

WORKSHOP ON COMMUNITY-BASED

REHABILITATION

AND

COUNTRY EXPERIENCES OF CBR

INTRODUCTION

The workshop on CBR was organised by the Italian Association Amici di Raoul Follereau (AIFO), 4 Via Borselli, 40135 Bologna, Italy. Tel. (3951) 43.34.02, Fax. (3951) 43.40.46.

The idea of organising this workshop came from Dr Enrico Pupulin.

Dr Enrico Pupulin and Dr Ann Goerdt, from the Rehabilitation Unit of WHO also gave valuable suggestions and comments about the persons to be invited as participants. In addition, they also contributed to the definition of the workshop programme. Without their support, it would not have been possible to organise this workshop.

The Training and Cultural Co-operation Unit of Directorate General for Development of the Commission European Communities, provided financial support for part of the expenses of this workshop, especially for participants coming from ACP countries.

Other international organisations which supported the organisation of this workshop were:

Norwegian Association of Disabled (NAD), Galleri Oslo, Schwelgaardsgate 12, 0186 Oslo, Norway. Tel. (4722) 170.255; Fax. (4722) 176.177.

Action Aid, Hamlyn House, Archway, London N19 5PG, Britain. Tel. (4471)281.41.01; Fax. (4471) 272.08.99.

Radda Barnen, Torsgatan 4, S 10788 Stockholm, Sweden. Tel. (468) 69.89.000; Fax. (468) 69.89.012

Red Barnet, 4 Borgardsvaenget, DK 2820 Gentofte, Denmark. Tel. (4531)680.888; Fax. (4531) 68.05.10.

Save The Children Fund, Mary Datchelor House, 17 Grove Lane, Camberwell, London SE5 8RD, Britain. Tel. (4471) 703.54.00 Fax. (4471) 793.76.26.

ORGANISATION OF THE WORKSHOP AND

THE WORKING METHODOLOGY

WHY WAS THE WORKSHOP ORGANISED: According to the WHO estimates, disabled persons constitute about 4 to 7 percent of the population. In the majority of the developing countries, barely 2 percent of the disabled persons are able to benefit from the Institution Based Rehabilitation services. The Alma Ata declaration in 1978 proposed the Primary Health Care approach to provide basic health care services to reach all the population. About that same time, the idea of Community Based Rehabilitation (CBR) was born.

In the last decade, this approach has been tried in different countries, and now, many others are planning to use it. Out of the experiences of the CBR programmes, came the realisation that the rehabilitation services for disabled persons cannot be limited to only medical rehabilitation activities and a multi sectoral approach, involving other key sectors like education, labour, social affairs, etc., is needed. Disabled persons themselves and the communities where they live, have to play an equally important role in the rehabilitation activities.

The workshop was organised with the idea that it would be useful to get together CBR programme managers from different countries, for sharing of experiences, as well as for discussing some specific issues related to the CBR programmes. Four main themes were identified for the discussions: Multi sectoral approach; Community Participation; Launching of new CBR programmes; and Evaluation. For each theme, one discussion coordinator was identified and the participants were asked to suggest the priority areas related to each theme, for discussion. On the basis of the suggestions received from the participants, each co-ordinator prepared a list of topics for the discussions.

During the workshop, discussions on each theme were organised in the following way: short introduction by the co-ordinator about the priority areas for discussion in a plenary session; discussions in small groups of 5 or 6 persons; presentation of the results of group discussions in a plenary session.

During the last part of the workshop, while dealing with the issue of evaluation, the participants identified another priority theme for discussion, that is: Indicators for CBR programmes. This was examined as a separate topic for group and plenary discussions.

During the workshop, each co-ordinator prepared a summary report of the discussions. To these reports, examples from different countries were added by the participants, as a way of illustrating some specific issues. These were all put together to prepare this final report.

The themes discussed during the workshop and the co-ordinators who prepared the related reports were as follows:

Multi sectoral Approach: Dr Brian O'Toole (Guyana CBR Programme). Community Participation: Mr Lawrence Offori Addo (Ghana CBR Programme). Launching of New CBR Programmes: Dr Tran Trong Hai (Vietnam CBR Programme). Evaluation: Dr Maya Thomas (Action Aid, India). Indicators for CBR Programmes: Dr Sunil Deepak (AIFO, Italy). Compilation of final report was done by Dr Sunil Deepak (AIFO, Italy); editing and preparation of the final text was done by Ms Geraldine Maison Halls (Guyana CBR Programme).

