

## **India: Leprosy related Activities of AIFO Supported Projects**

### **Bangalore, 11 December 2006**

**Introduction:** A small group of AIFO supported projects was invited for a discussion on leprosy related activities carried out by them.

Following the integration of leprosy diagnosis and treatment services in the primary health care services, the work load of leprosy has decreased for the AIFO supported projects. Since the focus of our monitoring is on diagnosis and treatment of new cases of leprosy, this change reflects very strongly in decrease of leprosy related activities. Therefore, it is important for AIFO to understand the different leprosy-related activities carried out by AIFO-supported projects, especially in terms of referral services for Governmental primary health services and in terms of needs of ex-patients.

The following projects participated in this discussion: Gudivada (Sr. Dr. Prashanti), Bellary (Sr. Ida), Cochin (Dr. Daisy Kadathil), MOB Mandya (Sr. Leela), Kollapur (Sr. Celine), Sumanahalli (Fr. George), Mr. George (Manglagiri), We care (Fr. Trevor) and Malavalli (Mr. Narsimha). Other participants were from AIFO India (Mr. Jose, Dr. Mani, Mr. Jayath & Mr. Patrick) and AIFO Italy (Dr. Enrico Pupulin & Dr. Sunil Deepak).

**Mandya – MOB:** The project continues to operate an outpatient service from Mandya Government hospital for diagnosis and treatment of leprosy, where annually 3-4 new cases of leprosy receive treatment. The project has discontinued the community surveys for finding new cases of leprosy.

At community level, project supports the district leprosy officer in organisation of skin camps and health education activities on leprosy. The project is also referral centre for leprosy for the whole district, as part of which it treats persons with leprosy reactions. These community level activities cover three taluks (sub-districts) – Mandya, Pandavpur and Nagamangala. As part of the new Disability Prevention and Medical Rehabilitation (DPMR) of Indian Government, the project also takes part in follow-up of ex-patients, education for self care, distribution of footwear, artificial limbs and other aids such as wheel chairs.

As part of its community development activities, the project has 164 self-help groups, each with 10-20 members, many of whom are leprosy affected persons.

**Bellary:** The project continues to work in two taluks (sub-districts) of Bellary province for following the persons who have completed anti-leprosy treatment and are released from treatment (RFT), who receive information about ulcer care and prevention of disabilities. These activities are carried out as part of CBR activities. At the same time, possible new cases are asked to report to Government primary health care services for diagnosis and treatment of leprosy. The project also has a specific component of school based health education and community health education on issues such as leprosy, AIDS, etc.

The project also provides referral services for persons with leprosy related complications such as reactions, while persons requiring reconstructive surgery are referred to appropriate centres. It supports needy persons for wound dressings, ulcer care, provision of artificial limbs and aids. At present, the project is not providing any footwear to leprosy affected persons with foot ulcers and plantar anaesthesia.

The project had about 4000 RFT patients in its registers that were handed over to the Government. The project maintains contacts with about 50% of these ex-patients.

As part of its community level activities, the project has self help groups including 35 groups of persons with disabilities and 50 women groups, many of the members of these groups are leprosy affected persons.

**Malavalli:** This is a CBR project that was never involved in diagnosis and treatment of leprosy, so there has not been any change in their activities. The project follows about 16,000 persons with disabilities including persons affected with leprosy.

As part of its activities, the project provides community awareness on leprosy and supports persons requiring specific anti-leprosy treatment to visit health centres and to take regular treatment. It also helps leprosy affected persons to access different services such as footwear, artificial limbs, integration in self-help groups, vocational training, bank loans, etc.

**Kollapur:** Till now about 400 persons have completed anti-leprosy treatment at Kollapur. For answering the needs of these persons, the project provides ulcer care, free protective footwear, dressings, etc. Project has a 10 bed hospital, where persons with complications such as reactions can be admitted. Persons requiring reconstructive surgery are referred to appropriate services. After the surgery, persons can receive physiotherapy services at the project.

Project also provides health awareness on leprosy to communities and schools. Organising street-plays is one of the modalities for health awareness. Project also promotes self-help groups and a few leprosy affected persons are members of these groups. When persons with suspected leprosy lesions come to the project, they are referred to Governmental services. The project is also involved in food for the needy programme that also benefits some leprosy affected persons.

The project is in a difficult to access area with problem of Maoists. There are also problems with integration of leprosy work in primary health care services as vertical leprosy staff continues to take care of leprosy work. Government wants to create a nodal centre for leprosy in collaboration with the project.

**Gudivada Assisi centre:** The project covers an urban area for diagnosis and treatment of leprosy. Till now about 6,500 persons have completed anti-leprosy treatment at the project. At present 6 patients are receiving anti-leprosy treatment from the project. From the areas outside the project areas, project can not provide anti-leprosy treatment, but they can come to the project for ulcer care and complications such as reactions.

