

CBR AND LEPROSY ORIENTATION TRAINING PROGRAMME

Introduction:

CBR is one of the strategies within the community development for answering the rehabilitation needs of PWDs (Health, Education, Social and Economic etc.) Developing countries like India, Pakistan, Nepal, Bangladesh, China, countries in South Africa and South America, where the disability rates of prevalence and incidence rates are high, due to poverty, illiteracy, poor hygiene, lack of awareness, diseases, accidents, mal nutrition and many other factors. Many NGOs in the developmental field has followed CBR approach as an innovative method for addressing the needs of disabled in India. Recent results have shown CBR is one of the approaches for the community development. The approach has covered comprehensive rehabilitation aspects including protection of rights, equal opportunities for people with disabilities, families and community.

As it is mentioned by the National Sample Survey Organisation India (NSSO) in the year 1991 according to the sample survey, the disabled population of India is about 5.2% of the total population which includes all category of disabled. Majority of these people are lacking to access the resources of basic needs like, food, clothing and shelter, especially women with disabilities, mentally challenged, multi-disabled are facing even the worst situation in the society. Many times it is even difficult to afford basic health care, which is essential for prevention of further worsening of the situation.

65-70% of the total population in India, lives in rural areas and 40% of the total population comes below the poverty line, which means majority of the people needs rehabilitation, especially those living in rural areas.

On the other side, about 6 – 7 lakh of people are affected by leprosy every year. Many of them, who are cured but left with deformities are totally isolated and are migrated to settle in leprosy colonies or villages. Still in India, there are many colonies or villages, where leprosy affected people are finding their means of survival. Thus we can understand the magnitude of problems in the rural areas.

AIFO in India:

It supports rehabilitation programs for PWDs, PALs, children with vulnerable conditions and other developmental activities through GOs and NGOs. It has also planned to integrate CBR with Leprosy rehabilitation activities, mainly to bring PAL into the mainstream of the society.

Since, the community based rehabilitation is an innovative method, which is based on the principles of community involvement, social integration, cost effectiveness, wider coverage, etc, AMICI Bangalore decided to apply these principles in the leprosy projects, through training, exposures.

Biennial Meeting of AIFO in India, held at Cochin in 1993.

It was discussed in this meeting of all the AIFO supported projects in India, Dr. Enrico Pupulin who is the present Chief Medical Officer, Rehabilitation team, WHO and Dr. Sunil Deepak presently Head of Medical and Scientific Dept. AIFO Bologna, Italy, with Indian Representative, Dr. Daisy Kandathil, discussed the relevance of CBR in the changing scenario of leprosy. It was felt that, it is appropriate that all the projects supported by AMICI will incorporate the leprosy-related activities through CBR principles and new initiatives can be identified where these principles can be implemented. In the same year WHO CBR manuals were received and copies were supplied to many new initiators.

Feasibility Study in Mandya District in 1994.

Visits to Mandya districts of Karnataka and discussion with the local leprosy consultants, revealed that, Malavalli is one of the endemic taluks of leprosy in the district. Visits to SRMAB CBR projects and discussions with the management of the institution provided the essential information for taking up leprosy integration with CBR in Malavalli taluk. This feasibility study through observation and discussion helped to decide the above said integrated project in the district.

Biennial Meeting, Bombay in 1995.

Again wholistic approach for the community development was stressed and the principles of community participation was discussed, many projects came out seeking more information about community based rehabilitation. During the same year visit to H.B. Halli, Bellary and extension of support to NLEP programme through Assisi Leprosy Centre, since the district has high disability rate and leprosy endemic area, it was decided to incorporate the community based activities through NLEP programme.

CBR Training Programme 1996.

10 days CBR training programme was organised for the representatives of different AIFO supported projects in collaboration with SRMAB.

In the same year representatives of different leprosy projects referred for 3 months CBR training at TRC in Andhra Pradesh. H.B. Halli CBR project leader was also attended the course.