MULTISECTORAL APPROACH IN CBR

INTRODUCTION

Whilst the architects of Community Based Rehabilitation (CBR) conceived of the approach as involving all sectors of the society, the majority of early attempts to translate the philosophy into practice grew out of health based programmes. However, the goal of CBR is to contribute towards the empowerment of persons with disabilities, facilitating an independent life style in which they participate in all aspects of community life. Multi-sectoral collaboration is therefore imperative if such a goal is to be achieved, as no one sector alone, can achieve such a broad objective. The breadth of the challenge necessitates a partnership between various sectors including health, education, labour, vocational, housing, welfare, sports and agriculture, in collaboration with NGOs, Disabled Peoples Organisations (DPOs), and traditional and religious leaders within the community.

Rationale for a multisectoral approach

In many ways the needs of persons with disabilities are the same as their able-bodied peers. Such needs cut across all sectors. Moreover, as the community represents disabled persons of all ages, and at different stages of life, different sectors come into play. No one sector on its own, can respond to the comprehensive needs involved in the rehabilitation process. CBR programmes should seek to meet the needs of disabled persons of various aetiologies and of all ages. If the initiating group does not have the expertise to address the needs of a specific target group they should seek out the relevant partners to develop a more comprehensive approach.

Problems in achieving a multisectoral approach to rehabilitation

The one factor that unites disabled people throughout the world is the low priority they are given within their countries. Where a response has been forthcoming, it is often limited in effectiveness because of the lack of collaboration between government departments. A unified response has not been forthcoming for a variety of reasons including:

lack of political commitment which is reflected in the absence of a national policy on disability issues rigid ministerial demarcations which prevent collaboration as

different sectors vie for resources ministries have often developed an inertia of their own characterised by a fixed way of doing things poor communication between ministries competition between sectors, each of which wants to be perceived as the `lead' body lack of a tradition of collaboration and where the emphasis has been on vertical training which emphasises individual professional orientations

Difficulties in Establishing a Multisectoral Approach: Mongolia CBR Programme

In Mongolia, the national CBR programme was started in 1990 under the Ministry of Health. A CBR co-ordinating committee was established with a representative of the Ministry and three doctors.

After some time, the team realised that there were different government ministries as well as donor agencies, working for rehabilitation programmes for disabled persons and that some kind of co-ordination was needed. It was decided to organise, in 1994, a meeting of all the concerned organisations and departments working in the field of disability, to bring all the activities under a single cohesive strategy. This would serve to avoid overlapping and duplication of activities, as well as avoid destructive competition. In this meeting, the following organisations participated: the Ministry of Health and the Italian NGO, AIFO which work together for the national CBR programme; the Ministry of Special Education (MOSE) and the Danish agency DANIDA, which are co-operating in the training of teachers and in providing special education for disabled children; UNICEF and the British NGO SCF, which work at pre-school level and with mother and child care centres. This has been the first step towards a multisectoral approach in the CBR programme.

The challenge of establishing a multisectoral approach in rehabilitation

An essential element in promoting a multisectoral approach is the creation of a National CBR Co-ordinating Committee. Where such committees have been effectively established, a foundation has been established for collaboration between the various sectors. This has been the experience in societies as different as the highly populated country of Vietnam in Asia and the sparsely populated island of Rodrigues in the Indian Ocean.

However, it should be recognised that in addition to the multi-sectoral collaboration at the national level, at the regional and local levels, such collaboration must also be nurtured.

Development of a National Policy

An essential goal of the CBR Co-ordinating Committee would be to develop a National Policy on disability. Under such a policy, disability issues would be regarded as an integral element of all government departments. Within the sphere of health, disability would be seen as one element which would need to be addressed within a comprehensive primary health care programme. In a similar way, the adoption of a policy of inclusive education would promote a philosophy in which schools explore ways to respond to the diversity of needs of all children. Such a National policy would also inspire training centres to accept disabled persons on their courses. The Co-ordinating body will be able to draw on the UN Standard Rules as a guide to developing a multi-sectoral approach.

Such approaches would therefore, not be totally dependent on the vision of gifted and creative individuals, but would be considered to be the basic responsibility of all sectors. A National Co-ordinating body can play a key role in translating these hopes into reality. In Vietnam, for example, the Co-ordinating Committee assisted in the formal endorsement by the National Government of CBR as an integral part of the Primary Health Care approach.

Clarification of the respective roles of various sectors

A second major objective for the Co-ordinating Committee would be to clarify the respective roles of the various sectors involved in the field of disability. The Committee would press for specific commitments to the goals of CBR on behalf of various ministries. This commitment to CBR would be manifested in terms of the assignment of specific personnel, dedicated budgetary allocations for recurrent expenditure of CBR, and inservice training of staff along the lines suggested by the CBR philosophy. The problem of competition between various government agencies for scarce resources may be overcome if the budget is spread between ministries rather than having any one Ministry with the full responsibility for the budget. Another challenge for the Committee would be to co-ordinate the work of the NGOs and GOs, in order to avoid duplication of services or the implementation of parallel programmes.

