

ISSUES ON COMMUNITY PARTICIPATION IN CBR

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1. INTRODUCTION:

Community Participation is seen as one of the challenging tasks in CBR programmes. Trying to address these challenges requires a lot of time and dedication.

The best way to achieve meaningful participation is through transfer of information and relevant skills that would empower communities, not only to ask them to contribute their resources but to understand and appreciate the need to live with people with diverse needs and to provide support for their effective integration in family and community life.

1.1 Definition Of Terms:

Community: the term could be described as "a smallest administrative unit/area of a country".

Community Volunteers: persons supporting family members in the training and orientation of their disabled members; they do not receive any regular payment/salary from government or an agency outside the community.

1.2 Preparation For Full Participation In CBR By Communities:

Preparation of communities requires a lot of time and involves meetings with teachers and identifiable groups including social movements, churches and individuals. (Individuals of community should include parents of persons with disability and disabled persons themselves).

Community participation should not be limited at the community level but should also involve communities at all other levels: district, regional, national and international.

The focus of community meetings should be to provide sufficient information on disability issues and also relevant skills through which communities can support their members who have disabilities.

A multi-disciplinary trained team including disabled persons should carry out this preparation with a planned strategy. Their role is to serve as catalysts and provide external motivation, awareness and support.

Trained multi-disciplinary team including disabled persons, has to involve key people of the community (including both formal & informal leaders) to reach the goal of the community ownership of CBR programme.

Communities should be prepared to "own" a CBR programme instead of merely participating in it. An example from Vietnam was cited, where a disabled person received help from the community for taking care of his farm. This is very encouraging and a further attempt should be made to embrace all sectors of community life.

Adequate preparation of the community which involves transfer of information and skills, together with proper motivation would facilitate both ownership and participation at the community level.

It would be quite unrealistic to expect most communities to initiate programmes on their own, for their members with disability. Similarly, most communities would not participate effectively in programmes they were not involved with in the initiation.

Commitment of communities and maximising of successes would be very useful indicators of the community participation.

Example: Community Participation: Vietnam CBR Programme

When the CBR team arrived in the Long Trung community in Tien Giang province in the south of Vietnam, they found a boy named Nguyen Van Thans, suffering from cerebral palsy with moving, learning and speech disabilities. His father, a poor farmer, had taken his son to many hospitals including the rehabilitation hospital in the Ho Chi Minh city, but there had been no improvement in his condition. He could only crawl, could not go out of the house and no children came to play with him.

After, one year of CBR programme, now Thans' life has changed a lot. First he learned walking with the help of parallel bars and then with the help of a walking frame. Now he walks with crutches. All these technical devices were made by his father from bamboo and instructions were provided by the CBR worker.

Awareness activity in the school, carried out by the programme, resulted in some teachers going to his house, to provide him some lessons. It would have been impossible for him to go to school since his house was surrounded by bay-channels and he could not cross the small "monkey-bridges" made up of bamboo.

This problem was raised by the CBR worker and a teacher, at the meeting of community CBR steering committee. Following this, some neighbours and a youth group decided to help by building a brick bridge, to enable Thans to go to the school. Infact, now Thans is going to school and often, some of his class-mates come to his house to do the home-work with him. During the school break, often, you can see him playing with his non-disabled companions.

2. MECHANISM FOR SUSTAINABLE COMMUNITY PARTICIPATION:

Creation of sustainable mechanisms in the communities is needed, rather than building new infra-structures at the community level, as the creation of physical structures would mean need for extra resources for their maintenance. There is need for a CBR committee at the community level to push and monitor activities. Such committees can be an already existing committee like a development committee or could be specifically established for this purpose. In both cases, it is necessary that it should consist of cross-section of community members including some disabled persons and/or family members of disabled persons.

An essential element in community participation is to build into the community structures, the capacity to manage and address the needs of persons with disability at the community level.

Sometimes a CBR programme can be started at community level and later on a committee can be formed to manage the activities. However this would not encourage community ownership of the CBR programme.

3. ROLES OF THE COMMUNITY COMMITTEES:

The basic responsibility of the community committees is to create an enabling environment for the effective integration of persons with disabilities in the community life.

