

Monitoring process of AIFO in India

Part - I

INTRODUCTION OF AIFO

AIFO is an Italian Non-Governmental Organization (NGO) with its headquarters in Bologna. AIFO is recognized by European Union and by the Italian Foreign Ministry for Projects of Development Co-operation and collaborates actively with United Nations and has an official relationship with the World Health Organization (WHO). AIFO provides support to projects in developing countries, without any discrimination on the basis of colour, race, religion, gender etc. AIFO has no political or religious aims of any kind.

With leprosy relief work as its focus, AIFO also supports Rehabilitation of persons with disabilities and programmes for vulnerable children with Community Based approach. Raoul Follereau propounded the doctrine of love and brotherhood to all people, irrespective of their caste, creed, colour, religion, disability etc. AIFO was conceived based on this inspiration. The work of AIFO in India is an attempt to translate this doctrine into reality, in this rapidly changing society. The leprosy work, Community Based Rehabilitation (CBR) and the projects with children are a direct reflection of the doctrine of love and brotherhood.

In the early seventies, AIFO began its work in India by supporting activities carried out by NGOs through German Leprosy Relief Association. Dr. V Ekambaram, an eminent leprologist was appointed as representative of AIFO in India in 1979. His expertise and experience as the First State Leprosy Officer, Tamil Nadu helped to lay the solid foundation for all the future activities of AIFO. After couple of years, Dr. Daisy Kandathil, who began the work with several NGO's, joined

Dr. V. Ekambaram. 1983 Government of India requested AIFO to Support the MDT Programme in Chittoor District, Andhra Pradesh. Dr. Ekambaram was appointed as the consultant for the district. He monitored the National Leprosy Eradication Programme. Technical and financial help was now being provided by AIFO to Government projects. In the year 1992, The Government of India requested to support the Modified Multi Drug Treatment Programmes which was for endemic districts. This support for MMDT was also provided by AIFO. Two districts in Karnataka (Bangalore Urban and Mandya) and two districts in Madhya Pradesh (Vidisha and Raisen were included in this programme. This kind of collaboration, i.e. extension of support by AIFO to Multi-Drug Therapy Programme of the Government of India is indeed a pioneering concept and has been in practice since then. At present AIFO provides support to District Technical Support teams in five states which are Uttar Pradesh, Madhya Pradesh, West Bengal, Andhra Pradesh, and Karnataka.

AIFO also extends its support to Non-Government Organizations. A vast network of NGO's working for leprosy rehabilitation, CBR projects and projects for children are supported.

In the year 1996, a trust named, **Amici di Raoul Follereau**, meaning, *Friends of Raoul Follereau* which aptly describes our organization, was formed and the coordinating office was now based in Bangalore.



All projects are based at the grass-root level and are people oriented programmes. Our team of committed workers in collaboration with our local partners forms an extensive network all over the country and they ensure the functioning and monitoring of each project. Therefore, our projects are scattered all over rural India. Using this methodology we have been able to reach people in several remote and inaccessible areas.

At every stage the role of the NGO is clearly demonstrated. All the activities conducted for rehabilitation of the Persons Affected by Leprosy are a clear indication of the commitment with which these grass root level workers carry out their responsibilities. For example, focus group discussions conducted by involving project staff, disabled and Persons Affected by Leprosy in Malavalli, Karnataka reveals several issues faced by the Persons Affected by Leprosy. Based on these findings, rehabilitation programmes are planned for the extended area. Results of this discussion are briefly analysed in this document.

Presently, Mr Jose who is having a vast experience in the field of Leprosy and CBR, who is currently leading the whole process of managing all the projects in India as representative. At present 13 CBR projects are operating in different places, out of which, six are located in Karnataka, two in Andhra Pradesh, one each in Kerala, Uttar Pradesh, Assam, Haryana and Jharkhand. In all these projects, direct implementation of the activities is done by the grass root workers/CBR workers/volunteers in about 12 to 20 villages depending upon the need and situation in the area. Day to day planning and reporting of the happenings will be carried out by the same members who will report to the Taluk / Block level coordinators and through them to the project management.

Part-II

MONITORING PROCESS:

It is being deliberated among the board members of AIFO India including representative and the partners to analyse monitoring systems, in order to monitor AIFO supported CBR projects in the following ways. Monitoring is a process of collecting simple and relevant information to keep concerned persons informed about proceedings of the programmes as made clear in the discussion. This enables the project management to keep track of day to day activities as well as to make changes in the programme at grass root level. CBR workers / Grass root workers are the key people in developing links between the disabled, CBR committees, Government and General community etc. Implementation of day to day rehabilitation activities and monitoring the progress at local level is the important role which lies in the hands of CBR workers as discussed by AIFO board and the partner agencies. It will be supported and monitored by the Taluk co-ordinator, so as to enable the project management to keep track of all the proceedings as well as to make essential changes in the programme. This will be ensured through monthly progress review meetings and regular field visits by the co-ordinator.