Create a mechanism for effective collaboration between various sectors

Interministerial rivalry could be overcome by requesting a body higher than the implementing body to take charge of the co-ordinating role. This has been achieved in Vietnam through the monitoring role of the Vice Chairperson of the Peoples Committee which oversees the rehabilitation work of the various government agencies. In a similar way, a proposal is in train in India to establish a Commission for Rehabilitation in the Prime Minister's Office. The head of the co-ordinating body would need to be influential, able to command the respect of the various agencies involved, and at the same time, be able to devote time to the work of the Committee. This co-ordinating role could also be effective in

encouraging a measure of consistency from the various sectors, by ensuring that the individuals identified for the Committee attend the meetings regularly.

Other approaches have been adopted in other countries. In some cases a 'lead' ministry has been identified. However, a disadvantage of such an approach can be that it serves to confirm divisions between ministries and allows other government agencies to abdicate their responsibilities. In some countries, cochairmanship between the major ministries involved has been suggested as one way to consolidate the feeling of joint ownership of the Committee. In other cases, it may be necessary to create a post to ensure the proper functioning of this co-ordinating agency. A major objective of the Committee will be to examine existing legislation, identify gaps and initiate change. The Committee would therefore need to be composed of persons capable of exercising influence on the respective agencies to effect change.

Multisectoral Co-operation in Cape Verde

In Cape Verde, the Mother and Child Care Programme, organised under the Ministry of Health, is very successful. The immunisation of children has more than 90% coverage rate, while in 1978, this coverage rate was only 10%. The health posts network is well developed and the health workers make home visits to persons living in more isolated areas.

The CBR programme team, representing the ministries of Health, Social Affairs and Education, has trained the health workers in early detection and stimulation.

When the mothers and children come to the health centres for the visits, simple questionnaires are used to check if the child's development is normal. If the child has an apparent delay in development or a disability, the health workers use the appropriate training package from the WHO manual, in discussing the child's capacities and problems, train mothers about how to stimulate the child, etc. They meet regularly, every three or four weeks at home or at the health centre.

The training of health workers by the CBR team, has been carried out through a one week long formal course. This is followed by visits of the CBR team to the health centres, once a month in the beginning and then, two or three times in a year, for on-the-job training. Enough courses have been organised so that there is at least one health worker in each health centre, who is trained in CBR approach.

At the same time, an information campaign for social workers has been started, to involve them also, in the CBR programme.

All these activities play an important role in the prevention of disabilities, and can be considered as a "preparatory phase" for future community projects.

Multi-sectoral approach in Guyana

In the interior of Guyana, in the Rupununi, a multi-sectoral approach to CBR has been established. In each of the 42 villages of this region, a CBR team has been formed. Each team is composed of a community health worker, a teacher and a community leader. In this way, there is an integrated approach to rehabilitation.

On the basis of the effectiveness of this approach, the Ministries of Education and Health are interested in entering into a partnership with the CBR programme, for the expansion of this approach to two isolated interior areas. Consultations are now in process with these two ministries, and have so far resulted in the development of an integrated team, with representatives from the respective ministries and the CBR programme.

The development of a common Plan of Action

One of the major contributions to be played by the Co-ordinating Committee is the articulation of a unified plan. A number of countries have chosen to organise a National Conference on disability to help foster a multi-sectoral commitment to disability. In Eritrea and Guyana, such conferences addressed by Ministers and Heads of Government, and attended by a wide cross-section of the population, have been held to clarify roles and responsibilities in the field of disability.

During 1993, Indonesia hosted a National Seminar and Workshop on CBR. The primary objectives of the seminar/workshop were to clarify the roles of the different sectors, gain national commitment for CBR and to develop a plan of action for Bogor and Ujung Pandang, with assigned responsibilities.

The Co-ordinating Committee would help to ensure a regular flow of information between different government agencies to help facilitate a comprehensive approach to rehabilitation. The creation of multidisciplinary training programmes would also contribute to the development of a common focus to rehabilitation. The Committee would also examine ways in which disability issues could be included in wider community development initiatives in such areas as women and development, youth and leisure activities. As such, CBR would be perceived not as a 'separate programme' but as a perspective and philosophy of care that would be integrated into all community development programmes.

Multisectoral approach in West Java Province of Indonesia

The West Java CBR programme was started in Bandung municipality in 1985 by a team composed of: Society for the care of disabled children (YPAC Bandung), Bandung community based health organisation (DSB), Family welfare movement (PKK) and seven Municipality Government sector (Health, Social Affairs, Education: P&K and Depdikbud, Labour, Social Welfare, and Community Development).