Biennial Meeting – Bangalore 1997.

Keeping the views of previous 2 biennial meetings, it was decided to extend the support to SRMAB Bangalore and Assisi Leprosy Centre, Bellary.

As a result in the same year Malavalli CBR project of SRMAB was initiated, where, leprosy rehabilitation activities were integrated with CBR for the first time.

On the other hand Assisi Leprosy Centre, H.B. Halli, Bellary leprosy project has included CBR activities with leprosy control programme for the first time in AIFO supported projects.

1999 Workshop in Andhra Pradesh.

Two CBR workshops for managers were organised by AIFO, one at ADC Pedana in Machilipatnam and other at Warangal. Basic orientation to disability and rehabilitation was covered to leprosy projects working in Andhra Pradesh. Later CBR was integrated in Thiruvooor and ADC Pedana leprosy projects. At present six of the leprosy NGO projects have taken up CBR work along with leprosy activities.

Majority of the leprosy caseload is in India, hence agencies involved in leprosy work are working in close collaboration with Government in order to avoid duplication of work and maximum utilization of resources.

Keeping the vision of total integration of all the different activities for the future AMICI started CBR programmes and appointed a CBR coordinator in the year 2000 and started conducting CBR/Leprosy organisation. It has also defined, as one of the roles of the coordinator to organise training and exposures for AIFO supported projects in India.

BIANNUAL MEETING DECEMBER 2001:

During this meeting AMICI has organised a training programme on participatory rural appraisal for all the managers of AIFO supported programs in India. In the processes different participatory techniques like social mapping matrices ranking, resources mapping, community meeting, and seasonal mapping were oriented. In the same meeting discussions were held to adopt essential principles of community participation, in order to implement AIFO's strategies in India.

A) Decision regarding the courses:

After realising the greater need for rehabilitation of the disabled including PAL and also many years of experience in the field of leprosy, AMICI Bangalore, in consultation with AIFO Bologna, decided to adopt the principles of community based rehabilitation for addressing the rehabilitation needs of PAL in India. Need was also felt by the projects and requests from them were considered. Welfare activities of the projects in small and isolated way indicated the possibility of better and wider effect, if CBR training is provided.

B) List of projects selected:

It is not only the decision of AMICI Bangalore, but also the requests from the projects were considered for discussion and jointly decided the plans depending on their needs, proposals and convenience, requests etc. were taken into account, because many problems and issues are different from place to place. For example, in Haryana, Chandpur project, caste barriers and parda systems are still in practice, even among the Hindu women. So these kinds of issues are incorporated in the orientation courses. Other example is Assam CBR project, where land mortgage to the moneylenders is high. Here principle of community involvement and community organisation, especially the concept of S H G were strengthened and same content was included with disability and leprosy orientation. H.B.Halli CBR project Bellary, this project was started only two years ago, before the inclusion of CBR in the leprosy activities. So the approach was

easy to implement the activities. Malavalli CBR Project: here experience of the organisation in field of disability was considered for the integration of leprosy related activities with community based rehabilitation programme.

But in all the courses a orientation on leprosy, early identification, its consequences were covered in order to sensitise the projects and community based groups regarding the disease.

There are other projects, which are specifically oriented with CBR because, most of these projects already started leprosy eradication programme, mainly to combine the interventions for all category of disabled including the PAL.

At the end of each orientation courses, feed back sessions were conducted to understand the reactions or the feeling of the participants. Although there was mixed reactions in the beginning, most of the target groups reacted positively and accepted the contents of the course.

C) Characteristics of the Projects:

There are 11 projects taken for the CBR and the Leprosy training so far, out of which 8 are managed by the congregations and remaining 3 are managed by N G Os. 3 big projects are managing about 80 to 180 villages, with a population from 151,000 to 224,000. 6 projects managing about 9 to 45 villages as their target area, with a population of 40,000 to 100,000. Remaining 2 are having programmes in urban areas, one, with 11 wards and the other managing with 44 wards including 25 villages, in Gudivada, with a population of 21,000 to 220,000.

