

Rehabilitation of Leprosy Affected Persons Problems & Challenges for Provision of Services

The last decade has seen a dramatic decrease in the numbers of active leprosy patients. This change has also influenced the lives of many Persons Affected with Leprosy (PAL), specially in terms of prevention of disabilities in new cases, through early diagnosis and treatment of the disease. At the same time, the situation of provision of rehabilitation services for the majority of PAL has not been touched by this decrease.

The discovery of multi-drug treatment and the possibility of treating the persons with active disease at home, has not been accompanied with development of new strategies for providing rehabilitation services in the home situation. Infact by and large, the provision of rehabilitation services, has remained concentrated inside the old institutions like leprosaria and leprosy hospitals, managed by medical, paramedical and, less often, social services.

As differnet countries reach the statistical goal of eliminating leprosy, which means, reducing the prevalence of disease to less than one active case per 10,000 population, more attention is being directed towards the rehabilitation services. While we talk about the provision of rehabilitation services for PAL, there is need to clarify some of the basic issues about the role of these services.

1. How many PAL need rehabilitation services?

Who needs the rehabilitation services, is the first issue which needs clarification. Do all PAL need these services? The limitation of resources means that some selection of potential beneficiaries of rehabilitation services is needed. So how can we make sure that the services give priority to the more needy persons? Do only the persons with visible deformities need rehabilitation services? If PAL with visible deformity are well settled, live in their families and have good income, do they still need to benefit from rehabilitation services? What about the needs of those persons who don't have any visible deformity but still have lost their jobs and families?

Do women PAL have access to the rehabilitation services? Is their need more than those of men PAL? How about the use of resources for the benefit of families of PAL? What about the problems faced by children of PAL?

It may not be practical to try to come at standard answers to all these questions. The answers must be flexible and suitable to each local stiutation. However, it is important for the service providers to pose themselves these queastions while deciding about the beneficiaries of their rehabilitation services.

2. What kind of rehabilitation services?

Often rehabilitation services are seen mainly as medical services like physiotherapy, surgery, etc. To this can be added activities for PAL-education regarding self-care and prevention of disabilities. Other less common services are related to economic self-sufficiency and income generation. Rehabilitation activities dealing with formal or non-formal education are rare. How to enlarge the focus of rehabilitation services so that the non-medical rehabilitation activities receive adequate planning and resources is a crucial issue.

The activities for promoting economic self-sufficiency need some other considerations as well, in terms of their ability to reach the needy persons. Thus PAL with some educational and entrepreneur skills may be the ones to benefit more from income-generation activities while the more needy persons may not have access to such activities, since they may lack the basic necessary skills. Many of the leprosy projects may have developed a very “scientific approach” as far as the treatment of the disease is considered, at the same time, their approach to non-medical rehabilitation activities remains largely confined to welfare and charity.

There is another aspect of rehabilitation, the psychological aspect. Thus persons may have low self-esteem, feeling of inferiority or guilt related to the disease and they may not benefit from any rehabilitation activities till they also feel as human beings, equal to others and with right to their dignity. How can such a psychological process of healing be promoted? Such aspects may be completely ignored with the idea that higher income or a job may automatically lead to higher self-esteem and psychological healing. Much more thought needs to be given to these aspects.

Who is going to provide the rehabilitation services?

The vertical national level programmes for control of leprosy have given very little resources and thought to the rehabilitation services. The smaller, NGO/missionary run projects have paid much more attention to these services, specially for medical rehabilitation. While they may have good services for education of PAL about self-care for prevention of disabilities, the impact of such an education/information campaigns has been very limited till now. This is easily understandable if we think that self-care is a life-long activity and needs repeated reinforcing of knowledge and motivation.

While looking at the PAL benefitting from integrated rehabilitation services, open to all disabled persons, there is often a feeling that only a small number of PAL get included in such services. However, it is often forgotten that such integrated rehabilitation services are very limited and the overall percentage of disabled persons benefitting from such services is also very low. Still, in some situations it is possible that the stigma associated with leprosy may influence negatively on their inclusion in such services.

The gradual dismantling of vertical services related to leprosy means that in future, rehabilitation services can't depend solely on specific anti-leprosy projects. At the same time there is very little thinking on finding alternate ways for the service delivery. This is another crucial issue while thinking of the future strategies.

Organizations of PAL (OPAL):

Comparitively, very little has been done regarding the development of organisations of PAL. Most often they are seen only as “Unions” fighting for concessions like pension benefits, free transport etc. However in the present circumstances, they may represent the most viable option for brining rehabilitation services to PAL spread over large areas in the home-communities.

Creation of community units of OPAL in the endemic areas could provide opportunity for PAL to meet, promote reflection-action strategies for better understanding of issues facing them and searching for suitable solutions, promote networking with similar organisations of PAL as well other organisations of disabled persons. With the help of trained animators, they can reflect on issues like access of services for women, need of services for children of PAL, etc.

They may be best placed to tackle issues like creation of savings and credit funds, leadership training, formation of cooperatives, etc. With adequate training support and community-based programmes they can do much for advocacy for their human rights, promote sharing of experiences, identify aspects of social integration which need action, break the barriers of isolation. They may be much more effective in promoting concepts and knowledge of self-care and prevention of disabilities, ensuring repeated messages and motivation. The United Nation's Standard Rules and the United Nations Convention on rights of the Child, can serve to measure the gaps between the existing and the desirable, and evolve strategies to reach the desirable at community and national levels.

In the past, the relationships between anti-leprosy projects/centres and OPAL have often been characterized by confrontation and antagonism. If OPAL have to develop and strengthen, such confrontation and antagonism must give way to better understanding of each other's roles and a constructive approach to solve the problems. Community level activities carried out by OPAL will need to be supported by reference level, specialized activities of anti-leprosy projects and both have much to gain by working in collaboration.