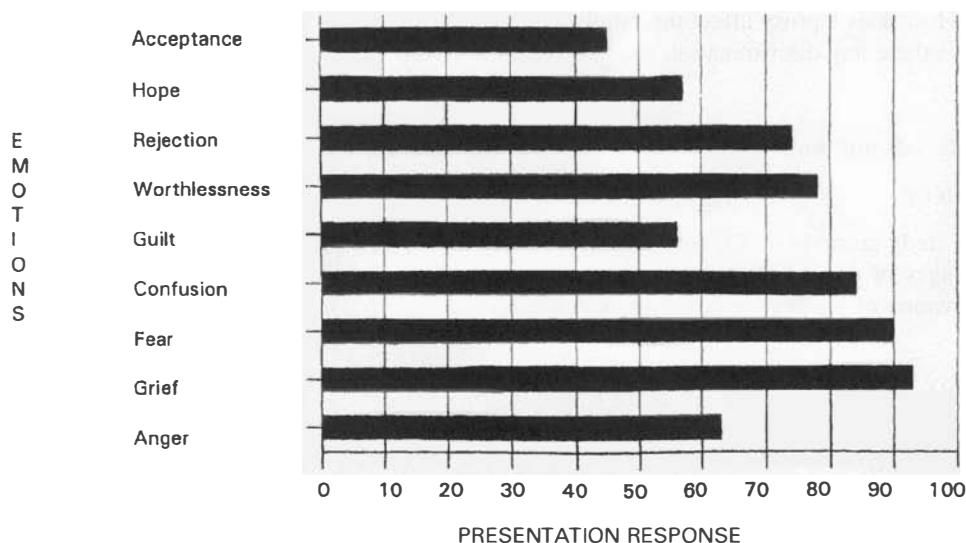


Figure 1. Nature and intensity of emotions directly after diagnosis as obtained by means of semi-structured interviews.

emotions that followed directly after the diagnosis of the illness. They had to grade the intensity of emotions, e.g. anger, grief or fear. The results are shown in Figure 1. Heartsore, fear and bewilderment were the most common emotions directly after diagnosis. Acceptance of the disease and hope for the future scored very low. Subjects blamed God, their ancestors, relations and family members for the disease. Many of the subjects did not know who had brought the disease to them. This could possibly explain the observation that only 10 subjects felt aggression towards the person that had given the disease to them. Intense grief was the most general reaction on hearing the diagnosis of leprosy. The grief originated from the following factors:

- Stigmatization because of certain passages in the Bible. Some leprosy sufferers were isolated because members of the community felt that such patients must be segregated according to biblical injunctions. In spite of these data, religion can offer an emotional crutch for many leprosy sufferers.
- A (sometimes justified) fear of rejection by family, friends and the community. A feeling of distinctiveness within the leprosy community and the resulting loneliness.
- The belief that leprosy is incurable.
- Fears of relatives and the community regarding the contagiousness of the disease. Twenty-six patients reported that people were afraid of physical contact with them.

All respondents worried while they were in hospital. Factors that caused the most worry were: financial matters (23), spouse and/or children while still married (30), subject's attendance at work (28) and possibility that subject might lose his/her job (30).

The majority of leprosy sufferers felt that lengthy institutionalization had more disadvantages than advantages. It is therefore not surprising that respondents rather wish to die. Eleven patients had contemplated suicide; six of these were male.

TRADITIONAL HEALERS

In lieu of medical treatment, 11 subjects first consulted a sangoma before visiting a medical doctor/clinic. The reasons were as follows: belief that a spell had been cast on them, family influences (relatives had convinced the patient that they had been bewitched) and the influence of tradition (observations such as 'This is our doctor'). In some cases where medical doctors were unable to make a diagnosis, some patients turned to sangomas for advice.

SATISFACTION WITH MEDICAL TREATMENT

Only eight subjects stated that they did not believe the medical doctor who told him/her that they had leprosy. Some subjects were of the opinion that the doctors had not imparted the essential medical information to them. In certain cases, a definite fear for the disease among nursing personnel in general hospitals existed. These tendencies led to aggressiveness by some respondents. Generally speaking, the subjects were very satisfied with the treatment they received from the Leprosy Mission and at Westfort Hospital. This is reflected in the fact that 23 of the respondents, after being discharged, requested that a rehabilitation officer or a representative of the Mission should pay them a visit. Only two of 30 leprosy sufferers had been treated insensitively by rehabilitation officers in their own opinion.

MARITAL RELATIONSHIPS

Twenty-three members of the group studied were married at some stage. From this married group, nine men and seven women had been deserted by their marriage partners because of the leprosy. Contributory factors leading to this were an inability to provide security (psychological, social and economic) as well as problems concerning sex with his/her spouse. Of the 21 leprosy sufferers who were partners in a sexually active relationship, nine were less active after they contracted the disease. The following reasons were suggested for this decline:

- A decline in physical strength.
- Impotence.
- Uncertainty about the true feelings of the sexual partner. Some leprosy sufferers were hesitant to make a sexual approach, being under the impression that their spouses had a fear of contracting the disease and therefore did not wish to have sexual intercourse with their partners.
- Embarrassment by ulcers.
- Afraid of the possible transmission of the disease.
- Marriage partner fearful of contracting the disease.

FAMILY LIFE

In certain cases where leprosy sufferers were abandoned by their spouses, the family or their household served as an important source of support. Rejection appeared quite frequently, as 10 of the respondents' families had rejected them after diagnosis. Many of the subjects kept the name of their disease secret. When subjects did make it known, 20 were rejected by their friends. Fear of the transference of the disease is accepted as the largest single cause.

WORK

All subjects were afraid of losing their work, and 17 did not mention the name of their disease to their employers. Doubt about the productivity of sufferers was the main reason why employers displayed a negative attitude towards the subjects. Patients also complained that the disease did indeed handicap them in their daily activities. Lack of mobility was a further handicap to participation in social activities in church, cinemas and dance halls.

Discussion

Leprosy can exercise a strong influence on the behaviour of a leprosy sufferer. Where the disease has been present since childhood, it can influence a patient's behaviour for the rest of life. The high rate of suicidal thoughts by leprosy sufferers (11 in this group) highlights the patient's concept of disease and their way of coping. The identification of the needs of leprosy patients has been presented. A variety of emotions are intensely experienced by leprosy sufferers. Grief appears to be the first and most general reaction. This implies that the leprosy sufferer must receive support as soon as possible. Also, doctors must supply factual information about the disease (and especially about the origin of deformities) to leprosy sufferers as soon as possible after diagnosis. The fear of this disease among some of the nursing staff in general hospitals emphasizes the importance of effective training in the medical aspects of leprosy. Leprosy sufferers in general are negative about lengthy institutionalization. Therefore, hospitalization can have a negative effect on his/her view of the disease. It is important that patients should have the freedom, as far as possible, to decide whether they want to be institutionalized or not.

In many instances, a rehabilitation officer gives a person the first indication that he/she is suffering from leprosy. The swift provision of essential information about the disease to the sufferer and their family and relatives is of utmost importance. At present, the absence of a training programme for field workers on the effective counselling of leprosy sufferers is a concern. The design of such a programme and effective training of field workers is very important.

Marriage and family ties are all influenced by leprosy. Even where communication between leprosy sufferers and their marriage partners is unrestricted, lack of information (with both partners) can cause wrong perceptions about the disease, which in turn have a detrimental influence on the marital relationship and could in some instances even lead to divorce. Rejection by family members is based on a wrong perception regarding the contagiousness of leprosy. If the family members accept the leprosy sufferer after diagnosis, the household members are an indispensable source of support. Churches should intensify their support for patients. Erroneous interpretation of the Bible gives rise to stigmatization, and therefore church teaching should rectify this.

The question can be raised, however, whether employers can be blamed for not employing or retaining the services of leprosy patients when jobs are scarce even for physically fit people. To find a solution, attention should focus on supporting bodies for leprosy sufferers. If leprosy sufferers could receive training while institutionalized, this might enhance their chances of employment.

In conclusion, the psychosocial needs of leprosy sufferers in South Africa are similar to those of leprosy sufferers in other parts of the world in three ways:

- The need for self-acceptance. Respondents' views of life and the way in which they conceptualized the disease were decisive factors for their levels of mental health. The intensity of emotions experienced by leprosy sufferers immediately after diagnosis underscores how important it is to have support immediately available.
- The need for social acceptance. Of leprosy sufferers who had been married during the period of diagnosis, 40% of men and 30% of women were deserted by their spouses. Steyn *et al.*'s¹¹ claim that security (psychological, social and economic) has become increasingly important for some South African black women was substantiated in this study, as male subjects gave this as the reason why their marriage partners had deserted them.
- The need for acceptance by the community. The extent to which the psychosocial needs of leprosy sufferers will be met depends in part on the way in which they are treated by their support systems. These systems include patients, families and relatives, employers, medical doctors and hospital staff. The information transmitted should be consistent.

The following recommendations can be made based on these findings:

- The design, implementation and evaluation of a training programme for leprosy field workers regarding the effective counselling of leprosy sufferers.
- The development of strategies to de-institutionalize leprosy sufferers and to integrate them into the community.
- The design, implementation and evaluation of a marriage enrichment programme for leprosy sufferers and their marriage partners.

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Leprosy: between acceptance and segregation. Community behaviour towards persons affected by leprosy in eastern Nepal

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Summary This study describes community behaviour towards persons affected by leprosy in the eastern Terai districts of Nepal. The results show that 95% of the persons affected by leprosy recognized by the community have visible signs such as wounds, swellings and deformed feet or hands. Persons affected by leprosy still experience negative behaviour. Motives for negative community behaviour are mostly found in the fact that people fear infection by germs, but fear of a curse from God is also mentioned. This study shows that negative community behaviour is still present in eastern Nepal. Leprosy is more than a disease; the disease can nowadays be medically cured, but the sickness of leprosy still remains. Leprosy control programmes should focus on prevention of impairments and disabilities, because it seems that a visible sign is an important trigger for negative community behaviour.

