

Answering the rehabilitation Needs of Leprosy Affected Persons in Integrated Setting through Primary Health Care Services and Community-based Rehabilitation

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Summary:

This article aims to discuss the strategies for answering the rehabilitation needs of persons with leprosy related disabilities in integrated settings through primary health care (PHC) services and Community-based Rehabilitation (CBR). While the provision of rehabilitation services through the PHC system remains problematic in most developing countries, the article concludes that CBR programmes have potential for rehabilitation of leprosy affected persons in integrated settings. However, the limited coverage of CBR programmes may pose an obstacle to such an approach. The author suggests use of existing specific rehabilitation infrastructures meant only for leprosy-affected persons for initiating, sustaining and extending CBR coverage in the surrounding communities. At the same time, the authors asks for support and strengthening of organisations of leprosy affected persons, promoting their active involvement in all rehabilitation processes.

Leprosy and disabilities:

Leprosy is an infectious disease and is associated with disabilities. It is unusual among disabling diseases in that the disabilities are often insidious on onset and progressive in nature. Unless active steps are taken to prevent deterioration, patients with relatively “minor” problems can progress to severe disablement. About 20% of leprosy patients may suffer from physical disabilities and psychosocial handicaps and may be in need of some type of rehabilitation help and continuing medical care. (1) Those who contract leprosy may be handicapped because of disabilities and also because of stigma attached to leprosy. Disability, “dehabilitation” and destitution of the badly crippled and rejected patients perpetuate the prejudice against leprosy and thus there is a great need to prevent disabilities and to rehabilitate disabled leprosy patients both from a humanitarian aspect as well as to demonstrate the successful leprosy control programmes.(1)

The goal of the disability prevention programme in leprosy patients may be defined as: no disability to occur in the leprosy patient apart from that found irreversible at the time of diagnosis. Preventing and limiting disability has two objectives: (a) to prevent the occurrence of new disabilities; and (b) to prevent worsening of existing disabilities.(1)

However global data about number of persons continues to be elusive and the discussions mainly limit to estimates. Thus, while the total number of persons with leprosy related disabilities is estimated to be around 2-3 million persons (2). Information about different kinds of impairments is even less easily available and very variable. For example, it is estimated that the ocular complications of leprosy affect around two million people worldwide, causing blindness in approximately 250 000. In most of these people, blindness and ocular morbidity are avoidable (3). This may be

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because there is lack of systematic data collection on disabilities among leprosy-affected persons. Despite the fact that most health workers are identifying disabilities among new cases, this information is rarely collected and reported. (2)

Surveys among leprosy affected persons who have completed MDT showed prevalence of grade disabilities to be variable between 17 to 50% (4, 5, 6). An analysis of global data on the new cases with grade II disability shows a decreasing trend. However, if we exclude data from India from this analysis, the decreasing trend is very small and slow (7). On the other hand, recent reports from WHO related to leprosy elimination (8, 9), while conceding the importance of grade II disability among new cases as an indicator to measure the quality of leprosy control programmes, do not provide specific data regarding this.

Leprosy related disabilities and Primary Health Care Services (PHC):

Over the past two decades there have been repeated declarations about importance of integrating leprosy control programmes and rehabilitation services for leprosy affected persons in to PHC and community-based programmes. At the same time, some times it has also been argued that in majority of countries such services are already integrated, although many of them have specialised supervisory and referral services. (10)

The concept of Primary health care has emerged from a long line of ideas, which evolved, gradually with the re-evaluation of existing approaches and assimilation of innovative experiences. (11). The concept of PHC was proposed in the Alma Ata declaration in 1978. Article VII.B (PHC) of Alma Ata declaration addressed the main health problems in the community, by “providing promotive, preventive, curative and rehabilitative services accordingly”. However, soon after while planning PHC services, many of the key components of this concept, including the “rehabilitative services” were left out.