The programme is co-ordinated by the wife of the Mayor of Bandung, who is also the head of Family welfare movement. Until now, the CBR team has been able to manage the CBR programme with local resources only (funds from local district authority and the communities).

After the success of the programme, the CBR team has been joined by two more Government sectors (Information and Religion). A similar team has been established at sub-district level. All the programme activities like, planning, implementation and evaluation, are carried out under the multisectoral approach.

Endorsement of the philosophy of `Schools for All'

The CBR movement is greatly reinforced by the UNESCO initiatives in Education which promote the philosophy and practice of inclusive schools. The UNESCO pack, `Special Needs in the Classroom' compliments the WHO Manual on CBR and helps teachers to re-examine their role and practice. The UNESCO materials will contribute to an improvement of the learning environment for all children. The materials will prove to be a catalyst on a number of levels. By encouraging a more reflective approach on the part of the class teacher the process of a more flexible, child-centered approach to the curriculum is promoted. The approach encourages a broader role for existing staff in the area of special education. In Ghana, for example, special education staff are now employed in a peripatetic role, serving as multidisciplinary resource teachers in support of the regular teacher. The CBR approach can provide the stimulus to begin a review of relevant legislation and a reform of the school curriculum.

School for all: Guyana Experience

One of the video training packages developed in the Guyana CBR programme focuses on the integration of children with disabilities into the regular school system. In collaboration with the Ministry of Education, CBR workers are being trained to present modules on Inclusive Schools for school teachers in the regions in which the CBR programme is operational. In addition to providing a multi-sectoral approach to rehabilitation, the training courses use a pyramid model of training. With this model, potential resource persons are trained to present the

modules to their colleagues as an integral part of the on-going in-service teacher training programme in the country.

Skills acquisition and work

The terms 'skills acquisition' and 'work' are used rather than 'employment' as often formal employment is not a realistic prospect for many persons in developing countries. The CBR process would seek to integrate disabled persons into the existing system. The CBR programme would begin with an analysis of what is available to the able bodied persons in the community. The goal would then be to get these ongoing systems to accept persons with disabilities. In terms of skills acquisition it could, for example, examine possibilities of obtaining apprenticeships with master craftsmen. In Malawi, this opportunity has been facilitated by providing the craftsmen with materials, such as wood, tin or cloth depending on the particular trade, in exchange for taking on a disabled person as an apprentice. In the home, the goal might be to more effectively integrate the person with a disability into the daily activities of home life, such as cooking, cleaning and looking after the animals. At other levels, the CBR programme would seek opportunities to promote part time work, self employment and income generation activities depending on the abilities and interests of the persons with disabilities.

Involvement of disabled persons at all levels of the CBR process

An essential element of the philosophy of CBR is the involvement of disabled persons in all aspects of the programme, as decision makers, resource persons and trainers at all the stages of planning, management and evaluation. Persons with disabilities are not passive clients of CBR programmes, rather, they are active members of the process. CBR programmes in Mauritania and Zanzibar bear eloquent testimony to this philosophy in being initiated and managed by persons with disabilities themselves. The disabled community in some other parts of the world have been slower to assume this leadership role. In such cases, the CBR programme will need to nurture and facilitate this role. The experience in Ghana has revealed the need to commit resources in a tangible way in the form of a budgetary allocation for transportation and translations into sign language and Braille. Philosophical statements alone will not achieve the goal of the empowerment of persons with disabilities.

In many countries, the disabled persons movement is weak and fragmented, training is therefore needed to develop and strengthen Disabled Persons Organisation in areas such as management, communication skills, financial systems, project planning, monitoring and evaluation. In a similar way, in the case of work with children, the parents need to be regarded as equal partners and as key resource persons.

Involvement of disabled persons in a CBR programme: Uganda Experience

At the national level, the National Union of disabled persons works in close collaboration with the Government for the CBR programme.

At district level, associations of persons with disabilities, collaborate with the district rehabilitation officer and the community development officer for different activities like, identification of staff for training, selection of income-generating projects for the disabled persons, etc.

At sub-county (village level), community development assistants, should work in close co-operation with animators who are usually disabled persons, in the identification of other disabled persons, in the training of parents of disabled persons, in the formation of income-generating co-operatives, etc. The Uganda CBR programme has discovered that in areas where such collaboration is present, the programme activities are more successful.

Role of Disabled Persons in Burkina Faso CBR Programme

In the province of Bobo Dioulasso, the CBR programme has been able to work together with a number of organisations of disabled persons. Through this collaboration, disabled persons play a very important role in the programme, especially in activities related to community awareness and in motivating the local population. For this, a theatre group has been formed and through their plays, they have been able to create awareness and to reinforce the positive image of the disabled persons, in the families and different community groups.