If suspected cases of leprosy come from outside the project area, they are referred to primary health care services. The project monitors these persons to ensure that they receive anti-leprosy treatment and it has been observed that for some of these patients, the starting of treatment can be delayed by 2-3 months.

The project has been involved in capacity building of Governmental staff for conducting reconstructive surgery for persons with disabilities due to leprosy. Activities for prevention of disabilities, follow up and health education are also carried out. The project also reaches leprosy affected persons through the CBR programme.

**Mangalagiri:** This project started rehabilitation activities related to leprosy in 1990, especially in terms of plantar ulcers through supply of protective footwear. Project has a trained orthopaedic technician (Mr. George) with specific training on needs of leprosy affected persons at Karigiri. Some of the recent activities of the project include supply of orthopaedic appliances in two taluks (sub-districts) of Guntur district in collaboration with ALIMPCO (a body of Government). The

appliances include tricycles, wheel chairs and hearing aids. They also receive raw materials from ALIMPCO that is used by their limb-fitting centre.

**Sumanahalli:** The project is responsible for leprosy control in 25 wards of Bangalore with a population of 1.2 million persons. At present, they have 23 cases receiving anti-leprosy treatment. So far, a total of 4,600 persons have completed anti-leprosy treatment at this project. Persons come from all over Karnataka and even from other states for accessing the rehabilitation services of Sumanahalli. The project runs five clinics in the city, there is a centre for ulcer care. The project provides vocational training to about 75 persons every year. 862 children receive support for education. The project runs a school and two tuition (coaching) centres for students. Project also has a garment production unit. Project also produces protective footwear, that is provided also to Government centres. A mix of beneficiaries, both persons affected with leprosy and other disabled persons, benefit from these activities.

Other activities include support for housing, facilitation of marriage for affected persons, provision of aids and appliances, provision of disability certificates, etc. Project supports 20 self-help groups (including 8 mixed groups, one group of persons with disabilities, one youth group containing children of leprosy affected persons and one children group).

Project is also involved in training on leprosy awareness to medical officers and other students such as from departments of psychology, nursing, CBR workers, teachers, etc.

As number of persons needing anti-leprosy treatment is decreasing, the project is placing more emphasis on rehabilitation activities. Two years ago, activities were opened to persons with non-leprosy disabilities.

At present, around 70% of the beneficiaries of different activities are persons affected with leprosy.

**Cochin:** During 2006, no new case of leprosy was diagnosed in the project area. A survey was conducted in a slum area but it did not identify any new case of leprosy. Project continues to provide dressings and ulcer care for ex-patients, at the same time, project maintains contacts with families of treated persons. So far, the project has about 1000 persons who have completed anti-leprosy treatment.

**We care:** Project started in 1999 with charitable activities towards poor children. Gradually the project adopted CBR approach and in 2003, started work in 4 wards of Bangalore for identification of persons with disabilities. Project covers about 400 children. They identified 8 leprosy affected persons who were referred to local institutions for support.

## **Summary of the situation of leprosy related activities in AIFO supported projects in India**

### (a) Diagnosis and Treatment of Leprosy:

- Projects are no longer involved in it; if they are involved in it, their area of coverage has decreased and the number of new cases of leprosy is decreasing significantly.
- Projects with community activities continue to play a role in referring suspected cases to Governmental primary health care services; in some cases, they can monitor if the new cases are receiving adequate treatment; they can support patients in ensuring that treatment is taken regularly.
- Projects are involved in health education and awareness creation on themes of leprosy.
- Support for complications (reactions, ulcers, reconstructive surgery) and prevention of disabilities among active cases receiving treatment at Government services.

- Capacity building of Governmental personnel
- (b) Activities for leprosy affected persons who have completed specific treatment
- Promoting empowerment of affected persons, persons with disabilities and families
  - Wound dressing and ulcer care
  - Provision of protective footwear
  - Prevention of disabilities, teaching self care, medical rehabilitation, reconstructive surgery
  - Promoting economic independence and income generation
  - Promoting formal and non formal education of affected persons and families
  - Promoting social integration and marriages
  - Residential care of persons with severe disabilities and other social problems.

**Proposals:**

- Look at leprosy globally and not just as an issue of diagnosis and treatment; therefore, other activities for leprosy affected persons should be given proper emphasis in reporting and monitoring.
- Look at all the persons who have completed specific leprosy treatment and identify needs such as provision of footwear, prevention of disabilities, reconstructive surgery, social and vocational rehabilitation, etc.
- Promote inclusion of leprosy affected persons in all community development activities such as self-help groups.
- Continue to support Governmental structures for diagnosis and treatment of leprosy.

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