All these projects are having activities based on their original objectives. Many of these projects are implementing the activities related to leprosy and its rehabilitation. Some projects like, Malavalli, Assam CBR projects are conducting activities for rehabilitating disabled, as well as activities of rural developments, mainly focussing on the economic and social rehabilitation, like in Assam are also part of it. Primary Health Care and educational activities are also covered in some projects like, I M A Cochin and Chandpur project, Haryana, in collaboration with the government and N.G.Os.

During the processes of training programme, majority of the target groups reacted positively and the resource personnel observed interest among the participants. In some occasions, maximum co-operation was observed inspite of unconducive circumstances. But in some places like, ADC Pedana and Bellary, participants strongly debated on some of the challenges of CBR such as interventions for multi disabled, activities for mentally retarded and mentally ill, sustaining the self help groups etc.

D) Regarding contents of the course:

It is the combined decision by the resource persons and the projects. In each of the training programme, learning needs assessment will be done at the beginning of the course. Needs of the trainees will be very much taken into account and the discussions among the project leaders will be done to define the course contents. However a tentative programme will be given to the participants on the first day before the actual commencement of the course. Thus, there will be changes in the course contents for different projects depending on the situation and the needs like changes made in Chandpur and also in Assam.

Tentative Content:

1. Poverty analysis – Meaning, causes with regard to disability.
2. Value analysis – Types, qualities of social workers, sources value.
3. Orientation of Disability – Meaning, types, degree, causes and its prevention.
4. Survey techniques – Key informant, PRA, RRA, Community meetings.
5. Important concepts, such as health, disease, impairment disability, handicapped.
6. Meaning of rehabilitation – History and models.
7. CBR concepts, principles:
 - a. Wider coverage
 - b. Cost effectiveness
 - c. Social integration
 - d. Community participation
 - e. Differences between IBR and CBR
 - f. CBR components like health, education, community organisation and occasional training and income generation activities.
 - g. CBR activities
8. Community organisation – SHG concepts, group dynamics, formation of SHGs and other Community Based Organisation (CBOs)
9. Visual Impairment – Meaning, Causes, Prevention and rehabilitation activities.
10. Locomotor – meaning, causes, prevention and rehabilitation activities.
11. Mental Retardation and Mental Illness – Meaning, causes, prevention and Differences between MR and MI.
12. Communication Disability – Meaning, causes, prevention, rehabilitation activities
13. Developmental approaches like, Integrated, people oriented, relief oriented and target oriented approaches.

14.CBR as a sustainable development – Meaning, its strategies such as awareness creation, advocacy, networking, training and human resource development, activating existing, infrastructure, community organisation and participation etc.

15.Attitude and Self-motivation.

16.Early Identification techniques.

17.Legislation for PWDs with reference to PDA India 1995.

18.Education for PWDs with special reference to inclusive education.

19.Self-awareness and personality development

20.Leprosy, cause, signs and symptoms, treatment, consequence of leprosy, prevention of disability, self-care, rehabilitation activities, current situation of leprosy.

As experience was gained, changes were made towards stressing the social components of rehabilitation - attitude, caste barriers, parda systems, respect and dignity of life, effective net working with other organisation etc. Gender equity, prejudices, and social problems of disabled including PAL was also added.

E) Regarding articulation of the course: subjects such as:

1.Disability and Rehabilitation

2.Leprosy, its consequences and rehabilitation

3.Community based rehabilitation

4.Principles and essential components of it.

5.Poverty analysis

6.Government schemes and facilities with special reference to India.

7.Legislations for PWDs with special reference to India.

8.Education for PWDs with special reference to inclusive education.

9.Medical rehabilitation (prevention of disability and rehabilitation of PAL)

10.Attitude and other social issues in general.

11.Value analysis.

12.Gender analysis.

13.Community organisation and participation.