The Alma Ata formulation of Primary Health Care came under attack almost from its inception. This attack came even from within the public health sector itself. If health statistics were to be improved, it was argued, high-risk groups must be “targeted” with carefully selected, cost effective interventions. This new, more narrow approach became known as Selective Primary Health Care (SPHC). This new approach stripped PHC of many of its key concepts. (12)

Initially, some of the resource materials linked to organisation of PHC services and training of community health workers did mention some aspects of rehabilitation services. For example, the working guide for community health workers by WHO (1987, reprinted in 1990) had a small chapter about disabilities and mentioned leprosy related disabilities and the possibility of preventing these disabilities through simple measures (pages 97-100).

However, the participation of PHC in rehabilitation services has remained very limited (13,14). The reasons mentioned for lack of rehabilitative services through PC include:

- Insufficient coverage of PHC services

- Lack of sufficient staff and structures in PHC systems
- Lack of time by the PHC staff
- Vertical programmes and special campaigns, by providing incentives get more attention from PHC staff, leaving less time for other activities
- Lack of training on rehabilitative aspects in the training curriculum of primary health care workers

The multi-tier health system has often been perceived as being complex, centralized and inefficient. Meanwhile, most people depend on the system's lower, resource-starved tiers (health posts, clinics, dispensaries, health centres and so on) run by inadequately trained and poorly motivated staff. (15)

In spite of rhetoric about need of a holistic vision of the health needs and strengthening of primary health care services, the last decade has seen different developments, which continue to have a negative on these services. These include cuts in national health budgets, reduction in health care personnel and "services for payment" philosophy through Structural Adjustment Programmes (SAPs) pushed by international financial institutions in countries burdened with external debt, creation of new international bodies outside the United Nations system for launching of special programmes such as Global Fund, etc. In fact, Governments are asked to progressively hand over health care services to private sector, which is more market and profit driven, and may not share the priorities of primary health care philosophy.

The decrease in the health spending and the percentage of contribution by the Government means that the State becomes one of the many partners in achieving health instead of playing a central role. For example, the percentage of health spending covered by the State resources is reported to be as follows - in Canada 74.7%, in Germany 72.5%, in Brazil 66.7%, in Indonesia 35%, in Thailand 22%, in India 21.7%, in Sudan 15.2% (16)

Lack of funds for the health budget means that Governments may promote community-based approaches for providing "unproductive" services asking communities and unpaid community volunteers to provide PHC services. An example of these changes negatively affecting PHC comes from Guatemala, "Health care reforms in Guatemala has been promoted since 1991 by advisors on the Inter-American Development Bank (IDB) and successive governments... The new 'Health code' now offered primary health care through the Integral System of Health Care (SIAS) – a network of voluntary health workers on contract. ...Consequently, the present health system is very fragile. If the volunteer fails, the system fails. It also limits government accountability and helps the government to get away with low budgetary allocations for health. (17)

Disparities and inequities in the way the already insufficient health budgets are used, may worsen the situation for PHC services. "An estimated 40-60% of the health budget in Africa is expended on a few hospitals in and around the urban centres catering to the elites. A report from Kenya states that a full 40% of the health budget has been spent on Kenyatta National hospital while rural health centres received a mere 1.4%... infant mortality is often 2-5 times higher in rural areas compared with urban areas, while life-expectancy is 3-5 years less. ... In sub-Saharan Africa, health spending has declined

during the 1980s to an average of less than 4% of public expenditure and less than 2% of Gross National Product (GNP)". (18)

The requirements implicit in the concept of PHC are as follows: that there be total coverage of the population, taking into account the differential needs of the sub-groups; that services are effective, accessible, acceptable and affordable; that services are comprehensive including promotive, preventive, curative and rehabilitative approaches to health; that communities participate actively in the planning, implementation and evaluation of health services; and that health services are related to other sectors involved in development.(19)

Thus in the present context, the PHC services, though theoretically well-suited for providing support for rehabilitative services for disabled persons, can be expected to have limited impact on rehabilitation needs of persons with leprosy related disabilities.