2.1 Monitoring at local level:

As mentioned above, CBR workers will have links between the community, CBR committees and with the project management. This will be done through day to day planning and reporting as well as through the monthly review meetings. Planning with the technical team and the supervisors will enable the workers to directly implement the rehabilitation activities for the needy persons. Along with this, they maintain day to day diary, reports, monthly reports, Case files of individual disabled, reports of CBR committees, disabled persons organizations/self help groups and these are some of the areas to be considered as sources for monitoring process. On regular basis coordinators will monitor the proceedings done by the CBR workers/volunteers at the community level to make necessary changes.

2.2 Monitoring at Taluk/Block level:

Co-ordinators of the Taluk are the persons in charge to monitor entire progress in the area. However they do not directly implement rehabilitation activities, but, this will be done through CBR workers. Conducting monthly review meetings, participating in community based activities, visiting field, and suggesting changes to the CBR workers are some of the monitoring activities in which the co-ordinator has to perform. Training of workers/DPO members, facilitating community meetings, developing links with the local government and other NGOs to involve them in the CBR program are some of the activities which will be directly done by the Taluk level co-ordinator.

He / she will produce consolidated monthly, quarterly – half yearly and annual reports of the entire area, which will be taken as information for monitoring the progress at taluk level. In addition to this, yearly plan will be prepared and it will be made available for the co-ordinator at project/district level.

2.3 Monitoring at project/district level:

Project Level co-ordinator/manager will constantly monitor the situation through discussions and reporting every quarter to the national level monitoring system. Regular review of progress with the taluk level co-ordinator, visiting field activities, developing capacity of taluk co-ordinators, improving the relationship with the government and other NGOs are some of the activities that will be implemented by the project coordinator. Strengthening the links with the partners, consolidation of all the blocks report annual planning and reporting along with the taluk level coordinators are some of the examples which could be considered as sources for monitoring at project level. He, along with the project management will be responsible for the progress assessment/final evaluation as well as for making major changes in the approach of the program in the area.

2.4 Monitoring at organizational/national level:

CBR co-ordinator-team will regularly monitor the changes and progress of each project every year in consultation with the representative. His/her role is to develop capacity of the project team, suggesting major changes in the approach, facilitating Zonal and National level review meetings, organizing training and exposures for projects, assessing the progress along with the project management. Quarterly, half yearly as well as the annual progress report, monitoring form and plans of each projects are the sources for the co-ordinator in order to monitor the developments.

Added to this, project visits and review meetings with the individual project management will be done by the CBR co-ordinator, for monitoring the ground situation at project level. His visit reports and comments on the annual plan as well as report of each project could be referred as monitoring information by the supporting agency. His recommendations and suggestions for easy monitoring at project level are the additional factors which are included in this role. Over all supporting of projects planning, organizing, implementation, and evaluation will be also part of co-ordinator role in the process of monitoring CBR programmes at national level. This is done by setting objectives and his activity plan for each year, some examples of such programmes are listed below for our information.

2.5 OBJECTIVES:

- To develop human resource along with the AIFO partners in the field of CBR/Leprosy rehabilitation.
- To facilitate technical support/training/exposure to the grass root organizations.
- To review the progress of CBR programmes along with the partner agencies.

In order to achieve the above mentioned objectives, (building capacity) is the strategy planned for the inclusion of most marginalized groups like the disabled in the society. Regular training on CBR and Leprosy will be organized, to develop inclusive approach by integrating CBR principles with the existing programmes. Below given list of activities are being followed for this purpose in collaboration with the supportive agencies at national level.

2.6 Activities

1. Facilitating CBR and Leprosy training courses as well as exposures.
2. Project visits for understanding the activities, for conducting basic CBR training programme.
3. Leprosy training for staff and disabled persons organizations along with regular consultation with representative.
4. Consolidation of annual reports like AIFO monitoring form for CBR projects in India.
5. Organising review meetings along with EENET coordinator in CBR pilot projects and conducting progress assessments.
6. Maintaining essential documents like project visit reports, annual report and presentation to AIFO representative / team.
7. Participating in the workshops, seminars at state, national and international levels.
8. Collection and sharing of information with EENET co-ordinator.
9. Field visits to disabled families, group activities and other general programmes.
10. Providing consultancy services to AIFO partner agencies working in other countries apart from India and others out side AIFO.

2.7 Following table will help us to understand the monitoring process and the mechanism at different levels of CBR programme.

