

GUEST EDITORIAL

BEST PRACTICES IN THE SOCIO-ECONOMIC REHABILITATION OF PERSONS AFFECTED BY LEPROSY AND OTHER MARGINALISED PEOPLE IN THEIR COMMUNITIES: FINDINGS FROM NINE EVALUATIONS IN BANGLADESH, INDIA AND AFRICA

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ABSTRACT

This paper presents an overview of findings from the formal evaluation of 9 socio-economic rehabilitation programmes (SER), in 4 countries in Africa, in Bangladesh and in India from 2002-2005. Bringing together the recommendations resulted in a description of best practices in the implementation of socio-economic rehabilitation programmes, derived from actual experiences in different contexts.

All the 9 programmes focused on supporting individual leprosy-affected beneficiaries or their families. Four projects also supported other marginalised clients. The usual interventions were micro-credit, housing and sponsoring of education for the children.

The recommendations touched upon each of the five steps in individual rehabilitation: Selection of clients, needs assessment, choosing an intervention, monitoring / follow--up of clients during rehabilitation, and separation at the end of the rehabilitation process. The evaluators also suggested ways in which participation of the client in their own rehabilitation might be boosted, made recommendations for the organisational structure of programmes, on maximising community involvement and emphasised the importance of information systems and of investing in the programme staff. A number of recommendations were specific to the types of interventions implemented i.e, housing, education or micro-credit.

Evidence of the impact of SER on the quality of life of clients is limited, but suggests increased self-esteem and increased respect/status in the family and community.

INTRODUCTION

Working to improve the quality of life of leprosy-affected persons involves both medical and socio-economic interventions. During the time when isolation was necessary, the socio-economic interventions were focused on improving the quality of life in so-called leprosy villages, by providing adequate housing, water and sanitation, food production and income generation, as well as education for the children of leprosy-affected parents.

The Leprosy Mission (TLM) has been implementing socio-economic interventions ever since it was founded in 1874. A better understanding of the causes of ulceration was gained in the 1950s and this led to the concept of self-care and the introduction of modern occupational therapy, helping clients to carry out activities in such a way, that damage to the hands and feet would be avoided (1).

Now that there is a consensus that leprosy-affected persons can remain integrated in their communities, interventions to meet basic needs aim at helping those who are marginalised because of leprosy-related disability, while at the same time, helping them to protect their hands and feet. As a result, persons with leprosy-related disability are better appreciated as members of their families and communities, since they become an asset rather than a burden. In this way, integration becomes a more feasible and realistic option. At the same time, many leprosy settlements continue to exist and receive support (2,3).

Many projects of socio-economic rehabilitation (SER) began small. They relied on very few workers who were personally involved with the clients and often arranged things rather informally. As success was achieved with a few clients, the desire to scale up the activity was felt by the staff, by the management or by the donors. In the late 1990s, TLM took a strategic decision to give more importance to SER activities and scale up this type of work - in line with discussions among professionals involved in leprosy at the international level (4). Scaling up meant involving more staff and so it became necessary to develop written policies and protocols (5,6).

This paper presents an overview of findings from the formal evaluation of nine socio-economic rehabilitation projects in four countries in Africa, in Bangladesh and in India. Projects were in different stages of development and were implemented in different cultural contexts. Naturally, a number of recommendations were specific to the types of interventions implemented such

as housing, education or micro-credit. At the same time, many recommendations addressed issues of organisational structure, staff skills, criteria for the selection of beneficiaries, community linkages etc. which were common to all these projects.

In bringing together the recommendations from different projects, common pitfalls are identified and important lessons in the management of this type of work, emerge. The result is a description of best practices in the implementation of socio-economic rehabilitation projects, which derive from actual experiences in specific projects.

METHOD

The nine evaluations (7-15) were conducted in the years 2002-2005. Table 1 gives an impression of the magnitude of each project. Five other reports were not included because the SER work done was not the focus of the evaluation and therefore, not given adequate attention, or because the work had started only recently as a pilot project. Each project or programme was evaluated by a team of 2-4 evaluators.