Introduction

Leprosy is more than a biological disease, it is also characterized by social stigma. The origin of social stigma is found in individuals who have certain attributes that do not concur with the prevailing standards of the normal and good in a group. Stigmatized individuals are treated by society in a negative way.

According to Robinson,¹ leprosy can be explained in terms of disease (biomedical perception), illness (self-perception) or sickness (social perception). In this tripartite it is the term sickness that reflects the social stigma. In the case of leprosy, health workers tell patients that they have the disease leprosy according to physical symptoms. The illness leprosy is experienced by the person and this is shaped by social and cultural influences. The sickness leprosy, is the problem as perceived and named by the society, expressed into social stigma.²

In Nepal it seems that persons affected by leprosy have tried to hide their disease, out of fear of negative community behaviour. They stop going to the clinic (non-compliance), which

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seems one of the defence mechanisms to conceal their disease and thus to maintain their social integrity³⁻⁵

The major problem the Eastern Leprosy Control Program in Nepal has to deal with is this high non-compliance rate which has remained stable over the past 5 years at more than 40%.⁶ Looking into the problem of non-compliance, the following three levels were identified to reduce it; the leprosy programme, the person affected by leprosy, and the community. If at any level something is not going well this will influence decisions taken at another level and lead eventually to non-compliance of the patients. For example at programme level, medication must be available and the quality of care must be good. Motivation at the other hand is important at patient level, which can be influenced by the attitude of the community. The studies conducted at programme level³ and patient level⁴ showed that persons affected by leprosy have tried to hide their disease out of fear for negative community behaviour. In this way, stopping going to the clinic (non-compliance) can be seen as one of the defence mechanisms used by patients to conceal their disease and thus to maintain their social integrity.⁵ However, it is not clear if such fear of negative community behaviour is based on stories from the past or on actual experience.

Lots of terrible stories about negative community behaviour are known; persons affected by leprosy were reported to have been buried or burned alive. Other research shows that persons affected by leprosy experience exclusion from social life.⁷ For example, they have to sit and eat separately and are not allowed to use public facilities.^{7,8} They have difficulties in gaining employment or they are refused jobs.⁹⁻¹³ Younger persons affected by leprosy suffer from restrictions at schools.⁷ In general persons affected by leprosy experience unsympathetic reactions, insults, hate, abandonment or rejection.⁸⁻¹¹ Community members also favour some form of segregation; they want persons affected by leprosy to be kept and treated away from their homes and villages.^{12,15}

Unfortunately, no recent data about community behaviour in Nepal, towards persons affected by leprosy were available. The existing research about community behaviour describes community behaviour from more than 5 years ago. Furthermore, most studies do not specify when the events took place. Persons affected by leprosy and not community members are usually interviewed about the experienced community behaviour. As a result, reasons for community behaviour have rarely been investigated. Moreover, most persons have been interviewed in leprosaria, which does not reflect the situation in the community. Many leprosaria are closed nowadays, so these reports do not represent the actual situation at present.

Therefore, this study investigates how communities behave towards persons affected by leprosy in eastern Nepal today and whether fear for negative community behaviour is based on actual behaviour. Furthermore, this research looks into the motives for community behaviour. Based on the results of this study, recommendations to reduce the defaulter rate will be presented.

Materials and methods

The study was conducted in Nepal, in the Eastern Leprosy Control Project (ELCP), a co-operation between His Majesty's Government (HMG) and the Dutch Leprosy Relief Association (NLR). In Nepal the leprosy control programme has been integrated into the basic health services since 1987. Hence persons affected by leprosy are predominately diagnosed and treated at the primary health care level.

Three hundred community members were selected at random in five communities in eastern Nepal (Golbazaar, Barsain, Rangeli, Kuwarkhod and Bhadrapur). Two teams, each consisting of two field workers, interviewed the community members. During the interview notes were made. The research instrument was pre-tested and is shown in Appendix 1.

The community members were asked to tell about community behaviour towards a particular person they knew was affected by leprosy. Asking somebody directly about his own behaviour can result in their giving social acceptable answers; therefore the interviewer asked about behaviour other community members showed towards the patient.

In this way 192 narratives about community behaviour towards persons affected by leprosy were collected. These narratives describe what is told today and give a picture of the past and the situation at present.

Results

RESPONDENTS

Three hundred community members (respondents) were interviewed: 148 men and 152 women. The majority of the respondents was between 21 and 55 years old (73%). The largest group (84%) of them was Hindu. Due to the complexity of the Nepali caste and ethnic group system it was not possible to categorize these data.

Among the 300 community members, 57% could tell about actions taken towards one or two patients they knew, 23% did not know any of the local names for leprosy, 18% knew about leprosy, but were not able to tell about a person affected by leprosy and 2% did not have time to do an interview.

PATIENTS

In total, the respondents could tell about 192 persons affected by leprosy: 144 men and 48 women (75% and 25%, respectively). The majority of persons affected by leprosy were found in the age group between 21 and 55 years old (62%) and again the largest group was Hindu (87%).

Looking at the signs the respondents mentioned in the narratives it is seen that: 5% had no visible signs of leprosy, 10% had only patches or skin rash, 7% had blackness or swelling and 78% had visible deformities or wounds. This means that the majority of the narratives were about persons having deformities and 95% of the persons affected by leprosy has visible signs.

COMMUNITY BEHAVIOUR

Community behaviour mentioned during this study is categorized into the following groups; 'usual behaviour' and four categories dealing with negative behaviour: 'eating limitations', 'individual negative behaviour', 'social-public restrictions' and 'segregation' (Table 1).

The categories had a certain degree of severity, starting with 'eating limitations' and ending with 'segregation'. Persons affected by leprosy were categorized in the group of the most severe behaviour they experienced. For example, a person affected by leprosy who experienced 'eating limitations' and 'social-public restrictions' is placed in group 3. During the pre-test not only negative community behaviour has been found, but also usual behaviour.

Table 1. Categories of community behaviour groups

Group 1 Eating limitations	People do not eat food touched by person affected by leprosy ('jutho'), person affected by leprosy has to eat separately
Group 2 Individual negative behaviour	Person affected by leprosy has to sit separately, is not allowed to enter homes, people do not visit, is hated or ignored, is not allowed to touch
Group 3 Social-public limitations	Person affected by leprosy is not allowed to use public well, not allowed to enter temple, not allowed at school, not allowed in social functions, not allowed to attend festivals, not allowed to use public facilities, not allowed to enter the teashop, problems to get medical care, problems in job, everything separately
Group 4 Segregation	Send out of village
Group 5 Usual behaviour	Person affected by leprosy is allowed to enter homes, everything together, being treated well

A separate group, 'usual behaviour' (group 5), was included for those persons affected by leprosy who did not experience any negative behaviour; they are treated well or the community does everything together with them.

In this research, community behaviour has been divided into different time periods. First, the distinction has been made in behaviour that happened more than 20 years ago, because a period of 20 years is considered to reflect one generation in Nepal. Second, the period '0 to ≤ 5 years' reflects behaviour which have been shown recently. Finally, the community behaviour of the last year have been described separately, to present reliable information and to show what happens nowadays.

Table 2 shows that there has been a trend that during the last 20 years; negative behaviour seems to decrease while usual behaviour seems to increase. Usual behaviour means that community members refrain from negative behaviour. It does not mean that they give real support. It is interesting that no differences towards male and female persons affected by leprosy are found. Furthermore, negative behaviour only ended when a person affected by leprosy died. This occurred in 23 cases.

Table 3 shows that it is hard to distinguish a trend in specific behaviour over the years. However, when we compare the period '5 to ≤ 20 years' to '0 to ≤ 5 years', it seems that negative treating behaviour increases while social public restrictions and segregation decreases. Although segregation decreases, even last year three persons affected by leprosy were sent out of their village.

Table 2. Percentages of negative and usual community behaviour groups, in relation to starting time ($n = 186$)*

	>20 years <i>n</i> (%)	5 to ≤ 20 years <i>n</i> (%)	0 to ≤ 5 years <i>n</i> (%)	0 \leq 1 year (<i>n</i> = 23) %	
Negative behaviour (groups 1, 2, 3, 4)	10 (83)	58 (67)	57 (65)	12	52
Usual behaviour (group 5)	2 (17)	28 (33)	31 (35)	11	48
Total	12 (100)	86 (100)	88 (100)	23	10
				0	

* Six persons affected by leprosy missing.

Table 3. Percentage of negative community behaviour groups, in relation to starting time (n = 125)*

	>20 years n (%)	5 to ≤20 years n (%)	0 to ≤5 years n (%)	0 to ≤1 year n (%)
Group 1 Eating limitations	—	3 (5)	2 (4)	—
Group 2 Negative behaviour	4 (40)	12 (21)	24 (42)	6 (50)
Group 3 Social–public limitations	4 (40)	29 (50)	23 (40)	3 (25)
Group 4 Segregation	2 (20)	14 (24)	8 (14)	3 (25)
Total negative behaviour	10 (100)	58 (100)	57 (100)	12 (100)

* Data on four persons affected by leprosy are missing.

MOTIVES

Motives reported for rejection are mostly found in the fact that respondents think that leprosy is a very contagious disease. Others are afraid of the curse of God, whereas there are also community members who mention both motives as the reason for their behaviour. On the other hand, motives for acceptance depend on the benevolence of the community and on the characteristics of the person affected by leprosy (for example the person affected by leprosy is a child or important community member). Other motives for usual behaviour are that the person affected by leprosy takes medication or that people think that leprosy is not infectious.

Discussion

It is obvious that 77% of the community members know what leprosy is. This is in contradiction with the suspected lack of knowledge about leprosy.

Leprosy seems to be recognized through deformities because more than three-quarters of the narratives are about persons affected by leprosy with deformities. Persons affected by leprosy with deformities are more likely to experience negative community actions than persons affected by leprosy without deformities. Therefore, Prevention of Impairments and Disabilities should get high priority in the leprosy programme.

It was expected that during the last 20 years negative community behaviour would have decreased. Unfortunately, the research shows that negative community behaviour is still present. Even nowadays persons affected by leprosy have to leave their village or are socially isolated. Therefore, it is understandable that persons affected by leprosy try to hide their disease out of fear of negative community actions.