UNHCR and CBR

UNHCR has tried to develop the CBR concept in the context of refugees by joining hands with WHO, AIFO and NAD in two refugee-receiving countries, namely Uganda and Benin where the Governments of these two countries are interested in assisting disabled and other vulnerable groups of persons from the local and refugee community.

The purpose of this approach is to develop models which can be looked at and adapted to other situations.

ISSUES ON COMMUNITY PARTICIPATION IN CBR

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.

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.

Preparation for full Participation in CBR by Communities

Preparation of the community requires a lot of time and involves meetings with local administrators, political leaders, teachers, persons with disabilities, parents of children with disabilities, and other identifiable groups.

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.

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

Communities should be prepared to own a CBR programme instead of merely participating in it. An example from Viet Nam was cited, where a disabled person received help from the community in 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 disabilities. Similarly, most communities would not participate effectively in programmes in which they were not involved from the beginning.

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

Community Participation: Viet Nam CBR Programme

When the CBR team arrived in the Long Trung community in Tien Giang province in the south of Viet Nam, they found a boy with cerebral palsy with moving, learning and speech disabilities. His father, a poor farmer, had taken his son to many hospitals including the rehabilitation in 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 the CBR programme, the boy's life changed. First, he learned to walk with the help of the 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 with 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 of bamboo.

This problem was raised by the CBR worker and a teacher, at the meeting of the community CBR steering committee. Following this, some neighbours and a youth group decided to help by building a brick bridge, to enable the boy to go to the school. In fact, now he is at 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.

Mechanism for Sustainable Community Participation

The 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 already in existence, for example, a development committee or could be specially established for this purpose. In both cases, it is necessary that it should consist of a cross-section of community members including 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 the community level and later on a committee can be formed to manage the activities. However, this would not encourage community ownership.

Community Participation: Guyana CBR Programme:

In each of the four coastal regions in which the Guyana CBR programme has been operating a Regional CBR committee has been established. A formal constitution has been developed for the committees, which are elected annually, by all those persons involved in the programme in that region. Representatives from the Regional CBR committees form the National Committee. Once/monthly meetings are held by the Regional Committees, while at the national level, meetings are held quarterly. The Regional committees are responsible for managing the CBR programmes in their respective communities.

In the interior of Guyana, in the Rupununi, a local Health Assembly is being elected in each of the villages. The CBR programme is working alongside another NGO working in the interior to train the members of these committees in the skills of consultation, problem-solving and leadership.

Through the establishment of the CBR committees, a mechanism is in place for members of the community to manage, guide and oversee the work of CBR at the different levels, and thus develop a sense of ownership of the programme.

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;

- select dedicated members of the community to train as volunteers and to motivate them;
- promote the integration of disability issues in all community activities;
- mobilise resources at community level for supporting the community activities.

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

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

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, for example, the population density is low 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.

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 programmes feel that the involvement of volunteers was not practical or easy to solicit. Other CBR programmes feel that volunteers are very important to ensure community participation, and they are considered assets to the programme.

Volunteers in the CBR programme: Guyana Experience

In 1986, when a pilot CBR project was launched in two areas of Guyana, it was decided to involve volunteers in the programme activities. Sixty-six persons applied to become volunteers. From the beginning, it had been explained that it was not going to be an "employment". Twenty six persons from different backgrounds (nurses, teachers, office-workers, family members of persons with disabilities, housewives, etc.) were selected. The majority of them had modest salaries and were selected on the basis of their desire to serve the community and their interest in children. Volunteers have played an important role in the success of the CBR programme in Guyana.

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

The 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 the East Coast Demerara, more attention was given to the role of volunteers. Only 5 percent of the volunteers left the programme in the first two years. After three years 70 percent of the volunteers were still involved in the programme.

A series of teaching material for the volunteers has been developed by the programme, and after the experiences of the past years, the training have been improved.

Selection and Training of Volunteers

Volunteers should be selected by community committees and can be members of the community coming from a wide range of 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 a training tool for the training of volunteers.

Countries already implementing CBR programmes should 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.

Problems identified with volunteers

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

- 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 overburdened 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 regarded in a positive way, as in the Kenya CBR programme. It was felt that trained and motivated persons leaving the programme and going back to the community are assets to the community and the whole society. Those individuals were considered as "drop-ins" rather than "drop-outs".

CBR and Community Development

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

This could be achieved through:

- Empowerment and capacity building - community committees and persons with disabilities should be encouraged at all levels to play an advocacy role in the community.
- 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.

Community participation in Lesotho CBR Programme

The Scott Hospital CBR programme in Lesotho introduced the Child-to-Child approach to disability into local primary schools. In the Boleka area, there was a young girl with brittle bones whose mother did not allow her to play with other children for fear that she would break her bones.