Evaluations in Africa and India were informed by the conceptual framework under development during the same period (16, 17), but in Bangladesh this connection was less clear. The Community Housing Programme in India was implemented in 21 locations and three different pairs of evaluators visited four of them. Of 22 evaluators, 11 were TLM staff who were themselves directly involved in project implementation. Four teams included 1-2 evaluators external to TLM (total 7). Four other teams included TLM staff who were involved full-time in evaluation work. Evaluators were medical doctors, social workers, physiotherapists, occupational therapists, public health specialists etc. Virtually all had extensive experience in leprosy and rehabilitation work. Evaluators were not involved in any decision making about the project that they evaluated. Project managers were contacted well in advance of the evaluation visit and had inputs into the drafting of the terms of reference and the evaluation questions. As a general policy, evaluators were encouraged to make positive statements about each project, as well as identify areas for improvement.

Table 1. Size of the projects on socio-economic rehabilitation included in this review

Project/Programme	Definition/Time period	No. of Clients
Africa		
Nigeria	Median number per year over 1999-2001 in all 5 centres	100
Guinee	Group members in 2002	213
Uganda	Median number per year over 2000-2004	59
South Africa	No. supported in 2002	115
Bangladesh		
Dhaka	No. supported in 2003	157
Chittagong	Loans in 2001	96
Gaibandha-Jaypurhat	Median number per year over 2000-2002	150
Education Programme Dhaka (CREAD)	Number added each year over 2002-2004	50
India		
Community Housing Scheme	Number of houses in all, up to 2004 21 centres In 4 centres evaluated	640 229

As evaluations were tailored to meet the needs of the individual project, the questions asked during the evaluations were not standardised. Most of the information presented in the present report is qualitative in nature. Recommendations from different evaluations have been brought together, to arrive at an overall picture of how this kind of work might best be done.

From every evaluation report, the executive summary, the summary of the conclusions and the complete list of recommendations were copied into a separate computer file. From these, all positive statements about the work evaluated and all recommendations were extracted and copied into the individual cells of a table. Every cell had a label identifying the report from which the statement came. Redundant statements, repeating the same ideas about the same project were deleted while all other statements were categorised according to subject

area. These categories were not pre-determined, but derived from the content of the statements themselves. However, specific attention was given to five steps in the individual rehabilitation process: selection of clients, needs assessment, deciding on an intervention, follow-up to monitor progress, separation.

Positive statements and recommendations for future development were grouped in any of the existing categories, to the extent possible. Although impact assessment was not the specific purpose of any of these evaluations, a number of the positive statements about projects included hints at the effectiveness of the interventions. These were grouped in a category "Impact".

The next step was to compare the categories from different projects and collect in one (computer) document, all statements from all projects that fell into the same category. At this stage, some harmonising of categories was done, but without compromising the data-derived nature of the categories.

Table 2. Classification of recommendations into categories by region

Theme	Africa	Bangladesh	India
Selection of Clients	X	X	X
Needs Assessment	X	X	
Implementing Micro-credit	X	X	
Implementing Housing Schemes			X
Implementing Education Scheme	X	X	
Client Participation/Sustainability	X	X	X
Monitoring	X		X
Separation	X		
Information System	X	X	X
Organisational structure	X	X	
Community Involvement	X	X	
Staff Skills	X	X	X
Impact	X	X	X
Future Directions	X	X	X

Note: An "X" denotes that reports from that particular region included recommendations in the category, as indicated.

These categories have largely determined the outline of the present paper. Within each category, the various statements were scanned to arrive at a summary and to see what conclusions could be drawn.

RESULTS

All the nine projects and programmes evaluated, focussed on supporting individual leprosy-affected beneficiaries or their families. Four projects (7, 9-11) also supported other marginalised clients. Clients had only a limited choice of what benefits were received, often as a donation or grant, sometimes as a loan or a mixture of both.

The usual interventions were micro-credit, housing and sponsoring of education for the children. Education could be anything from primary school, to secondary school to vocational training. Other forms of support were receiving a cow, buffalo or goat, a sewing machine, a riksha (India) or donkey (Uganda) for transport. These interventions are similar to those described by other authors (18, 19, 20, 21).

Selection of clients

Staff need to know and understand (internalise) the objective criteria that should be applied in the selection process to maximise the success of the programme. If the staff do not apply the criteria properly, either because they were not told, or because they misinterpret what has been said, or because supervision is lacking, the programme ends up being criticised by others in the community, who would like to benefit from the programme and do not understand why they do not qualify, or who perceive injustices in the way it is being administered.

Criteria concern, for example, socio-economic status of the family, disease/disability status and residence in a particular project area. Gender as a selection criterion was often emphasised and many projects maintained a good gender balance.