For which activities, sources and other related aspects for monitoring the progress of interventions are given in a format.

| Levels | Activities | Meetings | Sources/Record Keeping | Reporting |
|--|---|--|---|--|
| 1. Local Level (by CBR worker) | Home visit, Interactions, physical assessment | SHG meetings, Parents meetings, Volunteers meeting | Case File, Diary, Register, Individual Plans & reports | SHG and Volunteer's report |
| 2. Block/Taluk Level (by Co-ordinator) | Village Visit, Interactions with families & with CBR workers. | Fortnightly meetings, monthly meetings with CBR worker for planning and review | Movement and Activity Registers, Coverage Table and diary | Fortnightly, monthly, quarterly, half yearly and annual Report |
| 3. | Family visit, | Monthly | Programme | Monthly, |

| | | | | |
|--|---|---|---|---|
| Project/District Level (by District Co-ordinator) | Interactions with CBR worker/ block coordinator | meetings with block co-ordinator for planning and review | records, Movement Registers, Monitoring form, Coverage Table and diary | quarterly, half yearly and annual Reports + articles & review reports. |
| 4. Organisational/ country level (by CBR Co-ordinator) | Project visits, Interactions with the Team, field visit, review meetings, progress assessment | meetings with Project management, Representative for planning, reporting and review | Activity Registers/records, consolidated monitoring form, visit and training programme documents. | Monthly, quarterly, half yearly, annual reports, + consolidated form, project visits, training programme Reports and financial statements |

2.8 Indicators

As we are aware, monitoring indicators are the units of measurement of monitoring process. Indicators can be classified into coverage/input, process, out put, out come and impact indicators. They can also be classified in to quantitative and qualitative indicators. Some of the examples of such variable indicators are given below for our information which are being practiced in AIFO supported projects – India.

| Input Indicator | Process Indicator | Output Indicator | Outcome indicator | Impact Indicator |
|--|-------------------------------------|------------------------------------|---------------------------------------|---|
| No. of awareness programme conducted | Methodology of awareness programmes | No. of people participated | Change of attitude | Empathise/acceptance |
| No. of surgeries organized | Ways followed | NO. of persons underwent surgery | Improved mobility | Inclusion |
| No. of Children Integrated | Means of integration | No. Children going to school | Children acquired skills | Got through. |
| No. of persons trained in vocation skills | Process followed | No. Persons completed training | Persons initiated self employment | Earning livelihood, improved economic condition |
| No. of CBR personel trained in CBR/leprosy | Learning Methodology applied | No. Trainees completed | Persons improved knowledge and skills | Persons initiated new activities |
| No. of progress review conducted | Methodology used | No. Group/individuals participated | Individuals shared information | Issues tackled/addressed |
| No. of meetings conducted | Process of facilitation | No. Members participated | Members shared problems | Decisions taken |

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Part – III

Findings of the progress review conducted in Malavalli CBR project:

As part of the CBR progress review, an assessment was done on interventions carried out to integrate persons affected by leprosy in the community in Malavalli-Mandya CBR project supported by AIFO. Results of this review are analysed in this document. This pilot project is directly implemented and monitored by the Shree Ramana Maharshi Academy for the Blind (SRMAB) Bangalore, which is supported by AIFO India, Bangalore. Malavalli is one of the Taluks in Mandya district of Karnataka State. The Taluk consists of about 300 villages. 80 villages of this Taluk were taken as a target area in the year 1997, for implementing CBR programs, with a special focus for leprosy affected people. Project identified 1226 Persons with Disability including persons affected by Leprosy as its direct target group. After three years of the implementation, a review was taken up in order to understand the situation of persons affected by leprosy in CBR program through focus group discussions.

3.1. Focus group details:

Three discussions were conducted at different levels for above given purpose.

1. For a group of CBR workers,
2. For a group of Disabled and
3. For a group of persons having deformities due to leprosy both grade I and grade II disabilities.

In all the discussions both male and female were facilitated to elicit the information. In each of the discussion a group leader was identified and oriented with the questioner in order to facilitate the discussion in the local language (Kannada) and to take notes.

Following table gives the details of members who have took part in the discussions.

| <u>Sl. No.</u> | <u>Type of group</u> | <u>Male</u> | <u>Female</u> | <u>Total</u> |
|----------------|----------------------|-------------|---------------|--|
| 1. | CBR Workers | 7 | 3 | 10 (including 1 PAL and 7 loco motor disabled) |
| 2. | Group of Disabled | 4 | 5 | 9 (visually impaired, loco motor and Multi disabled) |
| 3. | Group of PAL | 11 | 2 | 13 (grade I and II disabilities) |

3.2. Questionnaire:

Different questions were posed regarding Leprosy affected persons participation in CBR activities, such as which are the activities? Usefulness of these activities and in what ways? How did their participation come through? Who promoted and supported their participation? Whether their visible deformity makes difference in their participation? Do they have any initial difficulties? What kind of difficulties? What was the attitude of other disabled.