Local school children, who had been exposed to the Child-to-Child initiative, started visiting the child at home. Then they began taking her to a secluded spot where she could teach them how to knit, while they taught her to read and write.

The girl was a good singer and together they formed a choir. They used the money collected at choir concerts to buy wool for their knitting. One day, a local school refused to let the choir perform, so the CBR team intervened. The girl's mother was invited to tell the teachers about her daughter's experience. The teachers gave the girl an entrance test and she was placed in the fifth grade, despite never having been to school.

The 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 to the school, the whole community helped in the building of a road. Recently, the community also collected money to buy her a wheelchair, so that now she can go to school regularly.

CBR Programme and Community Participation in Uganda CBR programme

In Uganda, Community Development Assistants (CDAs), have been trained under the CBR programme. The CDA's entry point is a home as a unit. They discuss disability management and other community problems faced by the family. Thus they can provide support and guidance for other needs like sanitation, potable water, etc. They can also help the disabled persons and their families in making contacts with other local groups, such as women's organisations, youth groups, etc. and guide them about credit schemes.

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 systems 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 have a degree level programme that would turn out personnel for the national/regional level hospitals, or diploma level programme that would provide personnel for district level activities.

Disabled Persons and Community Participation

Persons with disabilities 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 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 vital component of CBR. It becomes effective when it contributes to changing the perception and attitudes of people about disability.

Conclusions

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

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

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

Communities cannot be expected to take care of all the needs of the persons with disabilities and would therefore 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.

LAUNCHING OF CBR PROGRAMME

Introduction

The Community-based rehabilitation (CBR) approach was initiated by WHO, more than 10 years ago. In this period many countries have launched CBR programmes and a number of others have been expressing the need for launching such programmes. However, within the countries where there are on-going CBR programmes, there is a need to extend these to more provinces/regions/areas.

The new strategy of CBR builds upon several years of experiences of managing existing rehabilitation programmes, initiating the transfer of technology, and utilising various approaches for service delivery. The introduction of CBR demonstrates an effort to design a better system aimed at changing conditions and ensuring that there is better service delivery to all the persons in need while providing equal opportunities for disabled persons.

To stimulate the group discussions on the launching of a CBR programme, the coordinator had prepared a set of 8 questions. The following report follows the discussions according to the pattern of questions.

Who should start a CBR programme and what approach should be used

The initiator of a CBR programme can be a government ministry as for example in Vietnam, where the CBR programmes have been initiated by the Ministry of Health. In other cases, it may be introduced by a nongovernmental organization, for example, in Mauritania where the CBR programme was started by an organization of disabled persons (although, now it is managed by the Department of Social Affairs of the government). In Ghana, the CBR programme was started in 1992 by the Ministry of Social Welfare, partly because of the inability of the institution-based rehabilitation services to respond to all the needs of the disabled persons.

However, "who" starts the programme is not so important, but it is necessary that all the bodies related to the disability issue are involved and that they collaborate in the CBR programme. It is also important that the practice of multi-sectoral collaboration is nurtured right from the beginning of the activities, even if involvement of all the sectors may sometimes be difficult.

A CBR programme can be started from top-down, i.e. from national level, going down to the community level or from bottom-up i.e. starting the activities at community level and later involving the district and national levels. Both kinds of approaches have been successfully used in launching CBR programmes in different countries.

In the majority of countries where the CBR programme is launched by government, the top-down approach is generally used. However, this does not preclude the use of the bottom-up approach. For example, in Vietnam, the top-down approach was used in some pilot communes, but as other communes got to know about the success of the CBR programmes, they started programmes by their own initiative, using the bottom-up approach.

While the bottom-up approach can be more catalytic in promoting community involvement and attitude change, the top-down approach can facilitate multi-sectoral collaboration, as well as provide better support from the referral services.

How to select pilot areas for CBR programmes

CBR programmes are usually launched in small areas, which serve as a model, for extending the same approach to other areas. The original locations are called pilot or target areas. Among the main criteria for selecting these areas are:

High political will and commitment towards the CBR programme in the area;

Good transportation system and easy accessibility of the area;

Existence of some basic infrastructure like health centres, schools, etc. in the area

Existence of on-going activities of community development in the area;

Presence of good referral system in the area.

The importance of selecting pilot areas with good chances of success is emphasised since the experiences can then be replicated in other areas and can also determine the manner of the extension of the CBR programme on a wider scale.

Steps for starting a new CBR programme

(a) Comprehensive preparation of the pilot area including campaigns to create awareness and change attitudes with regard to disability issues should be carried out and political commitment to the CBR programme should be secured. Together with this a multi-sectoral CBR committee should be formed and the WHO manual on CBR should be formed and the WHO manual on CBR should be translated and adapted into the local language.