In some cases, a survey was recommended to establish early on the size of the target group and define sub groups according to levels of vulnerability. Surveys are expensive and time-consuming, however, and the actual situation may change quickly, particularly in urban slum areas. There was thus no agreement on this point.

One African project targeting leprosy-affected clients, combined self-care with SER and one criterion for getting a loan was to have ulcer-free feet. The same project experimented

with teaming up a client and another person not disabled nor affected by leprosy, to work together in an income-generating activity and this proved quite successful.

Needs assessment

The next step in the rehabilitation process is an assessment of the client's individual needs. In some projects, this is done informally, as a personal decision of the field worker responsible for this. In bigger projects, standardised formats are used and the written findings are submitted to a supervisor or committee, where a decision is taken.

In some projects, evaluators recommended that some research be done to obtain an overall picture of the socio-economic context of the target group and of possible income generating activities, so that the questions asked during a needs assessment and the interventions offered, are sure to be relevant.

Of course, whilst working with leprosy-affected clients on socio-economic interventions, the underlying assumption is that physical rehabilitation needs are taken care of. Where this is not the case, needs assessment should signal this and appropriate action should be taken.

Srinivasan (22), estimated that 21 to 45 per cent of persons affected by leprosy experience economic deterioration as a consequence of their diagnosis and therefore need assistance. Needing assistance is not synonymous with having impairments, but affects those who experience rejection by their families or communities and those whose impairments limit their capacity for productive work. Withington (21), presents data which suggests that rejection is more likely (although by no means exclusively) encountered by women, by those who have developed impairments, or who are visibly ill. Need for a change in sources of income is also important for those whose work leads to deterioration of their impairment status.

Deciding on an intervention

Depending on the project, clients could propose an income generating project, or choose from a limited number of possible interventions. It was found that many projects do not think to consult with an occupational therapist when choosing an income generating activity or planning a new house for a client. This is important for clients with disability - on the one hand to make sure they choose an activity within their capacity but, even more importantly, to prevent deterioration of the clients' disability status once they get involved in the activity.

Grant or loan

At least two projects in Africa gave grants rather than loans, while in the two other African projects, repayment rates were poor. Recommendations were for moving towards loans or for the development of criteria to decide when a loan should be given and where a grant would be appropriate. Then, there were projects where the amount that could be borrowed was essentially fixed and this meant that some clients got more than they needed, for what they wanted to do, while others complained that they could not realise their plans because the loan amounts were too small. Flexibility was recommended on the understanding, that stricter conditions would be applied when the amounts were higher.

In a project in Bangladesh supporting education of marginalised children, all that was needed (school fees, uniforms, materials) was paid for by the project. Evaluators suggested a financial participation by the parents would be feasible and in fact, beneficial to the success of the project. Similarly, evaluators of the SER work in Nigeria, felt that families should contribute to the cost of board and lodging for clients selected for vocational training.

Again, in the construction of houses for marginalised clients, an assessment of the capacity to repay by the clients and/or their families, should influence a decision as to what extent the subsidy should be granted or repaid.

An updated review of experiences with different approaches to funding for persons with disabilities, has recently been presented by de Klerk (23). He concludes that grant programmes are easier to administer than loan programmes. Ideally, clients should be helped to find their way to commercial micro-credit providers, so that they do not continue to depend on special programmes.

Skills training for clients

Evaluators of the SER programmes in Nigeria recommended, that before they are entrusted with considerable sums of money, clients be trained in business skills so that they have a better ability to handle these resources.

Evaluators in Bangladesh emphasised that where loans are given for income generating activities, training in the skills necessary for that activity (e.g. tailoring, crafts) should also be provided - possibly with the assistance of partner organisations (24).

Implementing education schemes

When children are supported to go to primary and secondary school, the question sooner or later comes up as to what to do for children who would have the capacity to go for tertiary education, but lack the means to do so. Sometimes, but by no means always, this problem can be solved by referring children to other NGOs who will support them.

An interesting question that was raised by an evaluator with expertise in education, is whether a project sponsoring children should make efforts to improve the quality of the teaching that the sponsored children receive, e.g. by providing inputs to the school or the teachers, or by providing extra-curricular tutoring as many parents in Bangladesh would do for their children, if they could afford it.