Community-based Rehabilitation (CBR) and Persons with leprosy related disabilities:

Like for PHC, the last decade has seen repeated calls for de-linking rehabilitation of leprosy-affected persons from the leprosy control programmes and their integration in CBR programmes. Such calls are justified by the argument that persons with leprosy related disabilities are part of the wider community of disabled persons and integration would be effective against segregation, isolation and stigma against leprosy.

A consultation organised by WHO on disability prevention and rehabilitation in leprosy in 1987 (1) suggested: "Expensive and difficult methods to correct deformities, alleviate disabilities and rehabilitate patients can be avoided to a large extent by the community based rehabilitation approach... At present, few leprosy control programmes are structured to carry out the tasks involved in disability prevention and rehabilitation. ..Where ever CBR services or a fully developed community health care programme exists, most of the rehabilitation needs of the majority of disabled/handicapped leprosy patients can be met through community services provided the providers of the services have had appropriate training." This report also recommended that "Leprosy control programmes adopt a systematic approach to prevent and limit disabilities as an integral component of the programme, with emphasis on prevention of wounds, preservation of sight and prevention of irreversible damage to nerves.; Community based rehabilitation to be adopted as the basic approach to rehabilitation in leprosy."

As for PHC, calls to delegate primary health care activities to community-based programmes come also from international financial institutions as part of Structural Adjustment Programmes, as this would mean that services can be provided by communities with little resources from national health budgets and governmental spending can be reduced. Thus, the proposals for promoting rehabilitation of leprosy affected persons through CBR programmes may also be motivated by the realization about limited amount of available resources for health, where rehabilitation may not be seen as a priority, since it does not have an impact on "public health".

The CBR approach was launched in late seventies, around the same time as the declaration of Alma Ata. Initial idea of CBR promoted by WHO was based on provision of simple technological knowledge to disabled persons and their family members, so that they could carry out activities of medical rehabilitation including production of simple appliances at home and in non-institutional settings. This came to be seen as “WHO model of CBR”. Later on other models of CBR appeared such as ILO model and the UNESCO model, applying similar approach to occupational and educational aspects of life. (20) In 1994, WHO, ILO and UNESCO came together to propose a joint position paper on CBR, recognising that to be effective CBR must be multisectoral with a holistic vision of persons and their needs. (21)

A more recent version of this joint position paper (22) signed by different United Nations agencies (WHO, ILO, UNESCO, UNICEF and UNHCR) gives the following definition of CBR: “CBR is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services. The major objective of CBR is to ensure that people with disabilities are empowered to maximise their physical and mental abilities, have access to regular services and opportunities and become active, contributing members of their communities and their societies.”

The calls for provision of rehabilitation services for leprosy affected persons through CBR programmes, need to consider two fundamental aspects:

- A. Can CBR approach be an effective way to provide rehabilitation services to leprosy-affected persons?
- B. If yes, are there sufficient CBR programmes, who can take over this responsibility?

CBR approach in centres involved in specific leprosy rehabilitation activities:

Institutions and persons involved in specific leprosy rehabilitation activities have proposed the use of some of the principles of CBR approach in their work. These include involvement of leprosy affected persons and their family members in planning and implementation of some activities (23). Apart from the participation of affected persons, their families and communities, importance of the involvement of organisations of affected persons has also been underlined (24).

Other examples of using some basic principles of CBR approach in centres involved in specific leprosy rehabilitation activities include promotion of self-care groups for ulcer care and prevention of disabilities (25, 26, 27, 28) and for promoting socio-economic rehabilitation activities such as loans, vocational training, etc. (29, 30, 31).

Some times, such examples have used the term “community-based rehabilitation” to describe their work since it is being carried out at community level. However, the activities may continue to be vertical (limited only to leprosy affected persons) and can continue to be managed by “experts” without a specific role for the clients or

community representatives in decision-making or planning. In addition, these may continue to be carried out in isolated manner without any clear links with other leprosy control activities, managed by health personnel.