Table 4. Motives for community behaviour

Motives for negative behaviour	%	Motives for unusual behaviour	%
Fear of infection by germs	64	No fear of infection by germs	20
Fear of curse of God	9	Person takes medication (MDT)	27
Infection by germs and curse of God	18	Benevolence of community	24
Other	9	Characteristics of patient	16
		Other	13

Many community members mentioned 'fear of infection by germs' as motive for their behaviour. We also see that community members mention both 'fear of infection by germs' and 'fear of curse of God' as motive for their behaviour. In these cases the perception of the aetiology of leprosy is completely different. It is interesting to see that both ways of interpretation exist at the same time. In Nepal, this dualism is also seen in health seeking behaviour. People often go to traditional healers as well as western doctors, sometimes even at the same time^{2,16}. When we want to reduce the negative behaviour towards persons affected by leprosy, we have to take this dualism into account. Communities should not only be informed about the (Western understanding) of transmission and treatment, but traditional thoughts should also be discussed.

Other research^{8,14} reports that women experience more negative community behaviour than men, however, in this study, no differences between men and women were found. It was expected that in Nepal women would experience more negative behaviour because in daily life women have fewer privileges than men. It is the sickness leprosy which results in negative community behaviour.

In conclusion, the results of this study show that fear of negative community behaviour of persons affected by leprosy is based on actual events. Persons affected by leprosy still experience many limitations and restrictions in their social life, and segregation still occurs. It is therefore very understandable that patients try to hide their disease and therefore stop going to the clinic (non-compliance) or delay seeking help. Leprosy is more than a disease, the disease leprosy can nowadays medically be cured in 1 year, but the sickness (the social perception of leprosy) still remains.

It seems that in the community leprosy is recognized through deformities. Therefore, Prevention of Impairments and Disabilities should be a priority. Health education campaigns should not only focus on signs and symptoms, but communities should also be informed about the (Western) understanding of transmission and treatment, and traditional thoughts should be discussed. In conclusion, leprosy control programs should focus on the acceptance of the sickness leprosy, so that persons affected by leprosy would no longer feel uncomfortable in going to the clinic and would not lose any privileges of social life.

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Appendix 1. Research instrument¹⁷

-
1. Introduction.
 2. Demographic variables of interviewee (name, age, sex, caste, ethnic group, religion).
 3. Leprosy awareness of the interviewee. Has the interviewee heard of the following diseases?
 - Charma rog, Kustha rog, Maha rog, Kord, Soon bairi, Dheen dha (local names for leprosy).
 - How many patients does he know with one of these 'diseases'?
 - Can the interviewee tell something about one patient? (maximum three patients).
 - What is the relation with the patient?
 4. Demographic variables of the person affected by leprosy (name, age, sex, marital status, family type, caste, ethnic group, religion).
 5. Leprosy symptoms of the person affected by leprosy.
 6. Community actions towards the patient. For every action ask: when?, why?
 7. Remarks.
-

Stigma reduction through group counselling of persons affected by leprosy – a pilot study

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Summary Stigmatization of persons with leprosy causes the emotional harm of social, economic and spiritual deprivation. Individual counselling has benefits in addressing these psychosocial problems but is a slow process and effects few people at any one time. Our experience of group counselling of stigmatized persons achieved the following: addressing common issues to more than one person at a time, encouraging the unity of sufferers, developing compassion for others, understanding the common effects of stigmatization, and beginning to overcome its harmful effects.

Introduction

A man who is isolated and alone can be regarded as a sort of discarded person. He is a man cast out of society, and that type of man, in the old days, would have been killed. Let me say this – and I say it very seriously: there is nothing worse than being isolated.

Dinizulu, King of the Zulus, c. 1910

Humans are holistic beings with intricately intertwined parts. Healing an illness such as leprosy has multiple facets, as we look to cure the disease and heal the fear and despair that its diagnosis and stigma engenders. Emotional pain is inflicted upon its sufferers as they are avoided, rejected, and treated as if they were animals. Their own confusion and self-doubts bring on suicidal thoughts and depression. Spiritual pain is endured as they are forbidden to enter places of worship due to the prevailing belief that the disease's aetiology is their 'sinful' state. Economic pain ensues due to reduced ability to work from nerve damage, rejection by their employers or being put out by their family.

Health education about the disease, drug treatment and self-care are important factual and objective reason-orientated aspects of the healing process. However, these alone will not heal the deep-seated wounds that years of rejection have inflicted upon the person's emotions and spirit. To heal these deeper wounds people need healing of their personhood or self-image.¹ 'Many tears have been shed. Those they have loved have turned against them. Now the way back seems hard and hazardous, and the heart shrinks from the prospect of yet another rebuff at the end of the effort.'²

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In October 1993, the Counselling Department at Green Pastures Hospital (GPH), Pokhara, Nepal was started to help heal and rebuild people psychologically and socially. A nurse and a counselling psychologist worked together to understand and respond to the counselling needs of the inpatients. Psychosocial assessments for all inpatients were provided and then individual counselling offered to those needing specific help in emotional, social, spiritual or reproductive health. Patients needing vocational training or an economic assessment were referred to the local Rehabilitation service (Partnership for Rehabilitation). Due to time restraints and the recurring themes of stigmatized patients we decided to conduct a pilot study on the efficacy of group counselling in dealing with stigmatization issues. We surmised that group counselling would help people to: develop relationships as they described their similar sufferings, educate them on the common effects of stigmatisation (i.e. social isolation, depression and decreased self-esteem), and encourage them to think constructively on how they can begin to rebuild their self-esteem and thus, their lives.

Materials and methods

Groups composed of five to seven individuals meet for 2-h sessions each week for 5 weeks. They meet as single sex adult or children's groups. In these groups people are encouraged to remember things from three phases in their lives: before contracting leprosy, after contracting leprosy, and life as an inpatient at GPH. Themes that arise are despair and depression, stigmatization, reconciliation, dependency and rebuilding one's life. Due to the low literacy level of the inpatients, our discussions are supplemented by simple pictures used to further explain these themes.

A database was started including simple leprosy demographics and specific questions regarding WHO Impairment Scores, marital status, and family support. There were 22 counselling groups from March 1994 to February 1998. Seventy-four percent (86/117) had WHO impairment scores of 1 or 2. Women had less family support than men.

Within the first week after admission patients are given a psychosocial assessment. If they demonstrate one or more of the following they are offered group therapy: their own recognition that their low self-esteem is due to stigmatization, they have been rejected by their families, or despondent but not clinically depressed. They are given a brief description of group therapy and their consent to join the group is requested.

The group therapy 5-week cycle follows the pattern described below.

Week 1

We sit in a circle on floor mats or chairs depending upon their physical needs. People are introduced to one another and data are collected. The group process is described and they are encouraged to be active participants in helping one another look at and build their self-esteem. They are told that telling others about their hurtful experiences is painful, but like operating on an ulcer is necessary, likewise, coming to resolution with the past hurts helps to give new energy for building a future. People are then asked to close their eyes and remember in as much detail as possible what their life was like before leprosy. Then a few minutes later, what it was like when they first discovered they had leprosy. Followed by, what it was like over the last few months and years before they came to GPH. They are then asked

to think about their first few days at GPH and then open their eyes. We ask someone to begin by telling us their life story. It often takes one person 30–40 min to tell their life story, so some people will need to tell their story in the second meeting.

Week 2

Most people seem to be more relaxed during this second session. Bonds begin to develop between patients as they hear others tell about their experiences of 'hate filled words from family and friends' and the ensuing isolation that occurred. Often someone will cry during the telling of their story. We encourage someone near them to show a sign of care for the person. In this context, women seem more easily able to put a hand on the person's shoulder or arm. Men, when asked to do so, will put a hand on the person's shoulder, but look less natural in doing so. We also allow time for the person to cry and get in touch with their pain. Many people, especially men, are hesitant when asked to share their story yet after doing so almost all of them are glad to have shared the story of their pain in living with leprosy. We summarize briefly at the end of each person's story and use feeling words to acknowledge the pain the person felt.

Week 3

Teaching and talking about the depression that came from their stigmatisation normalises their depressive feelings, and shows us their mental, emotional, and spiritual resources. As we explain the Cycle of Depression Chart (Figure 1) we refer back to their personal stories or ask for other examples from their lives. Encouragement is given to forgive those who have hurt them and be open again to relationships with these people and others. Some time is allowed for thinking who they want to forgive and writing that name(s) on a paper, or making Xs on a paper to show how many they want to forgive. These papers can then be put into a rubbish bin

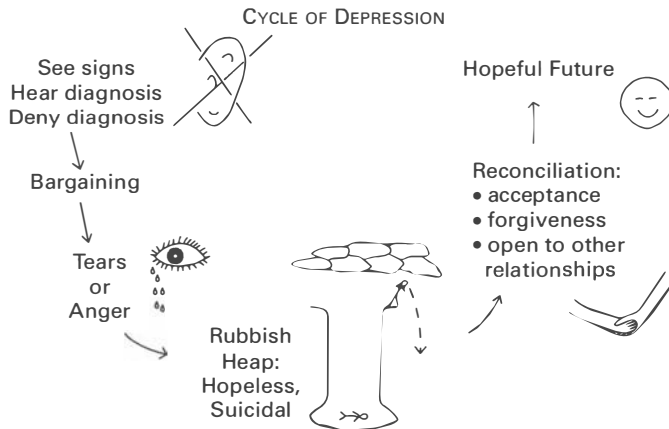


Figure 1. Cycle of depression.

and burned to show that forgiving is finishing with the past hurts and having a clean heart to return home with.

Figure 1 shows our visual representation of the Cycle of Depression. The following information briefly describes each stage of the chart.