Client participation

There are many recommendations about actively involving clients in their own rehabilitation. This means that very often this aspect of the programmes was found to be inadequate. At the same time, as most of these evaluations were conducted some years ago, the evaluators contributed to the dissemination of this principle across TLM and its application in practice.

In sponsoring the education of children, community involvement implies involving parents in the development of selection criteria, in choosing the school that their sponsored children will attend and the items the programme will or will not sponsor, as well as regular discussions about the children's well-being and progress in school. It may even take the form of organising the parents in an association, to advocate for their children in situations where they encounter stigma-related difficulties.

In building low cost houses for leprosy-affected clients and their families, community participation means at least involving them in the design of their new house to make sure it is adapted to their handicaps and suitable for the number of people who that will move in. It also means using local materials for the construction and obtaining financial participation from the client, or his/her family.

Little was said in these nine evaluation reports about the influence that recipients of micro credits had in the choice of an income generating activity. However, from a previous survey among project managers in India, it is known that this influence is highly variable (25). In The

Danish Bangladesh Leprosy Mission (DBLM) programme in N.W. Bangladesh, “the form of assistance chosen rested on a joint decision of client, health worker, family and community” (21).

In three instances, evaluators recommended project managers to take steps to facilitate the formation of an association of disabled or leprosy-affected people.

Monitoring / follow-up

Especially where income generating activities are started, but also when education is sponsored or repayment for a new house should be recovered, good follow-up is crucial. Good follow-up means that visits to the client are made regularly and that the field worker knows what to do during those visits, which information to collect and which actions to take when problems are identified. Regular follow-up shows the client that s/he is taken seriously and that the intervention or the repayment is felt to be important by the staff. This is an opportunity to spend quality time with the client, as was particularly practised in South Africa.

Separation

Of course, there are situations where long-term provision of welfare is the only option. Nevertheless, in a number of projects, it was important to emphasise that interventions should have a limited duration and that staff should not continue to work with the same clients endlessly. An end-point should be reached where clients can manage by themselves. Ideally, this end-point should be defined at the beginning of an intervention, either in terms of a fixed time-interval, or in terms of outcomes achieved. This is also the time to assess any progress achieved through the intervention. Alternatively, one can define an end-point in terms of inputs provided. If the intended outcomes have not been achieved even though the rehabilitation plan has been correctly implemented, it is time to think of other interventions, which are more likely to be successful.

Information system

Working with the community is not synonymous with poor recording practices. This means individual client files, regular consolidation and reporting of indicator data and analysis and discussion to make adjustments as necessary. Data to be reported include management information and indicators, but also feedback from the community. Reporting should include comparisons of present indicator values to targets and to values at previous time points.

Of course, this implies that reporting formats are available, which make it easy for staff to collect information quickly and in a standardised way.

Organisational structure

Especially when programmes begin small and informally, a time comes when it is important to define its organisational structure, define who is working for this programme and who is supervising whom. It is then also important to define how this programme relates to the hospital or leprosy control programme, within which it has grown up.

In general, evaluators recommend that important decisions are taken by a committee, in which all stakeholders are represented i.e. the staff, the target group, the community, related TLM programmes, local authorities and possibly partner organisations. It is important that in such a committee, enough expertise is present about the type of work that is being done.

In some projects, the field worker who had the first-line contact with the clients was also responsible for the decision making of which proposals of clients to approve and which to reject. This put too much pressure on the fieldworker and evaluators suggested that the fieldworker should submit the plans to a supervisor or to a committee, who should take the final decisions.

In the case of a project focussing exclusively on sponsoring education, evaluators recommended the creation of an advisory group, which could guide efforts to improve the quality of teaching and of coaching of the children.

An important discussion that has been generated from these evaluations is whether leprosy control workers who detect cases of leprosy and dispense MDT can at the same time be effective in working with clients to develop income generating activities. Although these roles were combined in a number of projects in Bangladesh, and often successfully so, there were also examples of situations where this did not work well. Gradually, a consensus has emerged in Asia, that the two roles should be separated wherever possible. On the other hand, the possibility of re-training leprosy control workers to change to a role of an SER worker has been admitted by all evaluators.

In Nigeria, the evaluators concluded, that the best way to scale up SER activities was to involve the leprosy workers from the local government authority in its process. This concurs with national policies, which specify that such workers have a role in rehabilitation. They do

an individual needs assessment after which the client chooses an intervention. The Local Government Authority (LGA) leprosy worker then monitors progress, gives advice and collects repayments of the loan (26).