3.3. Findings of the review:

1. In all the three discussions, most of the members felt that the persons affected by leprosy are taking part in the list of activities given below:

a) Health and Medical Rehabilitation activities:

Like Aids and Appliances distribution camp, nutrition camps.

b) Self Help Group Activities:

Like, attending regular meetings, awareness activities, and celebration of anti leprosy day, disabled day Celebration, street plays, film shows etc.

c) Economic Rehabilitation Activities:

Like carrier guidance workshop, self-employment loan, etc.

d) Group development activities like training and exposures program (Self Help)

2. Usefulness of the activities:

Each group stressed the point that, awareness regarding disability, health and rehabilitation, is helping them to come out of the inferiority complex within the individuals and to integrate themselves in the society. Their participation enabled them to be aware of Govt. schemes and facilities, especially early treatment helps them to prevent secondary deformities.

3. Regarding their participation:

It has come through well. Expressed quite confidently by the members during the discussion of leprosy affected persons. But group of disabled felt it has come through slowly after regular counseling and motivation, where as the CBR workers shared that, mild and moderate (grade I) disabled have active participation, on the other hand severe and profound (grade II) are bit hesitant at initial stage but slowly and steadily their participation also improved.

4. Promotion and support :

In each discussion it is openly discussed that, CBR workers of Malavalli CBR project, who promoted and supported their participation. On the other side group of leprosy affected people also expressed that the Para medical workers, who are also helping them to integrate in the society.

Hence, facilitators understood that the project has effective networking system with the Govt. Local Health Departments.

5. Differences in visible deformities:

Group of CBR workers and disabled persons felt that, sometimes or in the initial phase, their visible deformities make difference in their participation. Where as the other group of leprosy affected persons have expressed their concern about their visible deformities in hands and face, which makes them to hesitate to participate.

However, the disabled group does not find any differences between the other disabled and disability due to leprosy.

6. Initial difficulties:

Yes: all the three groups accept that they had initial difficulties to participate.

7. Difficulties are:

Group of leprosy affected persons had lack of awareness, but the other two group's finds that their visible deformities, hesitation and negative feeling about themselves are some of the difficulties.

8. Attitude of other disabled persons towards persons having deformities due to leprosy.

Groups with out leprosy affected persons clearly clarified that, they don't have discrimination in terms of attitude and behavior towards persons having deformities due to leprosy, because of the fact that it is curable and prevention is important. The other group with persons affected by leprosy also expressed the attitude of the other disabled, is: Some times few behave very positively, but, it depends on the knowledge regarding the disease.

Based on the findings of this assessment, both the managements of AIFO and SRMAB has decided to extend the area to the whole district of Mandya. This decision was made, keeping the previous 80 villages of Malavalli Taluk as follow up area for the entire district. Results of this pilot project will be used as base for covering the interventions for addressing the issues of the people living in the colony and to include them in the community activities. Now six taluks of Mandya district are already covered under CBR programme by MOB Mandya and Malavalli project-implimentation is in process.

3.4. Conclusion and Review team:

a) Conclusion:

Thanks to our partners for their continuous excellent support and collaboration, which is one of the essential factors for the implimentation of any rehabilitation activities in the field of development. Our journey of ten years reveals that, significant changes like referral for further special and technical training, expansion of the area under CBR, integration of disability and rehabilitation activities have been observed in Leprosy control as well as in other programmes. Several issues of the marginalized people has been addressed by our projects, part three of this document could be one such example of our learning, where attempts have been made to integrate leprosy affected people in the community. There are still, many other burning issues, which need to be tackled for the integration of disabled in the society, negative attitude towards them would be a best example. It is a great pleasure and opportunity to share our experiences, through which we are learning together with our friends/partners. Flexibility and openness among the stakeholders to learn and to accept according to the real needs as well as situation of people is enabling us to widen our vision of inclusion in the society. So that, we could reach more and more disabled in larger community through the strategy of community based rehabilitation.

b) Review team-

Dr Sunil Deepak head of medical and scientific department AIFO Bologna,

Dr. Giovanni gazzoli manager Indian programmes, projects division Bologna Italy.

Mr Jose M.V. representative AIFO India,

Mr Jayanth Kumar Y.B., CBR co-ordinator AIFO India,

Mr Ramesh project co-ordinator Malavalli CBR project and the participants[CBR workers, disabled and the persons affected by Leprosy].

Mr. Jayanth Kumar

CBR coordinator

AIFO India

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