14.Self Help Group Concepts for disabled families and community in general.

15.CBR as a Social Model.

Were tentatively planned. Modifications were made depending on the duration, needs and convenience of the participants. However, 4 – 10 days duration will be taken into consideration for the above said content. Training was planned in module wise, like:

- a) Basic CBR orientation: This module needs 8 – 10 days duration to cover the fundamental aspects of CBR for grass root level. For the middle level 6-8 days and for the managerial level 4-6 days. It was implemented in 7 projects of AIFO for grassroots and middle level workers. In one project managerial level workshop was conducted to sensitise CBR.
- b) Advanced CBR or Follow-up training programme: This was done in 2 projects for the middle level workers with duration of 4-6 days.
- c) SHG Module: This was done in two phases for SHG leaders and grass root workers in Assam CBR project as a separate module. However the same contents were incorporated in the basic CBR orientation module, which is already done for the other projects also. It is done separate in Assam because, the whole project is based on the SHG concept with community development.
- d) Basic Leprosy Orientation Module: This is conducted in all the non-leprosy projects at all the levels with duration of 2 days. Content for this course is mentioned in the content list.
- e) Leprosy Refresher Training: 2 days leprosy training will be planned for the non-leprosy projects to orient the advanced technique and to review the field activities in non-leprosy projects. This will be a future idea for the projects.

Follow-up training programme for all the leprosy projects will be planned in the coming years to orient the social module followed by the advancement of CBR concept.

There will be practical components during the courses, like:

1.Participants will be taught on survey techniques and they will be asked to collect and to analyse the case study of individual disabled in the field, they will also prepare tentative action plan for their projects, which will be presented at the end. In Assam CBR project training was conducted for the group leaders with in the village itself, in which the groups belong.

2.Courses will be reviewed on day to day basis with the participants, and resource persons will make the necessary changes if any. The selected participant will prepare reports of each day proceedings and the same will be presented to the group.

Evaluation was done at the end for the managerial level with 3-5 simple evaluation techniques. For the grass root and for the community based groups an informal evaluation was done through group discussions.

AMICI team members comprising, Dr.Daisy Kandathil, Mr.Jose, Mr.Victor, Mr.Ramesh, Dr.Lighaiah, Dr.Kiran, Mr.Jayanth and also resource persons among the participants were the facilitators. One of the two resource persons from the project will have the role of coordinator and some times translator.

F: Participants: It is the decision by the management of the projects. As an average of minimum 10 and maximum 30 participants attended the CBR and Leprosy orientation training programme in the year 2000 and 2001. Sometimes project leaders also consulted AMICI regarding selection of the participants.

G: Learning methods applied:

1. Field Visit:

Different survey techniques like PRA, R.R.A. etc. were oriented, the participants were asked to collect individual disabled case history in order to prepare effective action plan for each family.

Participants were divided into groups with assignments as explained above and each group prepared activity plan with a case study.

2. Social Games:

Various social games were used in order to understand the concept better and for the effective motivation of the community,

3. Group work and presentation:

This method was used for knowing the level of participant in which each participant actively shared their ideas.

4. Demonstrations and experiencing the disabilities

Under this method different conditions of disabilities and formation of disabled S.H.G. were oriented, during the process participants were asked to perform certain activities by blind folding, tying the other parts of the Body etc.

5.Audio Visual Aids:

Photographs and video films were used to understand disability and legislation for P.W.D.

6. Brain Storming:

Resource person reviewed the progress then and there by using this method. Questions were posed on specific topics both at individual and group levels.

7. Quiz Competition:

Participants were divided into different groups and questions were asked on point and term basis, in order to create a learning environment. So that the participants will feel free and comfortable to answer the questions.

8. Individual assignments and presentation:

Each participant selected a topic through pick and speak method and they presented their respective topics by using different methods. Topics like- problems of disabled, role of CBR worker, problems of community in general differences between IBR and CBR etc.