CBR activities 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 stigmatising those involved in such programmes (20). Starting a rehabilitation or CBR programme for leprosy affected persons is in fact starting a new vertical programme (32).

Including leprosy-affected persons in CBR programmes:

There is very little published literature on participation of persons with leprosy related disabilities in CBR programmes aimed at all the disabled persons in the communities. Two case studies from Indonesia and India on inclusion of rehabilitation of leprosy-affected persons in CBR programmes aimed at persons with different disabilities are presented below:

Case Study 1: Socio-Economic Rehabilitation of People Affected with Leprosy through CBR in South Sulawesi in Indonesia (33)

CBR programme is being implemented in 4 districts of South Sulawesi province of Indonesia covering about 1 million population since 1996. The programme is run under the Ministry of Health and also involves Ministries of Education and Social Welfare along with an Indonesian women's non-governmental organisation (NGO) called PKK. Leprosy affected persons form 8% of all the disabled persons involved in the programme. At community level, the programme is implemented through Posyandu (community health centres) managed by Kadres (community volunteers) under the guidance of village councils.

To understand the specific socio-economic needs of leprosy affected persons a survey involving 52 persons was carried out in 1999. The findings of this survey included the following – 73% were unemployed, 52% lived close to the families but in separate spaces while another 19% were completely cut-off from their families and 31% of them were illiterate. After the survey, the programme initiated specific activities to promote inclusion of leprosy-affected persons in the CBR programme.

The CBR programme carries out some specific activities for leprosy related disabilities including information and awareness campaigns for the communities and specific training courses for community volunteers and local supervisors. Leprosy affected persons are asked to participate in activities aimed at the other disabled persons like vocational training courses, creation of self-help groups and Savings-Credit groups, adult non-formal literacy courses, etc.

A study was carried out in 2000, after one year of implementation of this initiative. The study showed that the results were not very positive, though there was been some progress. For example, 5 leprosy-affected persons had become members of self-group groups while another 5 persons had received credits for income generation activities.

Case Study 2: Pilot project for promoting inclusion of leprosy-affected persons in CBR programme in Mandya District in Karnataka (India). (34).

AIFO supports three projects in Mandya district of Karnataka – a district level leprosy control project in collaboration with State Government, a CBR programme covering four sub-districts (taluks) managed by a local NGO (Sri Ramana Maha Rishi Academy for Blind – SRMAB) and a community health programme (MOB project) in two sub-districts managed by a missionary NGO (Daughters of Church missionary sisters). In addition, a local NGO K.W.A.B. is running a CBR project in another sub-district with support from CBM – Germany.

In 2000, it was decided to start a pilot district level combined CBR-leprosy control initiative in Mandya district with a two-pronged strategy: (a) Training all the CBR workers about leprosy and promoting inclusion of leprosy affected persons in the different activities of CBR, and (b) Training all the para-medical workers (PMWs) involved in district leprosy control programme in CBR approach. The initiative started in 2001 and the preliminary report was prepared in 2002 after about 18 months of the initiative. An in-depth study of the initiative is planned for 2003.

The preliminary report showed that by middle of 2002, all the CBR workers had received training in leprosy. As part of their work in the communities, the CBR workers participated in information and awareness campaigns about leprosy and supported the leprosy control programme for activities of early detection and tracing of persons abandoning the MDT treatment. At the same time, CBR workers have organised specific activities to promote inclusion of leprosy-affected persons in the different CBR activities.

However, at the time of the preliminary report, the progress for involving PMWs in CBR approach had had less success. Though some PMWs in the area covered by SRMAB did participate in the community meetings of CBR project, specific training for PMWs had not yet been carried out. The project had plans to invite the district MDT consultant and district leprosy officer in their quarterly review meeting and propose a plan for training of PMWs to them during 2002-03.