(b) A written plan of action for the CBR programme should be prepared which should include clearly defined objectives, time-frames for the activities, on-going evaluation mechanisms, etc.

(c) Multi-sectoral conferences on CBR should be organised at national, provincial/regional, district and community levels.

(d) Trainers of CBR programme should be identified and trained.

(e) Training of CBR workers/local supervisors should be carried out.

(f) House to house surveys to identify disabled persons should be undertaken. Persons needing rehabilitation the family trainers should be identified.

(g) the CBR programme is implemented together with the establishment of monitoring, follow-up and reporting systems. During the initial phase, persons with good knowledge and motivation can be identified as key persons and they may need to be given additional training.

(h) the referral system should be strengthened together with the establishment of adequate feed-back mechanisms.

(i) Evaluation strategies should be included in the action plan.

Steps in launching the CBR programme: Indonesia Experience

A CBR programme was launched in 1979 in solo area and in 1985 in the Bandung area, through a bottom-up approach. Later, the Ministry of Health started CBR programmes in other areas, utilising a top-down approach.

After 10 years of practical experience in the Bandung area, a set of well defined steps have been identified and these are used for launching CBR programmes in new areas of Bandung Municipality:

A meeting on CBR is organised at sub-district level and this is conducted by the Bandung municipality CBR team.

The CBR team at the sub-district level is identified and training of trainers is carried out.

Visits are made into the village to meet the rehabilitation workers.

Visits are made to the RW level (a unit area below the village level) and the community at this level chooses the volunteers (cadres).

Training of the cadres is done.

The CBR cadres carry out a house to house survey in their area for the identification of all the disabled persons.

Cadres, CBR team at sub-district level and community members carry out an assessment of the results of the survey.

Measures for preparing the communities for the CBR programmes

In preparing the communities for the launching of a new CBR programme, the following activities are most important:

awareness raising; Conferences, meetings and communication; Training of manpower; Selection of volunteers.

Organization of National Conference for the Launching of CBR Programme in Eritrea

A three day national conference on CBR is being organized in Asmara and will be held in March 1995. This conference will involve all the different Government ministries, local government authorities, national and international NGOs and other organizations like WHO, UNHCR, ILO, DPE, etc.

The conference will be opened by the President of Eritrea, so that all the involved ministries and organisations can feel that the highest office in the country is interested in the success of the CBR programme.

The different media will also be involved in the conference so as to get national press coverage and to stimulate interest and awareness around the country.

A preparatory committee for the conference has been formed and it includes persons from the University, Ministries of Health, Education, Construction and Agriculture, National Union of Workers, National Union of women, Eritrean Youth and Students Organisation, National Association of War-disabled persons, Labour Office, et.

To prepare for the meeting, a team has been mandated to go around the villages in both highlands and lowlands of Eritrea, to film interviews with disabled persons, their families and community leaders. This film will be shown during the conference, together with video cassettes showing the experiences of CBR from other countries will also be screened during the conference

Preparation for the implementation of CBR in Lesotho

The Scott Hospital PHC team introduced the concept of CBR gradually over a period of 2 years, through a process of consultation with communities in the Health Service Area.

Attitudes were challenged and possible solutions were discussed. No services were promised, rather it was expected that the initiative to deal with the problems faced by the disabled persons would come from the community.

Disability had been identified by the community as an area requiring the attention of the PHC team. The PHC staff responsible for CBR were determined to avoid the mistakes made in the implementation of the PHC a decade before. To this end, much effort was made to ensure that the programme would be developed and owned by the community.

Poverty was identified as a cause and a consequence of disability, so poverty alleviation became another major feature of the Scott Programme. Income generation projects were set up and managed by the CBR workers, who were primarily disabled adults and mothers of disabled children. The negative attitudes of teachers featured prominently in the initial consultation with the community, so gaining access to education becomes another important element of the programme.

Training of CBR personnel at different levels

The group agreed that the development and training of personnel is very important for CBR programmes. Clear frameworks and curricula for the training of different categories of personnel should be developed.

Training materials: Before the training, adequate training materials should be adapted and prepared. The following categories of training materials may be needed for CBR programmes:

WHO manual, manuals on specific disabilities, etc. Many countries have prepared manuals on specific disabilities according to their own needs, e.g. in Indonesia, Vietnam, Ghana, Guyana, etc.

Materials about managerial skills, including planning, teaching, evaluation, etc. Vietnam, Indonesia and Ghana are among some of the countries which have produced such materials.

Materials about inclusive education.

Materials about vocational training, job placement, income generation, etc.

Miscellaneous materials on subjects like toy making, puppetry, communication techniques, etc.

Materials for supporting organisations of disabled persons such as the UN manual on self-help organisations.