- ☐ *Denial* – person hears they have leprosy and denies this diagnosis.
 - ☐ *Bargaining* – person tries to bargain with god(s) to take the disease away stating their intention to be more devout.
 - ☐ *Tears or anger* – people describe themselves as crying on their own for days/weeks once they realize the diagnosis is true. *Anger*, which is a common response to bad news in the west, is not common in Nepal, probably due to Hindu/Buddhist fatalistic belief.
 - ☐ *Hopeless/suicidal* – person feels hopeless. Suicidal thoughts such as jumping off a cliff, often come to their minds. They feel like ‘rubbish or a non-person’. Heaviness, like a very cloudy day, covers any view of the sun (hope).
 - ☐ *Reconciliation* – person comes to peace about their situation.
- Acceptance – they accept the positive and negative aspects of life with leprosy, its disfigurement and disability.
- Forgiveness – they forgive those who have hurt them.
- Open to others – are again open to develop old and new relationships.
- ☐ *Hopeful future* – person has new hopeful vision for their future. They can again be a creative active participant in a community.

Week 4

We discuss the basic needs of humans, relationships with God, security/survival, significance and achievement. Then we look at WHO and WHAT they are dependent on in their lives (Table 1). Their past hierarchy of dependencies became imbalanced. The rejection they have encountered highlights their need to rethink and reset their dependencies. We then discuss options of HOW to meet their needs in the future.

Week 5

We ask people to describe how they viewed themselves before getting leprosy, after getting

Table 1. Hierarchy of factors that people are dependent on. Stigma challenges us to re-evaluate where we put our dependency. People internalize and rate these areas of dependency in various orders according to their age, disabilities, marital status, financial status, etc.

Place in the community
Friendships
Status/caste/profession
Health/job
Family/son(s)
Material wealth: house, animals, gold, possessions
Relationship with God: accepted and loved

leprosy, after coming to GPH and as they think they might be back in their home setting. We then draw this on our white board as a visual image that symbolizes their fears and hopes. Discussion covering the ways in which they have tried to work through stigmatization and maintain relationships occurs addressing new approaches to relationships they might try when they return home. They often feel very stuck and unable to try new approaches. We talk about their relationships and new skills learned in the hospital.

Discussion

From our pilot study we conclude that group counselling is a time efficient and productive method of counselling to use in reducing the effects of stigmatization on people with leprosy. More people can be treated at one time thus using the scarce resource of a counsellor more efficiently. Group participants bond with one another and realize that they are not the only ones who suffer. They understand the 'cycles of depression' that they have previously gone through and discuss practical ideas for reaching a positive hope-filled life for themselves.

Although we believe that group counselling is an efficient and productive method to use for this group of people, our outcome measures are weak. Self-image is difficult to evaluate. It has no objective external scale by which to measure it, but rather a relative scale based on how a person sees themselves compared to those around them, and how others see and respond to them¹. Therefore, the emotional effect of a person with leprosy's disease label or an ensuing impairment, may be out of proportion to the physical disability itself. Using an anxiety scale to test the group members on intake and exit from the group seemed the best method to test for efficacy, however no normative anxiety test is available for Nepal.

Thinking about 'who they are' is one important part in changing a person's low self-esteem. Valencia encourages sufferers to avoid self-pity and transcend their sickness. 'They should be taught to rethink their position in the community (and) positive ideas critical to their return to the folds of society, (that of) their original family and group affiliations.'³ However, only thinking about their low self-esteem will not produce the desired changes of behaviour. Increasing people's ability to act-out their new stronger self-image could be enhanced by role plays of confident and assertive behaviour. These two characteristics are lacking in leprosy patients in the Philippines and Nepal and result in less authoritative and prestigious roles being given to them⁴. Valencia's ³study in the Philippines encourages us to believe that 'the patient has an equal and shared responsibility in reinforcing the negative attitudes of others toward him ... Self-stigma is caused by the patient's inability to assert themselves in family and community affairs, by their wilful consent to be denied access to places where non-affected people can go, and by their quiet and passive acquiescence to actions directed toward them. ... (therefore) they will cease to be significant people in the community.'

Another aspect of improving the group is that of having a 'mentor' for the group, one who has 'gone through the changes themselves'. On four or five occasions there was one person in the group, who although very disabled, had been able to begin to re-develop their self-esteem. This person almost always had an active spiritual aspect to their life with an inner peace and a practical motivation to make the most of their situation. They seemed to have accepted their limitations and were realistic about what they could do to meet their needs. Training a person like this in basic group skills would be a useful tool that self-help groups frequently use.

Counselling alone will not improve the self-image and acceptance of persons with

leprosy. Disabled people are more readily marginalized and rejected from the middle and lower economic groups because their families struggle to feed someone who cannot help produce food or income⁵. Helping the whole family in vocational and economic rehabilitation, would help the family earn enough and therefore, keep the person at home.

Health education for the client, family and community is also necessary to help rebuild the self-esteem of the person with leprosy. Discussions covering the following issues would be beneficial.

The village as one family

1. Acceptance of each person in the village is important. This will go against caste system hierarchy and purity beliefs and will need to be explained in its benefit to the whole community by its love and care for the individual who is a part of the whole, rather than its detriment to the whole community by their uncomfortableness, fear, and rejection of one of them. This is particularly true for how women are treated in a family that they have married into. Women had almost 3 times less family support than men or boys (women had 46.5% negative support, men 16% and boys 20%). In our groups, husbands often divorced their wives after the wife contracted leprosy, but few wives of men with leprosy left them. A few women were put out to live with the animals and feed scraps 'like a dog' while the husband took another wife to live with him.
2. Allowing each person to have a role which benefits the entire village. Thereby, the entire village grows in confidence, efficiency, and output.
3. Impaired and stigmatized individuals may be able to continue in the roles they once had and this will benefit the family and community as these skills will not be lost. They may however, need a change of roles and the Health Worker could help the family/ community to look at which role(s) might be more suitable for them. They may need less strenuous roles or even times of convalescence, but they do need roles that they feel are important.

Group therapy is a good use of scarce counselling resources and we will continue to develop its use in GPH and hope to establish its efficacy in the future.

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Gender differentials in the social and family life of leprosy patients

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Summary A study was carried out at the Leprosy Control Unit, Government Medical College, Nagpur, India, to investigate gender differentials in the social and family life of leprosy patients. The study included 486 (268 males and 218 females) leprosy patients, who were diagnosed and registered at least 1 year prior to the data collection. It was observed that leprosy patients were isolated and refrained from various activities in the family. However, the effect of disease on this isolation was significantly greater in females as compared to males. Similarly, although, men and women were both affected in terms of their social life, women suffered more isolation and rejection from the society. The current study describes the gender differentials in the social and family life of leprosy patients in Central India.

Introduction

Even today, leprosy remains a public health problem in many countries of the world. The South-East Asia region accounts for 90% of the global leprosy burden and India alone accounts for 55%. With the introduction of multi-drug therapy (MDT) in 1982, the leprosy situation in the world changed dramatically. In 1997, for the first time, the number of registered cases reported globally was less than 1 million (0.8 million).¹ With the introduction of MDT, India too has had a significant reduction in the prevalence rates in many states, where MDT is in operation.² However, reduction in registered prevalence alone is not sufficient as the social consequences of the disease on the life of the patient are often severe and persist even after its cure.

Leprosy holds a unique position among communicable diseases because of the frequency of deformity, physical handicap and ostracism due to social stigma.³ This disease is a highly

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stigmatized one and may lead to premature social death among patients.⁴ Once a person is correctly diagnosed as a leprosy patient, his/her roles in the family and society are restricted and constrained.⁴

Women are considered a socially vulnerable group,⁵ and marriage is difficult and acceptance is not total.⁶ The social impact of the disease affliction has been described by earlier researchers,^{3-5, 7-10} but few have investigated gender differentials in the social impact of leprosy.^{5, 11-13} The issue is of considerable significance for women, who are accorded a low social status in many communities in India and receive differential treatment from the members in the family and the wider society. Thus the understanding of the gender differentials in the social and family life of leprosy patients is important. We have performed a study to investigate the gender differentials in the social and family impact of leprosy in Central India.

Materials and methods

The present study was carried out at the Government Medical College Hospital, Nagpur, India. The study centre is a tertiary care hospital with a separate Leprosy Control Unit. A total of 486 patients attending this hospital and who were diagnosed and registered as leprosy patients at least 1 year prior to the data collection for this study, were recruited. Data were collected from this group using a structured interview schedule which included questions seeking information on demographic characteristics (age, sex, socio-economic status, areas of residence and marital status), impact of disease on daily life and attitude of family members, the impact of disease on social life and experiences of interviewees regarding the effects of disease on their lives. The structural interview was designed by framing appropriate questions to obtain required information and were pilot tested before its final use. The socio-economic status was recorded by using the Modified Kuppuswamy's scale of socio-economic status (SES) classification, using occupation, education and per capita income as parameters. This is a 5-point scale, with class I representing the highest socio-economic (Upper) and class V representing the lowest (Lower) status. Classes II, III and IV are represented by Upper middle, Lower middle and Upper lower SES, respectively.¹⁴ Statistical analysis was based on the use of the χ^2 test.

Results

Table 1 describes the subjects by the demographic characteristics. The study included 268 (55.1%) males and 218 (44.9%) females. 39.7% subjects were in the age group 20-40 years followed by 35% in under 20 years. The majority of the patients belonged to upper lower and lower middle socio-economic status and 63.9% patients were from urban areas. A total of 264 (54.3%) subjects were married.

