

Working together for consequences of leprosy

As we enter the third millennium, the goal of reducing the prevalence of leprosy to less than 1 case per 10,000 population, seems much nearer. The last decade has seen enormous progress in treatment of active cases of leprosy through wide-spread use of MDT. Between 10 to 11 million persons have been cured of the infection though MDT till now while the number of active cases is decreasing in a large number of countries.

For a large part of the last century, rehabilitation of leprosy affected persons had an important role in all projects dealing with leprosy but in the last two decades, the availability of MDT and the decreasing numbers of active cases in some countries have resulted in some changes in the situation. These changes include:

- *A medical view of leprosy and its effects:* The provision of MDT has been accompanied with strengthening of medical services for leprosy control while rehabilitation services, especially those related to socio-economic rehabilitation, have become gradually less important. Now that the need of leprosy control services is decreasing in many countries, this has resulted in search for integrated medical services for control of diseases like leprosy and tuberculosis, while the rehabilitation services may continue to be seen as a collateral or less-important activity.
- *Dismantling of old leprosaria:* In many countries, old existing leprosaria have been dismantled and the inmates have been sent back to be “integrated” in the communities. Very little or no information is available about the lives of these persons. It was expected that these persons, often with visible disabilities and problems like ulcers, would receive the required services through the existing primary health care services but no information is available about this. Anecdotal evidence shows that leprosy affected persons with any medical problems may need to travel to large distances to reach existing specific leprosy services, since they continue to have difficulty in accessing the primary health care services. How can we know more about the real situation?
- *Dismantling of leprosy hospitals and structures:* As the numbers of active cases of leprosy decrease, some of the leprosy hospitals and medical structures are being dismantled or their functions are changed, again with the assumption that persons needing services like ulcer dressings or protective footwear, will get these from existing primary health care services. Is that happening and up to what extent? What can be done to increase their access to the primary health care services?
- *Socio-economic rehabilitation needs of leprosy affected persons in the communities:* Over the last few years, there has been increasing realisation that for the leprosy affected persons living in the communities and no longer needing specific anti-leprosy drug treatment, the only cost-effective way of promoting socio-economic rehabilitation activities would be through projects and services catering to different disabilities in an integrated setting like the community based rehabilitation projects. However, there is still insufficient information available about the actual access of leprosy affected persons to such projects and services.

Available information about the rehabilitation needs of these 10 million leprosy affected persons, no longer needing specific anti-leprosy treatment, is extremely limited. According to WHO, among these there are about 2 million persons with grade II disabilities.

In addition, we know that in many countries there are still existing old leprosaria, where old disabled persons cured with dapson monotherapy are living but information regarding

them is again very limited. For example data from Vietnam shows that at the end of 1998, there were 20 leprosariums with 3,971 leprosy affected persons living there. Similarly data from Karnataka state of India shows that at the end of 1999, there were 25 leprosy colonies and 7 leprosariums/leprosy homes in the state.

Keeping in mind this situation, the two major challenges for the provision of medical and socio-economic rehabilitation of leprosy affected persons include the following:

1. To have a more realistic information about the medical and socio-economic rehabilitation needs of leprosy affected persons in the old leprosaria/leprosy colonies and in the communities.
2. To find the constraints about access of leprosy affected persons to existing primary health care services and community based rehabilitation projects and to promote strategies for over-coming these constraints.

There is another aspect related to socio-economic rehabilitation of leprosy affected persons which requires consideration - the role of affected persons in decision making and implementation of the rehabilitation services. At a global level, organisations of disabled persons have been fighting for a having a say in participating as equal partners in the decisions which affect their lives and for non-governmental development organisation, such client participation has promoted significant impact in the ownership, sustainability and continuity aspects of the rehabilitation activities. However, among organisations working for rehabilitation of leprosy affected persons, such client participation is still extremely limited and needs to be strengthened.

The Disability and Rehabilitation team from WHO/Geneva has proposed a joint initiative with ILEP associations to organise a joint workshop on "Working together for consequences of leprosy" which will be organised in Geneva in the last week of September 2000.