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Global Needs and Opportunity for Rehabilitation

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According to a WHO report in 1996, among the leprosy affected persons (including both registered cases and those who have completed treatment), there were estimated to be about 2 million persons with Grade II disability. Some studies in leprosy control projects had shown that the proportion of Grade I and Grade II disability in leprosy affected persons is roughly the same, which means that there could have been another 2 million persons with Grade I disability.

In the report of WHO Expert Committee published in June 1998, there are about 3 million estimated, total disabled persons (Grade I and Grade II) among leprosy affected persons in the world.

Thus, in spite of all the progress in the fight against leprosy, we still do not have a clear idea about the rehabilitation needs of leprosy affected persons, at a global level. Even at country or province or even, smaller "project" levels, often we have no idea of how many persons need rehabilitation services and which kind of services.

The persons having no visible disability but only loss of sensation (Grade I disability), are at risk of developing complications and more severe disabilities. Specific strategies are needed for identifying these persons and for making sure that this does not happen.

The persons who have already visible disabilities (Grade II disability), need specific strategies and services to make sure that their existing disabilities do not worsen and that they do not develop new disabilities.

Almost none of the national leprosy control programmes have developed any clear strategy, for either of the two groups. It is possible that the national leprosy control programmes may feel that prevention of disabilities and rehabilitation services should be the responsibility of other programmes/departments/ministries, but perhaps they need to make connections with these other departments/programmes/ministries to make sure that somebody does feel responsible for this?

Studies have already shown that delay in the diagnosis and starting of treatment is closely linked to the development of disabilities among the new patients. Thus, strengthening of leprosy control services for early diagnosis and starting of treatment remains probably the most efficient way of preventing disabilities.

The rehabilitation needs can be considered in two groups: 1. Needs related to medical services like POD activities, self-care, protective footwear, surgery, orthopaedic appliances, eyeglasses, etc. 2. Needs related to socio-economic rehabilitation.

Needs related to medical rehabilitation services

Prevention of Disabilities (POD): Affected persons and their families need to make life-long changes in their attitudes, behaviours and life styles and leprosy control programmes and rehabilitation services don't have enough knowledge and skills for promoting these changes. What are the long-term effects of patient education provided in leprosy control programmes? Studies on this subject are limited to relatively short follow-up periods and have shown effectiveness of self-care in prevention of new complications especially those related to occurrence of plantar ulcers.

Perhaps more can be learned from community-based rehabilitation programmes through the involvement of beneficiary groups, family members and community volunteers. Training and involvement of leprosy affected persons in reaching other leprosy-affected persons and their families, needs to be studied in a systematic way. Though Non-Governmental Organisations involved in development projects have been speaking for a long time about the need for active participation of the potential beneficiaries in planning, management and implementation of their project activities, leprosy related rehabilitation services often continue to be dominated by inequality, characterised by doctor-patient or care giver-care receiver relationships.

Footwear and Orthopaedic Appliances: Leprosy projects often continue to promote the production of special footwear for persons with plantar ulcers and there may not be adequate attention towards the acceptance and use of these footwear by the beneficiaries. Apart from other problems, such production services may not be enough to cover the needs of all the persons who need these.

Persons with plantar anaesthesia, without any visible deformity and before the occurrence of plantar ulcers, often do not receive footwear.

There can be increased scope for promoting use of commercially available footwear, at least for those persons who have no obvious foot deformity. Leprosy programmes may also need to learn more from community based rehabilitation projects in terms of involvement of local craftsmen and family members for the production of simple appliances through the use of simple technology and locally available raw materials. This requires a shift in the attitude among the caregivers, who need to share more information with the leprosy-affected persons and their family members.

Specialised services: With the decrease in the prevalence of leprosy, integration of leprosy control services in to general health care becomes a priority issue. Even in such conditions, it is important to ensure the continuation of national and regional level referral centres for more specialised services like for re-constructive surgery, orthopaedic surgery, ophthalmology services, etc.

Needs related to socio-economic rehabilitation

Reaching those who are most in need: While the resources for socio-economic rehabilitation of leprosy affected persons are very limited, more attention is needed for defining clear criteria to ensure that the most needful persons benefit from such services. In addition, because of the stigma and marginalisation still common in many areas of the

world, it is possible that the target group for socio-economic rehabilitation services may be much larger than the persons who have some disabilities. The criteria for defining the most-in-need must be sensitive to the social and cultural situations of each area and thus may be difficult to generalise.

Adopting a development approach: This means working with a strategy of providing opportunities for becoming self-sufficient and promoting independence among the target group. Traditionally, leprosy related rehabilitation services have worked more often with the charity model rather than the development model. Though the last decade has seen gradual strengthening of the development approach, probably much more can be done.

It is possible that most-in-need persons may be excluded from activities aiming at self-reliance and independence because of lack of prerequisites (education, psychological characteristics, entrepreneur spirit, etc.). Thus, special care may be needed to define appropriate strategies which promote gradual development and strengthening of this group of persons.

The development approach must necessarily be multi-sectoral, which means that it must involve different governmental, non-governmental and community partners, in defining the activities and their implementation.

Conclusion

Many countries still have some persons who may not benefit from a rehabilitation intervention and who need life-long care, who have severe chronic disabilities and are completely dependent upon others. They may be considered the weakest members of the society. A civilised society will need to make sure that care services for such persons are maintained and they are not sacrificed in the name of pragmatism and best use of resources.