Impact of disease on daily life of leprosy patients and attitude of their family members is described in Table 2. The table presents evidence that the study subjects were isolated or refrained from various activities in the family. However, the effect of disease on this isolation was greater in females as compared to males for all the parameters. Impact of disease on

Table 1. Distribution of subjects by demographic characteristics

Characteristics	Males (<i>n</i> = 268) <i>n</i> (%)	Females (<i>n</i> = 218) <i>n</i> (%)	Total (<i>n</i> = 486) <i>n</i> (%)
<i>Age (years)</i>			
<20	98 (36.6)	72 (33.0)	170 (35.0)
20–40	102 (38.1)	91 (41.7)	193 (39.7)
40+	68 (25.3)	55 (25.3)	123 (25.3)
<i>Socio-economic status</i>			
Lower (class V)	22 (8.2)	19 (8.7)	41 (8.4)
Upper lower (class IV)	108 (40.3)	88 (40.4)	196 (40.3)
Lower middle (class III)	80 (29.9)	66 (30.3)	146 (30.1)
Upper middle (class II)	47 (17.5)	37 (16.9)	84 (17.3)
Upper (class I)	11 (4.1)	8 (3.7)	19 (3.9)
<i>Area of residence</i>			
Urban	187 (69.8)	124 (56.9)	311 (63.9)
Rural	81 (30.2)	94 (43.1)	175 (36.1)
<i>Marital status</i>			
Married	134 (50.0)	130 (59.6)	264 (54.3)
Unmarried	121 (45.1)	69 (31.7)	190 (39.1)
Others	13 (4.9)	19 (8.7)	32 (6.6)

social life of leprosy patients is depicted in Table 3. Although men and women were both affected in terms of their social life, women suffered more isolation and rejection from family and society. The differences in impact of the disease on their social life between males and females were statistically significant. Table 4 shows personal experiences of the study subjects regarding effects of disease on their lives. Although the lives of both men and women were affected by the disease, females showed a significantly greater effect of disease on their lives as compared to males.

Table 2. Impact of disease on day to day life and attitude of family members

Factors	Males (<i>n</i> = 268) <i>n</i> (%)	Females (<i>n</i> = 218) <i>n</i> (%)	<i>P</i> value (χ^2 test)
<i>Isolated/refrained from</i>			
Cooking ^a	—	79 (36.2)	—
Touching others	38 (14.2)	67 (30.7)	< 0.0001
Eating together	19 (7.1)	50 (22.9)	< 0.0001
Sleeping together	54 (20.1)	59 (27.1)	0.073
Sex ^b	33 (24.6)	43 (33.1)	0.130
Using common articles of daily use	43 (16.0)	65 (29.8)	< 0.001
Mixing with other family members	40 (14.9)	59 (27.1)	< 0.001
Decision making in family matters	27 (10.1)	23 (10.6)	0.864
Breastfeeding the child ^c	—	25 (49.0)	—

^a Four male subjects were involved in cooking, who were staying alone.

^b Information related to sexual relationship was obtained from only married study subjects.

^c Information related to breastfeeding was obtained from female subjects (*n* = 51) who were breast feeding their child at the time of diagnosis.

Table 3. Impact of disease on social life

Factors	Males (n = 268)	Females (n = 218)	P value (χ^2 test)
<i>Refrained from</i>			
Going out	29 (10.8)	83 (38.1)	<0.0001
Travelling	32 (11.9)	76 (34.9)	<0.0001
Attending festivals	28 (10.4)	89 (40.8)	<0.00001
Going to the worship ^a places	03 (4.3)	08 (10.8)	.0141
Attending marriages	36 (13.4)	79 (36.2)	<0.0001
Attending family functions	32 (11.9)	77 (35.3)	<0.0001

^a Information was obtained from subjects who used to attend worship places before the diagnosis (males = 70, females = 74).

Discussion

Gender inequalities in health have a significant effect on women's health.¹¹ There are, however, many gender inequalities related to health and disease. The recently published review highlighted that there are many gender differences, biological as well as socio-cultural, which are related to leprosy.¹¹ In leprosy gender inequalities could be more serious, as it is highly stigmatized disease.^{11, 12} Although both men and women are negatively affected in most situations, the extent of the impact is more in women than men.¹² In India⁸ women could not work as efficiently as other female members of the family due to affliction by leprosy.

Considering socio-cultural outcome of disease, several studies indicated that the women were more affected by leprosy,¹¹ they suffered more isolation, rejection from spouses, children and relative, loss of freedom to touch and have more restrictions than men in India.¹² Women with leprosy are less likely to have the opportunity.¹⁴ The empirical evidence presented in the previous studies demonstrated the importance of analysing the situation of leprosy patients from the gender perspective as it has significant implications for disease control.

The degree to which men and women leprosy patients were isolated from their family activities and events is evident from Table 2. It was observed that by and large women were more isolated from all activities than men. Seventy-nine (36.2%) females refrained from cooking activity while 22.9% refrained from eating together. Isolation from touching others was again a strong reaction that many women (30.7%) faced, unlike men (14.2%). It was also

Table 4. Experiences of study subjects about effects of disease on their lives

Personal experiences	Males (n = 268)	Females (n = 218)	P value (χ^2 test)
Support of spouse ^a	69 (51.5)	39 (30.0)	<0.0001
Support of other family members	113 (42.2)	55 (25.2)	<0.0001
Impact on day to day life	39 (14.6)	75 (34.3)	<0.0001
Impact on social life	34 (12.7)	84 (38.5)	<0.0001
Marriage prospects	7 (2.6)	18 (8.3)	<0.005
Insulting treatment by family members	17 (6.3)	56 (25.7)	<0.0001

^a Information was obtained only from married study subjects.

observed that 49% of the breastfeeding mothers did not breastfeed their children. Loss of freedom to touch and to be touched, especially with their children, symbolized rejection. Similarly, they were isolated from sleeping in the same room along with the other family members and mixing with them. More women suffered from isolation from having sex with their spouses, using common articles of daily use and were not involved in decision making in the family matters.

Such isolation from domestic roles develops among women a self-image of being a less valued member of the family.¹⁶ Earlier studies^{4,17} also demonstrated isolation of leprosy patients in their own family from daily activities and attitudes of rejection from their own family members. These issues have not been extensively studied previously in relation to gender in Central India population.

The disease not only affects daily functioning in the family, but also considerable restrictions are enforced on patients due to the fear of social stigma. The impact of disease on the social life of leprosy patients is evident from Table 3. It is observed that more women seem to have these restrictions than men. The proportion of women who refrained from going out, travelling, attending festivals, going to the worship places, attending marriages and even attending family functions was significantly greater than men. Important gender differences were apparent on the social impact of the disease. While both men and women were negatively affected in most situations, the extent of the impact was more in women than men. Such restrictions clearly increase morbidity in women patients, and affect their treatment.¹²

These findings are further endorsed by the experiences reported by the subjects of the effect of disease on their lives (Table 4). A total of 18 (8.3%) of women admitted that the disease affliction affected their marriage prospects compared to 2.6% of men. Women might delay seeking medical care when they suspect having leprosy, since being diagnosed with leprosy might severely reduce their chances of marriage or may affect their position and role in the household when married.

The source of patients recruited for this study needs to be borne in mind when interpreting the findings. The study population is of those attending a tertiary health care facility and they may not be representative of all patients. There is no control group to demonstrate what gender differentials exist in Central India in people without leprosy.

In conclusion, important gender differences have been demonstrated in the family and social impact of leprosy. Although men and women were both affected in terms of their family and social life, women suffered more isolation and rejection from family and society. It can be seen from the current study that the family and social problems faced by women suffering from leprosy were mainly due to the associated social stigma. The need to reduce social stigma is therefore emphasized. To overcome this problem, the community educational component of leprosy control programmes needs to be strengthened. Perhaps groups such as Women's Clubs (which exist in many villages), women school teachers or women members of Panchayat (local village government) can be involved in educating women as well as community.¹² However, it is the attitudes of the community and the family that need to change, rather than the women themselves.

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Delay in presentation and start of treatment in leprosy: experience in an out-patient clinic in Nepal

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Summary Delayed presentation is a recognized risk factor for disability in leprosy but is the result of complex interactions between physical, social, economic and psychological factors. The present study is a response to the situation in an outpatient clinic in Nepal where the wide variation in delay in presentation was a cause for concern. A purpose-written questionnaire was used to collect information on 166 consecutive outpatient admissions. The data included demographics, the first symptom of leprosy, first actions, initial help-seeking behaviour, the reasons for finally seeking treatment and experience with professional health services. Initial analysis found a relationship between delay in presentation and age, rural environment, leprosy classification, walking time, housing not shared with another person affected by leprosy, and an inappropriate first action. The relationship with lack of education and total travel time just failed to reach significance. Further analysis identified that for the study population initial lack of awareness of leprosy and an inappropriate first action were the primary contributors to delay. Extensive and effective health education is needed to address this situation.

Introduction

In order to prevent disability amongst people affected by leprosy much emphasis is placed on encouraging early presentation and a prompt start of treatment. However, published statistics for 1998–1999¹ show a global grade 2 disability rate of 9% with wide variation between countries. Identifying the causes of local variation in delay in presentation remains a matter of concern. The present study was conceived as a response to such a situation in Nepal. The study describes the experience of consecutive new patients newly presenting at an outpatient clinic and seeks to identify the risk factors for delay in presentation.

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In their study in Ethiopia, Bekri *et al.*² identify wrong beliefs about leprosy, low awareness of modern treatment, stigma and the influence of traditional healers or community leaders as important factors associated with delay. Awofeso³ identifies a gap between the true number of people affected by leprosy and the number of cases actually registered. This is made up of people who may be aware of leprosy but delay in presenting, and those who are ignorant of leprosy. While knowledge is an important factor, there are social and cultural pressures that have an impact on decision making and contribute to delay. Even in situations where social pressures are minimal the individual's own perception of the risks involved in diagnosis are a further pressure on decision making. Scambler⁴ distinguished between enacted and felt stigma, the latter referring to fear of discrimination rather than to actual stigma. As a result of perceived stigma, people may adopt a first-choice strategy of non-disclosure and concealment. Scambler's conclusion, though expressed in the context of epilepsy, is very relevant in leprosy, namely that successful concealment resulting from felt stigma may prove more disruptive of people's lives than enacted stigma.

In their study in Tanzania, van der Broek *et al.*⁵ set out to assess the effectiveness of health education activities in changing knowledge, attitudes and behaviour towards leprosy. The authors found that while health education activities had some impact on the knowledge and attitude of school children there was no clear impact on knowledge and attitudes amongst the population at large. Croft and Croft⁶ found that health education programmes in northern Bangladesh had been effective in changing knowledge and attitudes towards leprosy and tuberculosis, though attitudes lagged behind knowledge. Similarly, Raju and Kopparty⁷ found that education programmes had been successful in increasing knowledge about leprosy but stigmatizing attitudes still remained.