For the preliminary report, focus group discussions with CBR workers, leprosy affected persons and other disabled persons were organised in Malavalli sub-district of Mandya district to understand the process of inclusion of leprosy-affected persons in the CBR activities and to identify the constraints to inclusion. There were 2,013 total leprosy affected persons in the sub-district who had completed MDT and there were 59 patients receiving MDT at that time. Out of them, 59 persons had grade I disability and 78 persons had grade II disability, with a total of 137 persons (6.6%) with leprosy related disabilities. SRMAB runs a CBR programme in this sub-district since 1997 and had identified a total of 1,226 persons with disabilities.

These focus Group discussions highlighted the following findings:

- Most of the leprosy-affected persons participate in CBR activities like self-help group organisation, career guidance workshops, loans for self-employment, group development training programmes, etc.
- CBR workers felt that the persons with milder disabilities were more active while those with more severe and visible disabilities needed time and support to become active.
- Initially most of leprosy affected persons lacked information about activities already existing in their communities and were hesitant about their acceptance. Often they had negative feelings about themselves.
- Most of persons with other disabilities did not express any overt discriminatory feelings towards leprosy-affected persons.
- After about 12 months, the initiative had succeeded in involving 23 leprosy-affected persons in the CBR activities. It was felt by the participants of the group discussions that non-involvement of other leprosy affected persons depend upon more on their own attitudes than on the CBR workers or other disabled persons.

Monitoring data from the CBR project for 2002 shows that the total number of identified persons with leprosy related disabilities are now 149 and out of them 141 are benefiting from the project through home visits and other activities. Thus, it seems that the activities for involving leprosy affected persons through CBR programme made much better progress in the second year.

Feasibility of CBR for answering the rehabilitation needs of leprosy affected persons:

The WHO manual on CBR (35) has three specific modules on “persons with lack of sensation” and provide information about prevention of disabilities and simple measures for preventing worsening of existing disabilities. In addition, other modules of the manual, especially those dealing with difficulty in movement and preparation of simple mobility aids are also useful for persons with leprosy related disabilities. In line with its philosophy of not mentioning clinical diagnosis but instead focusing on functional aspects of different impairments and different rehabilitation measures, the manual does not explicitly mention the word “leprosy” anywhere.

As the two case studies presented above show, inclusion of leprosy affected persons in the existing CBR programmes may not be automatic and can require careful planning and training. In the CBR programmes, this is not unique to leprosy related disabilities but can also be true for some other disabilities like intellectual impairment and to some extent for hearing and speech impairment.

As explained in the definition of CBR in the joint position paper of United Nations agencies, CBR does require appropriate support and referral services from health, education, social and labour sectors. Therefore, promotion of CBR for leprosy-affected persons should not be seen as a way for dismantling specialised support services. As for integrated leprosy control programmes, there is need to ensure that specialised advice about needs of persons with leprosy related disabilities are available to CBR programmes in leprosy-endemic countries.

While lack of knowledge and stigma against leprosy may be factors influencing negatively CBR programme managers for inclusion of leprosy affected persons in CBR programmes, there could also be issues of leprosy programme managers preferring to “keep” the leprosy affected persons in their programmes rather than promoting their inclusion in CBR programmes. The ownership of the CBR programmes may also be a hurdle since often CBR programmes are under ministries of social welfare or labour, while leprosy control programmes are under ministries of health, with consequent difficulties in collaboration between the two programmes due to lack of inter-ministerial collaboration.

In principle, it is feasible for CBR programmes to include persons with leprosy related disabilities, but lack of sufficient CBR programmes may be the biggest hurdle for putting this in to practice. Though, over the last two decades CBR approach has been adopted widely in a large number of countries, most often it is limited to pilot projects in limited areas. A survey on the status of rehabilitation services in 26 countries of Africa showed that while many countries consider leprosy as one of the significant causes of disability and have national policies for promoting CBR approach for rehabilitation of disabled persons, they lack resources for starting national level or local CBR programmes (13).

