

## Editorial

### LEPROSY AND COMMUNITY-BASED REHABILITATION

#### Introduction

Leprosy continues to be of major concern in developing countries, not only because of the large number of people affected by it and their potential for communicating the disease to others, but also because of the deformities in a proportion of patients.<sup>1</sup> The gradual decline in the number of registered patients needing multidrug therapy (MDT) in the last few years, has focused the attention towards the problem of disabilities caused by leprosy. The declaration issued at the Hanoi International Conference on the elimination of leprosy includes: 'To ensure that prevention and management of disability become an integral part of leprosy elimination programmes so that all leprosy patients are rehabilitated and reintegrated within their communities'.<sup>2</sup>

The suggestion that community-based rehabilitation (CBR) could be the approach for the rehabilitation of disabled leprosy patients has been put forward for many years.<sup>3</sup> A review of the literature related to 'leprosy and CBR' shows that often CBR is considered to be only an approach for promoting vocational training and economic self-sufficiency.<sup>4–6</sup> During the last ILA congress in Orlando, a workshop was held on CBR. Lastly, during meetings and discussions about leprosy, with increasing frequency, 'CBR' is nominated as the ideal approach for rehabilitation and proposals are made to 'integrate the rehabilitation of disabled leprosy patients in CBR programmes'. All this is done without properly understanding what CBR is and if it is a feasible approach for the rehabilitation of leprosy patients.

Thus before discussing how the CBR approach can be used for rehabilitation of disabled leprosy patients it would be useful to try to understand this approach and analyse its advantages and limitations.

#### What is CBR?

CBR can be considered as a philosophy of intervention rather than as a rigid system of programme organization. As the name suggests, a CBR programme is adapted to the community needs and communities differ widely from country to country and even

among the different areas of the same countries. Thus the CBR programmes may seem to be very different in different situations. Having said this it is, however, possible to identify and analyse some basic components of a CBR programme which are common to all programmes.

The joint position paper by the World Health Organization (WHO), United Nations Educational, Scientific and Cultural Organization (UNESCO) and International Labour Organization (ILO) gives the following definition of CBR: 'Community-based rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services.'<sup>7</sup>

Analysing the existing CBR programmes in a number of countries, the following common components of a CBR programme can be identified:

1 **Multisectoral approach:** the CBR approach looks at all the needs of disabled persons starting from participation in family life to self-sufficiency in activities of daily living, schooling, employment, participation in leisure and community activities, etc. This means that apart from the health ministry, other governmental ministries and departments, community representatives, teachers, social workers, labour officials, etc. all need to be involved in the CBR programme. Thus integration of young disabled persons in regular schools, vocational training, support for self-employment, production of orthopaedic appliances, techniques of medical rehabilitation, etc. all need to be organized.

In practice, the multisectoral approach seems to work more easily at the peripheral level while at the higher levels it is more difficult. Evaluation of existing CBR programmes shows that even if the multisectoral approach is accepted in theory, usually the programmes tend to give more prominence to certain aspects. However there are some programmes, as in Guyana where they have managed to involve different sectors, e.g. health, education, community volunteers in an effective way.

2 **Community participation:** it is important that the programme is developed in a gradual way and with active involvement of community leaders, so that it is not seen as something 'for' the community but is seen as 'of' the community. Right at the beginning, the formation of community committees involving political, social and religious leaders of the community is needed, which takes all the decision for the programme activities. It is also important to ensure that the external aid is limited and used only as a support.

When any new programme is started, the communities expect to receive things and/or aid. While in community development programmes, communities are expected to find their own solutions to their problems. The external support is mainly limited to training. The involvement of a community is strengthened if it can provide volunteers for working with the programme.

If the community is going to be responsible for decision making, it means that sometimes there can be decisions which are not shared by the external agency supporting the programme and this has to be accepted even if it may create difficulties.

3 **Role of organizations of disabled persons:** although the organizations of disabled persons can be considered as part of the community, for this analysis it has been taken as a separate component because of its importance. The final aim of the programme is

empowerment of disabled persons. Thus a CBR programme has to involve the disabled persons and their organizations in all stages of the programme: as members of community committees, as volunteers, and in planning, implementation and evaluation of the programme activities.

4 Rehabilitation workers: the CBR programmes train personnel at community level as rehabilitation workers (RWs). These workers in turn train disabled persons and/or their family members, in all the rehabilitation activities, with the help of a manual similar to the one prepared by WHO.

Some programmes run under the Ministry of Health may utilize community health workers as RWs; programmes run under other ministries may involve teachers, social workers or community volunteers as RWs. In many countries all of these may be involved. Among the volunteers, disabled persons and their family members often play a prominent role.

5 Referral system: a CBR programme is going to work at community level but it cannot substitute the role of specialists and specialized institutions, especially for severe cases and in the case of complications. Referral support should be seen in terms of all the different sectors that are involved in the programme, e.g. health, education, social services, vocational training.

### **Needs of disabled leprosy patients and CBR**

On the basis of the short information given above, we can consider the needs of rehabilitation for leprosy patients and see if these needs can be satisfied by a CBR programme:

A CBR programme cannot substitute all the rehabilitation services provided by a vertical leprosy programme, especially the identification of at-risk patients and the prevention of disabilities. Unless the RWs are community health workers already working in vertical leprosy control programme, they cannot know which patients have more chances of having neuritis and thus develop disabilities; they do not know how to treat neuritis and anyway do not have any drugs. However, if community health workers are involved in the programme as in Vietnam, Guyana, Indonesia such activities are possible.

Under the CBR programme, training is provided to RWs regarding detection of persons having insensitive hands and soles. However, if the persons do not have any visible deformity, it is possible that they may not be detected by the RWs, or if detected, may not be considered as a priority. In endemic areas studies need to be carried out to find the effective inclusion of leprosy patients benefitting from the existing CBR programmes.

It will be difficult to start new CBR programmes only for leprosy patients, because communities cannot be expected to start it for only one category of disabled persons. However, this can be done in leprosy villages or leprosaria, but in that case it may be impossible to adopt the community approach because the patients are generally passive recipients of everything from others. At the same time formation of community committees in the leprosaria giving them the responsibility for decision making may be unacceptable for organizational reasons to the persons managing the leprosaria.

### Can the CBR approach be adapted for rehabilitation of leprosy patients?

The basic principle of CBR is the transfer of knowledge and empowerment of disabled persons, so that they themselves become responsible for their own care. This principle is already used in leprosy programmes for teaching self-care to disabled leprosy patients as well as for the prevention of disabilities. This can be further strengthened by analysing the information which is not given at present to the patients and is known only to the medical and paramedical personnel, to see what other information can be transferred to the patients themselves.

This would require a change of perspective for the medical staff from being 'care-givers' to becoming 'partners' in dispensing care. In the paper entitled, 'A new approach to the challenges of the final stages of leprosy control' Hugo A. Vrakking also proposes a similar change of perspective for leprosy control programmes.<sup>8</sup>

Paramedical staff working for vertical leprosy programmes can be trained to become supervisors or RWs for CBR programmes, after appropriate training.

Leprosy programmes having specialized services and infrastructures for rehabilitation of leprosy patients can provide referral support to CBR programmes in their area.

Links should be made between vertical leprosy programmes and CBR programmes already existing in some countries such as Vietnam, Ghana and Indonesia to make sure that disabled leprosy patients living in the communities benefit from activities such as education, vocational training and orthopaedic appliances.

### References

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