It is clear that in describing the reasons for delay in presentation wide ranging medical, social, economic and psychological factors must be considered and their relative importance assessed. The present study seeks to identify the relationship between some such factors and delay in presentation in one location in Nepal.

Materials and methods

The study was carried out at the leprosy referral clinic of Anandaban Leprosy Hospital, which is held weekly in Patan City, Lalitpur, in the Central Region of Nepal. Patients are referred from hospitals within Kathmandu and elsewhere in Nepal. Some patients are referred from Government health posts, others by existing or former patients or family members, often travelling from remote parts of the country. During the period from October 1993 to March 1995, 166 consecutive newly registered patients were studied using a structured interview conducted in Nepali or with a translator if the patient was not Nepali-speaking. In the case of children an accompanying relative was interviewed.

The questionnaire was piloted in the clinic situation. In addition to demographic information, questions were asked about the patient's response to the first symptom of leprosy, their initial help-seeking behaviour, the reasons for finally seeking treatment and their experience with professional health services. Replies to standard questions were coded and entered into computer records for analysis using EPI-INFO and SPSS. A small amount of narrative information was also recorded.

Table 1. Study cohort profile

Sex	48 females (29%), 118 males (71%)
Age	Age range 6–72 years, mean 35.9 years, SD 15.6 years, median 35 years
Education	95 had no education (57%), 33 had 1–5 years schooling (20%), 28 had 6–10 years, 9 had more than 10 years (1 not known)
Occupation	84 farmers (51%), 18 housewives (11%), 11 factory workers (7%), 14 children of school age and 5 students. 9 occupations recorded as professional, clerical or teaching and 19 others included drivers, priests, beggars, fishermen, labourers, milkmen, wholesaler, cook, carpenter, postmen or tailor. Four individuals were retired (2 not known)
Home district, environment	Cases came from 32 of Nepal's 75 Districts. Seventeen (10%) cases were from India. Forty-seven (28%) came from a city or town and 118 (71%) from a rural environment (1 not known)
Distance travelled and cost	Total travel time to clinic: mean 13.4 h, SD 27.4 h, median 7 h Walking time: mean 6.2 h, SD 24.7 h, median 1 h Cost of travel: mean Rs 213, median Rs 60 but 37 cases reported expenditure of Rs 300 or more. For those working on a basic daily wage this represents the equivalent of several days' earnings

Results

The profile of the study cohort is summarized in Table 1. Details of leprosy classification, disability and overall delay to time of presentation are summarized in Table 2. The grade 2 disability rate of 42% reflects the concerns underlying the present study.

DESCRIPTION OF PRESENTATION AND DIAGNOSIS

Patients were asked about the first sign or symptom of leprosy. The most common signs were: patches (86), tingling (28), anaesthesia (28), ulcer (12) and swelling (7). The remaining five cases exhibited muscle weakness (foot drop), auricular nerve enlargement, dry skin, pain and fever.

Patients were asked what their first action was after discovering their first symptom. The largest group (42 cases, 25%) had done nothing until coming to the clinic, 36 (22%) had gone to visit the jankri or traditional faith healer, 35 (21%) had visited a private doctor, 15 (9%) had attended a hospital, 14 (8%) had attended their local health post, 13 (8%) had gone to a medicine shop and seven had used ointments from a variety of sources.

Patients were asked how long ago they first became aware of the possibility of leprosy. Eighty-three individuals (50%) said that they had only just realized the possibility, 55 (33%) said they did not know at the point of interview that they had leprosy, 28 (17%) had thought

Table 2. Leprosy classification, WHO Disability Grade, and Delay in Presentation

Classification	22 cases (13%) tuberculoid, 101 (61%) borderline (BT, BB and BL combined), 16 (10%) lepromatous. 5 (3%) indeterminate, 22 PN (13%)
WHO Disability Grade— (165 cases graded)	48 cases had grade I disability (29%), 48 (29%) had grade 2, 69 (42%) grade 3
Delay from first symptom to presentation for treatment	Range from within the past month to 35 years previously, mean 37.6 months, SD 58.9 months, median 18 months

they might have leprosy more than 6 months previously and of these only 7 (4%) thought they might have leprosy more than 4 years previously.

The most common reasons for not seeking treatment earlier was failure to recognize the possibility of leprosy (87 cases, 52%). Seventeen cases (10%) gave reasons relating to practical difficulties, the distance and actual or perceived cost of travel, a heavy workload or lost earning opportunity, seven cases (4%) did not know of the availability of treatment or of clinics, five cases (3%) reported reasons of fear and social consequences while five others spoke in terms of not having anyone to help them, suggesting at least a measure of isolation, 11 cases (7%) had attended health posts or bought drugs at local pharmacies and 26 (16%) were judged not to have delayed.

The most common single means of referral was by another person affected by leprosy (35 cases, 21%). Referrals by relatives, friends, neighbours or other individuals totalled 53 (32%), referrals from various health service providers totalled 66 (40%) and eight cases living locally referred themselves. Of 94 individuals reporting earlier contact with professional health services 38 said that a leprosy diagnosis had not been confirmed (40%).

Forty-two cases (25%) had family members affected by leprosy, 21 of which lived in the same house (two cases not recorded).

FACTORS ASSOCIATED WITH DELAY IN PRESENTATION

We assessed relationships between delay in presentation and the factors described above. We found the expected pattern of delay relating to leprosy classification with longer delays in lepromatous patients. There was a strong relationship between delay and the WHO Disability Grade, with 28% of cases delaying up to 2 years having grade 2 disability.

There was no association between sex and delay in presentation but there was a relationship between age and delay, younger people tending to present earlier. The association between delay in presentation and education was not statistically significant.

Where an individual shared a house with another person affected by leprosy, delay in seeking treatment was reduced compared to those who did not. The development of ulcers were the most commonly reported reason for final presentation. Only five individuals volunteered that social stigma delayed their presentation for treatment. Cases who took help from traditional healers or took no action at all had longer delays in presentation. Of 94 cases attending local health posts or local doctors, 38 (40%) had not had a leprosy diagnosis confirmed.

We found that living in a rural area was a significant indicator for delay. Walking time showed a very significant relationship with delayed presentation.

UNDERLYING RISK FACTORS

A number of variables (six) described above were found to be related to delay in presentation: age, delay to first action, urban/rural, walking time, classification and shared house. In order to ascertain their relative importance the six variables showing a statistically significant association together with educational level and travel time were subjected to a logistic regression. The results are presented in Table 3.

The multivariable regression provides an insight into the contribution of individual variables after adjusting for the effect of others. The two variables that are as statistically significant both relate to awareness of leprosy—a first action not directed towards

Table 3. Results of univariate and multivariate regression

	Single variable (univariate) regression analysis		Multivariate regression analysis	
	Exp(B)	Sig. Level	Exp(B)	Sig. Level
Age (± 35)	0.44	$P < 0.01$	0.65	NS
Education	2.12	$P = 0.057$	2.71	0.090
Rural/urban	0.47	$P < 0.05$	0.81	NS
Travel time	0.55	$P = 0.055$	0.58	NS
Walking time	0.43	$P < 0.05$	0.82	NS
Classification	0.39	$P < 0.05$	0.45	NS
Shared house	3.25	$P < 0.05$	4.23	$P < 0.05$
First action	0.43	$P < 0.05$	0.33	$P < 0.05$

professional health service providers and not sharing a house with another person affected by leprosy.

Discussion

Where individuals recognize increasing signs of disease, continuing delay in presentation is the result of an on-going process in which physical impact is only one of several factors affecting decision-making. Each change is assessed in the context of changes in knowledge and awareness of leprosy and the perceived or actual social or economic costs involved in being diagnosed and treated. Only when these processes are understood can we achieve earlier presentation and a reduced disability rate.

It is apparent that progress across these three continua of development of physical disease, increased awareness and a series of actions will be highly individualistic. For some individuals the learning process may be slow, for others there may be partial prior knowledge. The beliefs and attitudes of the wider community provide the context for assessing the risks involved in being diagnosed and recognized as a person affected by leprosy. There can therefore be no simple ordering of events or imposition of a standard time frame. Van de Weg *et al.*⁸ in their study of explanatory models and help-seeking behaviour in Nigeria found that differences in understandings of sickness and treatments resulted in widely varying choices and outcomes.

In conclusion, 50% of the study cohort delayed presentation for more than 18 months from time of first symptom (mean 37.6 months). For the cases included in the present study the most significant single factor causing delay in presentation and start of conventional treatment was ignorance of the disease. Amongst those who went to professional health services 40% did not receive a definite leprosy diagnosis. Fear of social consequences was not identified as a primary factor in delay though there is anecdotal evidence to suggest that some individuals were successful in concealing the disease from close relatives.

The present study has explored the relationship between selected clinical, knowledge, social and health service factors and delayed presentation. Future studies may address these factors in greater detail, using qualitative as well as quantitative methods and exploring knowledge, attitudes and practice in the community at large and amongst health service

professionals as well as amongst those directly affected by leprosy. Where groups are found with high levels of disability the concern must be to build an understanding of the full range of contributing factors and to address these through improved targeting and more effective programme activities.

Acknowledgements

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SHORT REPORT

Small loan schemes: the experience of Ethiopia

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Introduction

Leprosy is a medico-social problem and more than a disease. Statistics indicate that the disease, as a medical problem, has been decreasing steadily world wide since the advent of multi-drug therapy (MDT) in the early 1980s. However, the social dimensions of the disease in terms of stigma, poverty, disabilities and deformities, loss of self-respect and dignity have continued to constitute a major social problem in many developing countries.