Specifically they would be required:

- to create awareness among groups, families and individuals including disabled persons;
- to select dedicated members of community to train as volunteers and to motivate them;
- to promote the integration of disability issues in all community activities;
- and to mobilise resources at community level for supporting the community activities.

Establishment of a community committee should take into account the culture of the area. Where the settlements are so scattered or in a nomadic community, different mechanisms for promoting community participation need to be tried.

A community committee should be well oriented in their roles and assisted in their organisation. In Guyana, it is reported that community committees have a formal constitution which serves as guide-lines for their activities.

For training of community committees, periodic workshops and seminars are needed to update their skills and facilitate work in the communities.

In Mauritania exchange visits are organised among community committees for members to share experiences. Such visits could be encouraged in other countries.

Example: CBR Committees in Difficult Geographical Conditions: Mongolia Experience

Under the national CBR programme in Mongolia, CBR committees have been set up at national and provincial levels. However, at the district (Somon) level and at the level of the smallest administrative units called "Bag", establishing these committees is not easy. In some somons there are branches of the organisations of disabled persons and these have formed the CBR committees. At the community level, there are many difficulties with the making of CBR committees, like for example: The population density is very little and often a small group of families may be living together, separated from the next group by as much as 20 to 50 km. Since even these groupings are not fixed, as the population is nomadic, it is not easy to define the "community".

4. VOLUNTEERS AND COMMUNITY PARTICIPATION:

The issue of volunteers in CBR programmes continues to attract a lot of discussions. With growing emphasis on market economy some CBR programme feel that the involvement of volunteers was not practical or easy. Other CBR programmes feel that volunteers are very important for ensuring community participation and an asset.

For reasons of effective community participation and to ensure sustainability of activities at community level, the need for the involvement of such a cadre of motivated persons for supporting the communities, can not be overlooked.

Example: Volunteers in CBR Programme: Guyana Experience

In 1986, when a pilot CBR programme was launched in two areas of Guyana, it was decided to involve volunteers in the programme activities. 66 persons applied for becoming volunteers. Right from the beginning, it had been explained that it was not going to be an "employment". 26 persons coming from different backgrounds (nurses, teachers, office workers, students, housewives, etc.) were selected. They were all women. The majority of them had modest salaries and were chosen on the basis of their desire to serve the community and their interest in children. Since then volunteers have played a very important role in the success of CBR programme in Guyana. In this period, the programme has been extended to other areas of the country.

Apart from the volunteers, nursery school teachers were also involved in the pilot programme. However, the efficacy of the volunteers in the implementation of CBR programme was significantly higher.

Majority of volunteers had become very involved in the programme, taking active part in the sharing of their concerns, doubts and achievements with other persons working in the programme. They felt that the programme belonged to them. On the other hand, the nursery school teachers were not so involved in the programme.

In 1988, when the programme was extended in the areas of Corentyne and East Coast Demerara, more attention was given to the role of volunteers. Only 5 percent of volunteers left the programme in the first two years. After three years, 70% of volunteers were still involved in the programme.

The programme has developed a series of specific teaching materials for the volunteers and after the experience of past years, the training courses for the volunteers have been improved.

4.1 Selection And Training Of Volunteers:

Volunteers are to be selected by community committees and can be members of the community with different backgrounds. They can be family members of disabled persons or disabled persons themselves, retired persons, housewives, individuals from identified groups who are committed to the needs of disabled persons, school children, etc.

Volunteers are expected to be trained by CBR agents/personnel at the district level in simple rehabilitation techniques.

The WHO manual "Training in the Community for People with Disability", could be good teaching tool for training of volunteers.

Countries already implementing CBR programmes could also provide useful training materials, which can be adapted to local needs.

Training of volunteers should be on-going and should be based on identified needs.

4.1.1 Problems identified with volunteers:

Some problems identified with the use of volunteers in CBR are the following:

- High drop-out rate
- Low motivation
- Lack of confidence
- Poor quality of service

Suggested strategies to resolve some of the identified problems:

- ◆ Volunteers should be properly trained in their roles and should not be over-burdened with work.
- ◆ There is need to train and re-train volunteers to build the necessary confidence in them.
- ◆ Community committees should be encouraged to motivate their volunteers.
- ◆ The drop-out of volunteers can also be looked at in a positive way, as in Kenya CBR programme, where they feel that trained and motivated persons, leaving the programme and going back to the community are an asset to the community and whole society and should be called "drop-ins" rather than "drop-outs".