Leprosy rehabilitation centres for promoting CBR:

In the present situation where the coverage of CBR programmes is still limited, closure of specific services for rehabilitation for leprosy-affected persons may mean that they do not have access to any rehabilitation services, as happens to the vast majority of persons with other disabilities in developing countries, more so in rural areas and more so for women and girls with disabilities. However, projects promoting specific rehabilitation activities for leprosy affected persons can play a key role in initiation and extension of CBR programmes for all disabled persons, much as leprosy control programmes have been instrumental in many instances for extension of primary health care services to areas uncovered by PHC services.

Since early nineties, AIFO has promoted the extension of the leprosy control and primary health care projects supported by it, to CBR activities. This process has been followed up in a systematic manner in India, through an AIFO CBR coordinator. The comments expressed here are based on this experience.

There are some fundamental differences between institution-based rehabilitation (IBR) and the community-based rehabilitation (CBR), including differences in roles of decision-making and location of expertise – in IBR, the professionals based in the institutions are the experts and decision-makers; in CBR, professionals should be facilitators while the decision-making and expertise are with the clients and their families. Using institutional settings for promoting community-based approaches can become victim of these contradictions leading to failures or at the best limited success.

This means that involvement of institutions and centres involved in leprosy rehabilitation in initiating, sustaining and extending CBR in the surrounding

communities must be planned in a gradual manner and supported by adequate training of the personnel. Theoretical learning about differences in role of institutional personnel and working at community level, may not be sufficient and an adequate period of transition should be planned. The role of PMWs running village clinics for diagnosis of leprosy and distributing MDT is very different from that of CBR worker, visiting homes and promoting transfer of knowledge and skills.

Even if such institutions are unable to directly operate at community level, they can still provide valuable referral and specialised support to community level rehabilitation workers.

Organisations of leprosy affected persons and rehabilitation:

Sixties and early seventies saw the coming together of disabled persons and form their own organisations – Disabled Peoples’ Organisations (DPOs). This has resulted in strong critique of “medical model” of disability and proposes a “social model”, where emphasis is on the social, cultural, physical and attitudinal barriers which disable persons having impairments. This has strongly influenced the policies about disability, promoting a human rights perspective and debate about equal opportunities and access. The social model of disability has resulted in new system of classification (ICF) proposed by WHO in 2001 (36). Promotion and support for DPOs is considered an essential part of CBR approach (22).

As far as persons with leprosy related disabilities are considered, formation of their organisations like IDEA, MORHAN and HANDA has been more recent over the last decade and their role in rehabilitation activities directed at leprosy affected persons still remains limited and fragile. They still need to create links with the wider movement of other disabled persons. Projects involved in rehabilitation of leprosy affected persons still need to create equitable partnerships with these organisations.

Conclusions:

Answering the needs of persons with leprosy related disabilities continues to be a significant issue in many developing countries. While, there is a move towards integration of leprosy control activities in primary health care services, often such services do not include components related to rehabilitation and prevention of disabilities. In spite of the Alma Ata declaration, often rehabilitation of disabled persons is not seen as part of primary health care services. The last decade with globalisation and structural adjustment programmes has put additional strain on primary health care services in developing countries. In this context, it may not be feasible to expect adequate participation of primary health care services in rehabilitation of persons with leprosy related disabilities.

Community based rehabilitation approach has been shown to be effective in promoting holistic rehabilitation and empowerment of persons with disabilities. This approach is feasible for responding to the rehabilitation needs of leprosy affected persons, provided that adequate measures are taken in terms of training and preparation of CBR

personnel, communities and leprosy-affected persons. It is also important to ensure that specialised support services for persons for leprosy related disabilities are available for supporting CBR programmes. However, lack of sufficient CBR programmes remains a big hurdle in promoting this strategy.

Specific rehabilitation infrastructures working only for leprosy affected persons can play a key role in initiation and extension of CBR programmes. However, this may need to be done in a gradual and planned manner.

Organisations of leprosy affected persons still play a limited role in the rehabilitation initiatives directed at persons with leprosy related disabilities. Rehabilitation projects will need to strengthen such organisations and create equitable partnerships with them.

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