Until the 1970s, rehabilitation in Ethiopia was merely considered as an act of charity. It was undertaken by religious persons and institutions. Throughout the 1940s and 1950s patients were kept within the leprosy hospitals compounds where they were provided with shelter, food, and sometimes clothing in addition to medical treatment. In Addis Ababa, a volunteer (also a missionary) established a sheltered workshop in 1950 for 250 persons. The German Leprosy Relief Association (GLRA) established the Relief Center Bisidimo for treatment and rehabilitation of patients in 1958. A group of volunteers from Haile Sellassie I University (now named Addis Ababa University) initiated a resettlement and rehabilitation project for 80 displaced leprosy-afflicted families. In the north (Boru Meda) the Society of International Missionaries (SIM) used to provide rehabilitation services for patients; a sheltered workshop that has accommodated 62 households was erected at the end of the 1960s. The American Missionaries had been undertaking rehabilitation activities in Kuyera, near Shashemene, 240 km south of Addis Ababa; a total of about 570 families were resettled around the hospital to carry out farming on individual bases in 1950 and 1966.

Generally however, the pre-1970 rehabilitation efforts were all institutional. In the early and mid-1970s, approaches had incorporated some of the features of institutional and community based rehabilitation (CBR).

In a country where there is no clear social policy, rehabilitation takes many forms and up to 1990, rehabilitation in Ethiopia had been sporadic. Neither the National Leprosy Control Programme (NLCP) nor the donor agency (GLRA) had a clear policy on rehabilitation; they were concerned with the medical aspects of the problem. In 1988, GLRA in collaboration with NLCP set up a Social Rehabilitation Department with in the NLCP, to coordinate and promote rehabilitation activities. Since 1999 the government of Ethiopia has adopted a social policy (preventive, developmental and rehabilitative).

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In 1990 the Social Rehabilitation Department, GLRA-Ethiopia, made a study of the conventional rehabilitation centres, sheltered workshops and colonies, which comprised about 48,000 people affected by leprosy. Most of these communities/rehabilitation centres could not be self-supportive. A 3-year pilot programme was adopted in selected areas of the country using the CBR approach.

The aim of the small loan pilot project was to promote full participation and enhance integration of those affected into mainstream community life in their respective communities through alleviation of their social and economic problems that made such an involvement difficult hitherto. A revolving fund was allocated for the project to provide interest free loans to help set up new self-identified income generation (self-employment) facility or to maintain and improve existing ones.

At the end of the project period, December 1997, a study was conducted to evaluate the performance, and impacts of the pilot project on the beneficiaries. Specifically, the objectives of the study were to:

- Identify weakness and strengths of the small loan approach and its components in social and economic rehabilitation for people affected by leprosy.
- Produce information necessary for preparation of a guidance manual for implementation of the program in the future.
- Provide information to others interested in micro-credit schemes.
- Assist in development and improvement of project's internal monitoring and evaluation system.
- Set out recommendations on how best the programme can achieve its stated objectives during its subsequent phase(s).

Based on the outcomes and recommendations of the evaluation study, the programme has been launched in full in various other parts of the country since 1998. This paper presents the results of the evaluation study of the pilot project and the status of the programme in Ethiopia.

Materials and methods

The evaluation study was conducted in Gondar, Gojjam, Wollo and Addis Ababa programme areas. A sample of 36 beneficiaries/clients was drawn from a total population of 168 (beneficiaries) using simple random sampling technique. All questionnaires were administered to individual client by the researchers. This gave the researchers the chance to observe and communicate personally with respondents, their family and other relevant community members and leprosy control and programme staff, all of whom are involved in the programme.

A structured interview composed of open and close questions, case studies, participation observation, quantitative notes and reports documented by the program were used as data gathering tools to generate both quantitative and qualitative data.

The questionnaires were thoroughly examined and commented on by the rehabilitation officers and pre-tested on a randomly selected other beneficiaries. As part of its internal monitoring and follow-up mechanism, the programme holder had a database on the pilot project in the form of quarterly review meetings, annual progress reports and individual beneficiary files. Individual beneficiary files at project site were reviewed to obtain a more detailed information on frequency and helpfulness of follow up visits, level of technical assistance provided and level of loan repayment collection. The data for the assessment of the

status of the programme for the years 1998 and 1999 were obtained from quarterly and annual review meetings and reports.

Results

The sample of 36 beneficiaries included 22 men and 14 women, with two aged more than 60 years. Two-thirds of the clients were married while the remaining one-third were equally distributed among separated/divorced, widowed and single.

Seventy-eight percent of the clients had grade II disability and the remaining 22% had no visible disabilities.

As a result of the project, a change in the employment pattern of the study population was observed. The project created self-employment opportunity for some, others were engaged in new trades abandoning the previous ones, while still others expanded the existing trades.

There were a few cases where the loan taken to finance income-generating activity was spent totally or partially on non-income generation activity such like purchasing clothes and acquiring urban land from local authorities for house construction.

Respondents were asked to evaluate their economic and living conditions, to assess the attitude of their family and community towards them by comparing the situations before and after their involvement in the project. Savings, income, food intake, clothing and housing had improved for most clients. This implied that the pilot project had helped to improve the economic and living conditions of the study population as perceived by the respondents. It was observed that out of 22 clients who had their own 'house', nearly half had improved them either by renovating or reconstructing from the income accrued.

The pilot project had set out a fairly elaborate loan security procedures and repayment schedule. Analysis of the degree of compliance of the clients (loanees) to the terms and conditions set out for the loan scheme indicated that the majority (61%) always made regular repayments. A few clients (17%) showed some 'irregularities' in their repayment schedule, but in the strict sense, it was hard to label them as 'irregulars', because most updated their repayment status by making all their overdue payments at one time or during the preceding periods. The overall repayment rate was 78%. Assessment of follow-up reports and beneficiary files showed that all the defaulters were those who received a loan during the first year of the project.

SOCIAL AND ATTITUDINAL ASPECTS

As regards the attitudinal change and social relationships, over 86% (31/36) of the study population reported that attitudes of their community and family members towards them had improved considerably. This was expressed in terms of development and improvement of social relationships, membership in funeral societies and respect and recognition among their neighbours and family members.

Discussion

Apart from its (the loan component) contribution to development and strengthening of the local micro-economy, the pilot project has brought about a number of positive impacts on the

majority of the study population. The major impacts could be classified as economic, social and attitudinal.

Given the high degree of physical disabilities, lack of experience in running business, and the social and economic environment the clients operate, the repayment rate of 78% was generally high and encouraging.

Based on the evaluation outcome and recommendation, a 5-year project (1998–2002) was prepared and submitted to GLRA-HQ for approval. The programme at full scale started in 1998.

Flexibility of project staff on loan repayment collection/schedules was important. The relatively high repayment rate of loans was not only because the clients were successful in their self-employment, but there was good understanding between the staff and the clients. The staff made regular follow-up visits, gave advice to their clients and were flexible on repayment collection schedules should a client have a problem. They gave more consideration to the client's problem than to the financial aspects of the programme.

In a loan scheme for leprosy affected people with some socio-economic problems, repayment rate alone should not be assumed as a measure of success of the rehabilitation programme, since financial assistance alone could not bring a change in clients way of life.

Inclusion of other people with non-leprosy disabilities, who live close to and share the same social and economic deprivation with leprosy affected people will facilitate the change in attitude both among the non-leprosy disabled and in the community.

Timely follow-up and advice is indispensable for clients who are engaged in new trade and have no family support. Gradual transfer of loan clients to the formal financial institutions (micro-finance enterprises) is the ultimate aim of the interest-free loan scheme. Otherwise, soft loans may create a new form of dependency on the beneficiaries, should the loan continue for several phases. It will also create jealousy among community members where beneficiaries live.

SHORT REPORT

Evaluation of a housing programme

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The BMZ (German Federal Ministry of Co-operation) housing programme implemented through the German Leprosy Relief Association Rehabilitation Fund aims at providing houses for persons cured of leprosy and at improving their quality of life.

The housing programme was started in 1987 and has been implemented in 28 centres, benefiting 704 persons across India. In this programme, former leprosy patients were given interest-free loans of amounts ranging from Rs. 10,000 to 30,000 for the purpose of building a house of their own, to be paid back in instalments each month. The money is kept in the respective centres as a revolving fund from which loans for house construction are given to fresh applicants.

The programme was evaluated after 10 years to assess continuity and the benefits not only for leprosy cured persons but also for his/her whole family. The German Leprosy Relief Association Madras, the centre that receives the GLRA support to implement this programme, and the beneficiaries are the three main participants in the rehabilitation work. In this evaluation study, all three participants are included.

Materials and methods

For the purpose of evaluation, separate interview schedules were prepared for the three participants. The interview schedules for the Project Heads covered mostly the administration and monitoring of the programme and also their impressions of it. The interview schedule for the beneficiaries focused mainly on the benefits gained and their impressions.

The study covered 23 centres, which represents all the regions. All the 23 Project Heads and a sample of respondents were selected for interview. Table 1 gives the distribution by state of the centres selected, the sample from each centre and the total.

Results

The co-operation of the centres is greatly appreciated by the German Leprosy Relief Association Madras. The main problem with various centres is the delayed response for routine requests, which results in delayed start to the programme.

PROJECT CENTRES

The Project Centres selected for the study are involved in leprosy control work along with rehabilitation. The Project Heads expressed views that the leprosy cured persons should be

Table 1. Centres and respondents by state

State no.	State	No. of centres	No. of respondents
1	Tamil Nadu	8	24
2	West Bengal	2	6
3	Bihar	2	6
4	Orissa	1	3
5	Andhra Pradesh	4	12
6	Kerala	3	3
7	Rajasthan	1	3
8	Maharashtra	2	6
	Total	23	68

supported through the housing programme, which helps them to live as normal persons in society; interest should not be charged for the loan distributed; and the loan amount should be raised when required.

The centres in urban areas like Calcutta and Madras find it difficult to identify the persons for whom the loan can be given, because finding a leprosy cured persons with necessary land documents is a difficult task. Some have managed this problem on their own initiative; for example, one centre has pooled all the money from the housing programme and added their own contribution to construct a decent house at the urban centre, while others have helped the beneficiaries to buy land by raising funds from other sources.

Centres have different opinions about collecting back the money from the beneficiaries. The slow progress in this aspect may be due to the lack of staff, or the attitude of the patients.

BENEFICIARIES

Of the 68 beneficiaries interviewed, 44 were males and the remaining 24 were females. Twenty-nine were from rural areas and 39 from urban areas. Fifty-one were Hindus, 11 Christians and six Muslims. Fifty-five were married, two were unmarried and 11 were widowed or separated. Forty-six claimed to be literate and 21 had some form of deformity.