5. CBR AND COMMUNITY DEVELOPMENT:

For CBR programmes to achieve a greater community impact, disability issues should be integral part of all community development efforts.

This could be achieved through:

- Empowerment and capacity building. Community committees and persons with disability should be encouraged to play an advocacy role in communities.
- Public awareness activities should not be focused only on disability issues. Such activities should include all other needs of the community.
- The multi-sectoral dimension of CBR should be encouraged at all levels to provide the needed support to communities in their developmental efforts.

Example: CBR Programme and Community Development in Lesotho

Lesotho CBR programme introduced the Child-to-Child approach for disabled children in Boleka area. There was a young girl with the problem of brittle bones. When her mother realised that her daughter could not walk properly, she became over-protective. Thus the girl was kept at home and was not allowed to play with other children. This was all done with good intentions to prevent the worsening of the child's disabilities.

However, some children involved in CBR programme, started to visit the girl's home and take her away to a secluded spot. There, she could teach other children about how to knit while the other children taught her reading and writing. The girl could also sing very well and thus the children formed a choir. They sang to collect money for buying wool for their knittings.

When the children's choir was refused permission from the local school to sing there, the CBR team, visited the school to talk to them about the CBR programme.

During the introduction of CBR in the school, the girl's mother was called to explain her daughter's experience with other children. The school teachers organised a test to assess the knowledge of the girl. Even if she had never been to school, after the test, the girl was admitted directly to fifth standard in 1994.

This experience stimulated the whole community to think about the potential in the disabled

children. As there was no proper road from the girl's house for going to the school, the whole community helped in the building of a road. Recently, the community also collected money to buy a wheel-chair for her, so that now she can go to the school regularly.

Example: CBR Programme and Community Development in Uganda CBR programme

In Uganda, community development assistants, have been trained under the CBR programme. When they visit any disabled person, they also discuss about the other problems faced by the family of the disabled persons. Thus they can provide support and guidance for other needs like sanitation, drinking water, etc. They can also help the disabled persons and their families in making contacts with other local groups like women organisations, youth groups, etc. and guide them about credit schemes.

6. REFERRAL SUPPORT FOR COMMUNITIES:

Another essential demand for a successful CBR programme is the nature of referral support that communities require to complement their efforts.

Effective community participation, requires relevant and accessible referral system that would meet the needs of the community.

Current discussion in Ghana on the establishment of a training school for physiotherapists can be taken as an example. The problem is whether to set-up a degree level training that would turn out personnel for the national/regional level hospitals, or diploma level training programme that would provide personnel for district level activities.

7. DISABLED PERSONS AND COMMUNITY PARTICIPATION:

Persons with disability need to be encouraged to participate in all community activities through empowerment and confidence building, if integration is to be meaningful.

At home, they need to be trained and properly oriented in activities of daily living which would encourage positive integration in family life. They need to participate in decisions relating to their conditions, at all levels in the community. This allows them to build confidence in themselves and face the challenges required for full participation.

Parents, opinion leaders, disabled persons organisations should team-up to help develop the necessary confidence in individuals in the community to promote meaningful participation.

Community participation should therefore be seen as a vital component of CBR. It becomes effective when it contributes to changing the perception and attitudes of people about disability.

8. CONCLUSIONS:

Community participation is seen as a basic component of CBR and should be encouraged, not only in terms of contribution but should tend to change the perceptions, attitudes and ownership of activities for disabled persons.

For ensuring community participation, local CBR committees can play a very vital role and should be a part of all CBR programmes, right from the beginning of activities.

In many cases, the involvement of volunteers in the CBR programme, can help in increasing the community participation and in increasing the effectiveness of activities.

However communities can't be expected to take care of all their needs and need to be supported by an accessible and sustainable referral system.

Participation of disabled persons and their families in the planning and implementation of CBR programmes is very important and needs to be actively encouraged.

Finally, a CBR programme, if it manages to effectively involve the community, becomes a catalyst for promoting community development as a whole.

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