9. Role play:

Target group was divided into smaller groups and assigned to perform for the given situations like classroom environment with a special focus on inclusive education, family with a disabled child and atmosphere in the office like bank.

10. Lecture:

This method also used then and there for orienting the different topics like government schemes etc.

11. Story telling with live example:

This was used in order to orient the topics like counseling, motivation and personality development. Also qualities of a good social worker, problems of community in general and value analysis were explained through the above given method.

H: General analysis of the impact of the course:

After the CBR orientation training, projects have seriously taken up the principle of community organisation, participation and social integration in their related field. As a result, many self help groups of the disabled, their family members, women groups etc. were formed, especially in H.B. halli project, MOB, Mandya, Tiruvor CBR project of St.Catald, and other places. Some projects also improved and included many rehabilitation activities for disabled with existing programme like in I.M.A.Cochin project and MOB Mandya. A significant change was observed that the projects have come forward to accept and to combine the activities for PAL and PWDs. After the training on CBR concepts, projects also started seeking for more information and recommending their candidates for the special courses.

Positive and Negative factors

Positive: All the leprosy projects covered so far are quite open to learn the new concepts and to update the information.

Many projects themselves requested for the training programme and follow-up, which itself is a positive sign for the development.

Leaders of the projects have expressed their satisfaction and clarity about the concepts, which were learnt during the training programme.

Few projects like H.B.Halli, ADC Pedana, MOB Mandya have already integrated disability in their leprosy programme. On the other side, non-leprosy projects like Assam CBR project, Don Bosco Technical Institute Lucknow, has shown greater interest in learning about leprosy and to include the activities for PAL in their programme.

All the resource persons stayed within the training venue, which enabled the organisers to follow the timings and smooth conduct of the training programmes. It also facilitated useful interactions with participants.

Negative: One or two facilitators for longer period of CBR training for 2 to 3 weeks may be difficult to sustain the interest of the participants. However it depends on the methodology of the course and field activities.

It is also difficult to organise field visits for 20 – 30 participants atonce to a particular village or to a particular family, sometimes it is even more difficult to visit the distant and interior villages in the CBR training programme.

It may be bit hard for the very grass root workers and communities based groups to attend full day training programme and grasp the concepts in the CBR course.

In the case of leprosy training, it depends on the purpose of the visit.

It is a slow process to change the mindset or the attitude of the people who are working in the leprosy organisations, from role of service providing into the role of facilitating the services.

The inadequate availability of resource materials on CBR in the local language, is hindrance for the learners working in the leprosy projects.

Some times interpreters were used for translation, which consumed extra time both in CBR and Leprosy course.

Changes Expected:

Projects are expected to combine the activities for PAL, PWD and children with vulnerable condition, by incorporating the essential principles and components of Community Based Rehabilitation to the maximum extent. This will be a longer vision of AIFO in India, for sustaining the basic rehabilitation activities and to become partners in the future development

Projects should try to implement the programmes with wholistic approach for the future development.

Evaluation:

AIFO team members are regularly monitoring the projects through observation method. Some times review of field activities will be done during the project visits. Essential meetings will be attended in order to up-date the project activities. Necessary documents will be referred for the verification of the plans as a follow-up action.

As a part of the visit, members are also assessing the impact of the training through review meetings. This was done recently at Mallavalli where impact of leprosy training was reviewed. In which several case studies of leprosy affected people were discussed. Grass root workers illustrated many positive case studies and problems faced by them. In the same manner, review of training will be done in other projects, where CBR is integrated with leprosy work. On the basis of project meeting, a formal evaluation will be planned for the future.

The following recommendations are suggested:

1. It is better to familiarise the CBR concepts for the top-level management, before taking up any programme.
2. Providing learning materials in local languages for both CBR and leprosy courses will enable the participants to grasp the concept in a better way.
3. Initial training programme should be followed with some exposure visits, so that, the group will understand the concept better
4. At least 3 facilitators for 2 – 3 weeks course would be better for the effective participation in the course.

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