The beneficiaries had different occupations, including unemployed (19), and business (17). They had acquired loans at different time periods, starting from 1987 to 1995. Hence, the loan amount differed from one group of beneficiaries to another. When the programme was started, the loan amount was fixed as Rs. 10,000 each, which was gradually increased to Rs. 30,000.

The centres followed different methods in distributing the loan amount. Some gave money directly to the beneficiary in two or three stages, as the construction work progressed, others paid the expenditure bills incurred by the beneficiary. Some centres also took charge of construction work, and while the burden on the beneficiary is reduced to a greater extent, the freedom to design and have a home to their own taste is lost.

The sufficiency of the loan amount is closely related to the size and type of the house one wants to have; in certain cases, the loan amount is not enough to complete a house. In the majority of cases, beneficiaries have invested their own funds to complete the construction. During the study, it was thought that beneficiaries would find it very difficult to manage the extra cost of the construction, but in fact no-one complained about this. In fact, they were all eager to raise more money and build a house.

The beneficiaries also contributed their labour for building the house. The whole family participated in the construction, and the beneficiaries happily recollected how their relatives from far-off places came to help in the construction.

The housing scheme has improved the lifestyle and standard of living of former leprosy patients. Not all the beneficiaries were without a roof or living place before occupying their present house. To understand and appreciate the significance of the programme, one must know the brief family history of these beneficiaries.

A further 16 beneficiaries who had been living in rented huts built new homes of their own. Those who already had their own houses improved the condition of the house. Fifty-three beneficiaries now have tiled roofs. Electricity is available in 48 of the 68 houses visited. All the houses in urban areas have electricity. The houses in the rural areas of northern states in particular lack electricity. This is a feature common in every village, and is not specific to leprosy cured persons. A common complaint was the huge amount of money required to get a new electricity connection. Some beneficiaries asked for a further load to pay for this.

Only 26 houses had their own water source, that is, a well or tap water meant exclusively for their own use. In India, even in an urban area, people rely on public water systems. They do not plan for having a water supply in their own home, which explains why a number of beneficiaries do not opt for a water supply in their home. The beneficiaries do not like to have a toilet in their home, as a toilet is considered a luxury meant only for the rich. Constructing a toilet means additional expenses. It is interesting to note that the money given to a beneficiary to construct a toilet was instead used to build a kitchen.

Eleven beneficiaries have rented out a portion of their house to tenants. They seemed to have had this idea even before the construction of the house, as they built two separate units, one for themselves and the other for the tenant. Some beneficiaries have converted the front portion of their house as shops. Beneficiaries have therefore been able to turn the housing programme into an income-generating project.

Though the follow-up workers from many centres have reported poor repayment from the beneficiaries, in reality they have made significant progress in collection. From the study sample, 36 persons were found to be regular in their payments. The others paid as and when they were able.

Conclusions

Having a home has brought for the beneficiary a new social world. Some have married off their children. New babies have arrived. The social stigma, which is the greatest problem associated with this disease, has vanished in the beneficiaries' new-found life.

SHORT REPORT

Report on WHO AIFO Joint Workshop

A workshop entitled 'Working Together for the Consequences of Leprosy' was held at the World Health Organisation (WHO) in Geneva, 25–27 September 2000. The workshop was hosted by WHO and jointly supported by AIFO (Associazione Italiana Amici di Raoul Follereau). The participants included representatives of these two organizations as well as national governments, and national and international non-governmental organizations. This is a draft summary of the workshop and a full report of the workshop is being prepared for publication.

Summary

More than 10 million persons affected by leprosy have been cured with MDT in the last decade. However, many of those cured still continue to face problems due to existing or potential, physical and/or psycho-social disabilities. Many of them need particular care of the affected eyes, hands and feet to prevent onset of serious disabilities.

The main objective of the workshop was that of promoting a better understanding of the rehabilitation needs of persons having physical, psychological, and socio-economic disabilities due to leprosy. Another task was that of identifying strategies for leprosy work in the changing context of health services, leprosy control programmes, rehabilitation services, and community-based rehabilitation (CBR) programmes.

During the workshop, an attempt was made to quantify rehabilitation needs deriving from leprosy in specific areas or countries, as well as world-wide. Report about the global situation of leprosy as well as some country/project reports from Brazil, Ghana, Indonesia, China and Karnataka State (India), were presented. Based on global data from WHO, there are an estimated 3 million persons with leprosy-related physical disabilities (grade 1 and 2) in the world. Most of these need to practice prevention of impairment and disability (POID) activities to prevent worsening of existing impairments. Studies done by IDEA, DAHW and ALES suggest that up to 35% of leprosy-affected persons may need socio-economic rehabilitation.

Reports and discussions provided the basis for the identification of some key issues, for which the workshop participants made the recommendations. It was acknowledged that changes in rehabilitation approaches are required as a result of decreasing prevalence of disease and the shift from vertical leprosy programmes to the integration of leprosy into the PHC (Primary Health Care) system. New approaches would also help to decrease stigma and to increase coverage of POID and rehabilitation services.

Emphasis was placed on the need to adopt a multi-sectoral, holistic approach to address the issue of physical and socio-economic rehabilitation. The different and complex issues related to the rehabilitation of leprosy disabled persons can only be adequately addressed if

the affected persons, their families, communities, leprosy experts, and authorities in various sectors act as true partners. Empowerment and active participation of affected persons were acknowledged as indispensable, particularly in identification of rehabilitation needs, advocacy and the creation of effective networks at various levels.

For better assessment of physical disabilities and rehabilitation needs, leprosy programmes should be encouraged to collect disability data on a cohort basis. Particular attention may be needed for countries which have reached the elimination goal and where incidence of disability among new cases is increasing.

Despite the encouraging achievements of the past decade, some of the old leprosaria may be still needed to take care of persons with severe chronic disabilities.

Letters to the Editor

UNMET NEEDS OF REHABILITATION IN LEPROSY SERVICES

Editor

Leprosy, a disease caused by *Mycobacterium leprae*, if untreated results in various degrees of disability, deformity, debilitation, destitution and death.¹ The current leprosy services place great emphasis on MDT coverage but generally ignore preventative and timely management of disability, both physical and social.² Leprosy is a socio-medical disease, but the social aspect is often neglected. Usually a sick person is cared for by family members to become independent,³ which is not so with leprosy patients, who either hide the disease from their families or are disowned by them.^{3,4} Each person has a status and a role in society;⁵ inability to perform this role makes it difficult to meet the needs in life, especially as a main breadwinner of the family.

The Scheffelin Leprosy Research and Training Centre, Karigiri, has been responsible for carrying out the national leprosy control programme since 1962 in Gudiyatham Taluk (population 360,000 in 1961) of Vellore District in Tamil Nadu State. All patients detected are registered for treatment and followed up. Relevant data at registration and during follow-up to release from treatment (RFT) and are stored on a computer system. All persons registered during 1955–1985 were visited to assess their disease/deformity status and well-being. In 1989, it was decided to survey all persons registered for leprosy treatment to assess their medical and socio-economic needs.

There were 16,601 cured leprosy patients during 1955–1985, of whom 9245 could be interviewed; the remaining 7356 had died or migrated. A special proforma was developed to identify various medical and rehabilitation needs, and a multi-disciplinary team collected the data.⁶

More females (79%) had no source of independent living as compared to males (65%). Nearly 75% of the persons affected by leprosy had no land of their own, which is a reflection of their economic status in the community. Nearly 10% of the persons did not have their own shelter. Out of 9245 interviewed, 2040 (22%) were identified as having various rehabilitation needs. Six hundred and sixty (7.13%) needed socio-economic assistance and the remaining 1380 (49.2%) required some medical assistance. In all, 1275 persons (14%) had grade 2 deformity or more.

For the vast majority of persons treated in the pre-MDT era, rehabilitation help came rather late. Most had adapted themselves to a life of dependency or destitution. Many were suffering from a variety of general debilitating conditions. Among the persons requiring social assistance, more than half were in need of self-employment. The second highest category of persons were those in need of a pension/subsistence allowance. An overwhelming majority in this category were over 60 years of age and incapable of productive employment. The rest were in need of job placement and training.

The need for timely, effective and acceptable methods for socio-economic integration of leprosy cured persons is great. Assistance offered so far had ranged from simple welfare measures to enabling independence.^{2,7} Unless economic support is under-girded by strengthening social networks within the family and outside, they are likely to fail.⁸ Public health measures and rehabilitation programmes have not addressed this issue adequately.⁹ In a country such as India with over-population, illiteracy and poverty, the need for identifying effective and appropriate strategies is evident.^{3,10}

Several articles have referred to the needs of rehabilitation among leprosy patients, but no systematic

follow-up seems to have been done in the rural areas.^{11,12} A study done by Kushwah *et al.* in 1981 shows that even in a well-run leprosy control project, 9% had rehabilitation needs.¹³

Persons cured from leprosy have a wide variety of needs and should be offered a wide variety of vocations, compared to the traditional type of rehabilitation based on sheltered workshop in order to prevent them from debilitation. True community-based rehabilitation is essentially participatory, supplemented by counselling and assistance for those who find it difficult to take independent decisions. For those severely disabled who cannot be vocationally rehabilitated, the assistance should be extended to a family member, provided community support is attached to it.

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Letter to the Editor

ILEP SER GUIDELINES

Editor

The recent edition of the ILEP SER guidelines has been used by TLMI in a workshop for their African staff. Mr Peter Nicholls and Miss June Nash facilitated the workshop using the Guidelines as the basic text. The workshop was very interactive, with activities helping the workers to understand some of the new principles outlined in the Guidelines.

Some of the issues of economics and qualitative research were new to the medically oriented group of doctors, nurses and therapists. They appreciated a chance to discuss their case histories and to discuss solutions that might be appropriate in their home situations.

It was felt that the chance to meet together and have input from Peter Nicholls was a useful way of introducing the Guidelines to workers, and greatly enhanced their usefulness in the field.

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