Community involvement

Involvement of the wider community in the project, can often be achieved by including community leaders in the steering committees that take the final decisions on the requests for support (cf. under organisational structure). More and more, projects are advised to include representatives both from the target group and from the community in this committee.

Staff skills

The introduction of new ideas and new types of work means that staff need to be oriented to understand what is required. In many projects, recommendations concerned the drawing up of clear, updated job descriptions, protocols, guidelines so that staff would have clear frames of reference for their actions. Of course, drawing up guidelines needs to be followed by instruction and practical training. Staff need to internalise the criteria by which clients are selected, need to be able to ask the right questions to assess what are the needs and resources of a client. The use of standardised data collection formats may help with this. Staff also need to be able to assess what the viability of an income generation plan is likely to be and need to internalise the idea of giving loans and asking clients to repay. Staff need facilitation skills, if they are to work with groups or lead community consultations.

And so, when evaluators recommend scaling up of a programme or introduce new approaches, they usually also recommend (re-)training of staff or the recruitment of new staff that will bring in the necessary new knowledge and skills. Besides facilitation skills, the content of recommended training varies from an understanding of education principles, principles of marketing and economic development, to a better understanding of programme planning, community development and community-based rehabilitation.

In general, the success of a project is ensured, if all staff at all levels know what the objectives of the project are and how these can be achieved.

Impact

There is no doubt that in all SER projects, examples of clients can be cited, who have been quite successful and who have improved their lives thanks to support received from TLM.

At the same time, one may well ask as to what extent such clients would have succeeded without the project. Some people have the qualities and the drive to pursue success by any route that is available to them. It is pleasing to ourselves but probably unrealistic to think that all these clients have succeeded 'because of the support we have provided them', although it is undoubtedly true for a fair number of them.

Looking beyond financial success, therefore, it is encouraging to read in the same reports that clients have clearly increased their self-esteem through the activities that they became involved in, working with 'others and relating to the world around them' in new ways. The same reports speak of the "improvement in attitude, outlook, increased respect and status and role in family decision making".

Gershon and Srinivasan (18) reported increased employment and income after SER interventions; only 12 clients out of 78 said the programme had not benefited them at all. Nine of 13 clients who had experienced problems of being accepted in their families upon diagnosis of leprosy felt these problems had been solved after rehabilitation. Rao et al. (20) describe SER programmes in Andhra Pradesh and Orissa in India, and report that of 120 clients receiving assistance, 53 were restored to their initial economic status, while 58 improved partially. Unfortunately, no details were given on how this was measured. Ebenso et al. (27) interviewed clients of SER programmes in five states in Nigeria and members of their families and communities and reported positive attitudinal changes towards people affected by leprosy as they stopped begging but rather were able to make financial contributions when relatives or neighbours were in need.

FUTURE DIRECTIONS

Evaluators provided lots of ideas for future development of the programmes. Generally, evaluators felt the programmes should be strengthened and consolidated and then extended to serve more clients.

Often, SER interventions aim at providing some income or support to the client, assuming that family members will provide whatever other support is needed. In at least two projects, evaluators recommended that staff should be more ambitious and aim for full economic independence of their clients, by encouraging them to develop income generation activities which had sufficient potential.

Although the proportion of leprosy affected clients varied, evaluators in three programmes suggested that more persons with non-leprosy disability should be included to promote integration and work according to CBR principles.

In four reports, evaluators recommended moving towards a micro-credit programme based on groups. Already, many programmes had a few groups functioning side-by-side with the individual SER work (7,9,10,13) while the programme in Guinee (8) gave individual grants to members of self-care groups.

In the mean time of course, TLM has invested greatly in the formation of self-help groups, not only in India, where financial support for such groups can now be obtained from the government, but also in other countries. Membership of these groups consists of persons with disabilities due to different causes i.e. not exclusively leprosy. Thus, the importance of the traditional SER work reported on here, has waned, although individual SER interventions continue to be used for clients who cannot function in a group, or in situations where a better alternative is not available.

Given the frequent interaction with clients in SER programmes, TLM staff should seize those opportunities to make clients aware of the health and disability issues which are locally relevant. This includes basic understanding of leprosy and stigma, of disability rights, of locally prevalent diseases, of HIV/AIDS and in an education scheme, of child health.

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