

Issues related to integration of rehabilitation activities related to leprosy in CBR programmes

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The progressive abandoning of vertical leprosy control programmes and their integration in primary health care services, has been accompanied with calls for integration of rehabilitation activities related to leprosy affected persons in community-based rehabilitation (CBR) programmes.

Keeping this in mind, during the last twelve years AIFO/Italy through its partner organisation AIFO/India organised a series of workshops and training courses in India for promoting the conversion of vertical leprosy control programmes in CBR programmes and integration of persons with leprosy related disabilities in these CBR programmes. At the same time CBR projects targeted at all disabled persons including persons with leprosy related disabilities were initiated.

Recently a participatory evaluation exercise was carried out involving three CBR projects supported by AIFO in Karnataka state of India: SRMAB project in four sub-districts of Mandya district; MOB project in three sub-districts of Mandya district; and AMSK project in Bhalki sub-district of Bidar district. This participatory evaluation carried out through focus group discussions looked at two specific aspects –

- (a) Integration of persons with leprosy related disabilities in CBR activities: CBR projects have many components including medical, educational, social, etc. Integration of leprosy affected persons in CBR was evaluated mainly by looking at their participation in heterogeneous self-help groups.
- (b) Implications for change in role from vertical leprosy workers to CBR workers: To look at feelings of ex-leprosy workers, who were now working as CBR workers.

Regarding inclusion of leprosy affected persons in Self-help groups the discussions brought up the following issues:

- CBR workers, disabled persons, leprosy affected persons, all agree that integration of persons with leprosy disabilities in SHGs is problematic and requires proper planning and follow-up
- Persons with more visible deformities face more problems
- Self-stigma or perceived stigma among leprosy affected persons, their fear that they will not be accepted, is a big obstacle
- Other disabled persons may express negative feelings about integration of leprosy affected persons but usually this obstacle can be overcome through awareness and discussions
- The integration was gradual over a period of many years – examples of leprosy affected persons active in a SHG become example to stimulate more persons to join.

Regarding the feelings of ex-leprosy workers, the discussions showed that change of role from leprosy worker to CBR worker is perceived as a big problem, especially by persons with long-standing experience as leprosy workers. Some of the issues that came out included:

- Higher work-load (“before we just distributed drugs and explained some things, now the work is never over...”)

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- Loss of expertise – “before we had clear cut competence, now we have to facilitate but problems are more difficult to solve...”
- Closer contact with persons and their families by home visits – “earlier, people had to come to the ambulance, now we have to go to homes...”

For these reasons, for contemplating any change in vertical leprosy programmes to start CBR activities, the ex-leprosy workers made the following recommendations:

- From prescriber to facilitator role change of the health workers is a key issue and needs to be tackled by sufficient planning and discussions
- Workers need support in the transition period through training, dialogue, sharing of experiences, necessary to talk about problems
- Change must be planned and gradual

In conclusion, integration between leprosy related rehabilitation services and CBR is feasible; it improves sustainability of the project activities. It is felt that CBR approach has great deal to offer for integration and rehabilitation of leprosy affected persons. However, both these aspects require careful planning, preparation, support and training for gradual implementation.