Training: At all levels, training should be:

A two-way learning process; Multi-sectoral; Basic training should be followed by on-going training; Should be based on the identified roles and tasks.

At the family level, the family trainers need training to acquire skills in providing information, sharing ideas, demonstrating activities, selecting and using the training packages from the WHO manual, etc. The training can be informal for their specific needs and also to help in creating mutual support groups.

The local supervisors need to learn, in addition, technical skills like counselling, providing support, etc., while the intermediate level supervisors need to learn skills of a higher level.

The trainers of CBR programmes need additional training on teaching methods as well as specialized skills to deal with the multi-sectoral approach. The CBR programme managers, in addition need training in management, planning, supervision, evaluation, fund-raising, motivation, etc.

In general, each level of personnel is responsible for the training of personnel of the level below: international and national personnel for training provincial/regional staff; they in turn would train intermediate staff at district or subdistrict level; these in turn train the community level persons such as local supervisors; finally, the local supervisors will train the family trainers and the disabled persons.

If possible, all the training should be carried out under a clearly defined national government policy.

When to provide support for the referral system

The decision on when to provide support for referral system: before starting the community level activities or after, will depend upon the local conditions. It is important to take care that CBR programme is not seen merely as support for infrastructures or equipment. the referral system should always be multi-sectoral and should involve all levels: national, provincial; district and community. the support to the referral system should involve all the aspects such as: social welfare, vocational training, health services, education system, etc.

Problems in the maintenance and sustainability of CBR programmes

Some of the main problems related to the maintenance and sustainability of CBR programmes and possible solutions are given below:

(a) Problems of finance and transportation: such aspects should be clearly discussed right from the beginning of the activities and can be minimised by good planning.

(b) Problems related to manpower, referral system support, monitoring and evaluation: people need encouragement, discussions with the involved members are needed and if required relevant recommendations can be made to the government, appropriate training can be carried out.

(c) Disability is considered to be a low priority: increasing the awareness of the CBR programme as well as ensuring the success of the pilot CBR programmes can deal with this problem.

What are the most important things for the success of a CBR programme

Creating awareness; Involvement of disabled persons; Continuing commitment and motivation; Multi-sectoral approach; Manpower training at all levels; Clarity of vision and mission of CBR.

Although trained manpower is very important for CBR programmes, the importance of involving disabled persons in all aspects of the CBR programmes cannot be over emphasised.

EVALUATION OF CBR PROGRAMMES

INTRODUCTION

The field of rehabilitation, particularly CBR, is in an evolving stage in many developing countries. The only way to know if CBR works, if it is of benefit to disabled persons, their families and communities, is to continuously study all aspects of CBR programmes, at different levels. It is for this purpose that monitoring and evaluation are of crucial importance. Through these, one can find answers to many of the questions that are being raised about the CBR approach. At the same time, monitoring and evaluation will also help to improve programme effectiveness and to improve the planning for the future. It is therefore important to view monitoring and evaluation as an essential part of a CBR programme.

However, for the purpose of CBR programme implementing agencies, it is essential to demystify the concepts and processes of monitoring and evaluation, in order to overcome their resistance and to bring about an attitude change. Often, resistance to evaluation stems from a fear of exposing one's failures. If implementing agencies can see that monitoring and evaluation can be of direct benefit to them, in terms of better planning and results, the process of attitude change would be easier.

It is also necessary to keep the procedures of monitoring and evaluation, as simple as possible, for easy acceptance on the part of implementers. Even with the simplest methodology, a great amount of information can be produced which can help in programme improvement and planning.

Another aspect to be kept in mind, is the need to train the implementers in the skills of monitoring and evaluation. If the goal of evaluation is to improve programmes and plan better, it is important that the implementers carry it out on their own, rather than have external agencies do so.

Discussion Methodology

The discussions were carried out in three groups, each group being asked to discuss the issues related to monitoring and evaluation at one of the three levels: national, provincial/regional and community. For each of these levels, the groups were asked to examine:

The minimum information to be collected and records to be maintained.

A plan for evaluation, addressing the questions of goals of evaluation; what aspects to evaluate; who evaluates; how to evaluate (including indicators and costs); and the outcome of evaluation in terms of reports, plans, etc.

Some areas in CBR for further research and evaluation in the future.

Evaluation and Monitoring at Community Level

It is important to have baseline data regarding disabled persons, their families and the community at large.

It is important to have periodic plans (e.g. annual, biannual, quarterly, etc.) against which monitoring/reviews/evaluations can be carried out.

Monitoring and evaluation should be seen as an integral part of services at the community level and should be an ongoing exercise.

Monitoring and evaluation systems need to be simple at the community level.

Efforts should be made to utilise qualitative information, as well as, quantitative data.

It is necessary to train workers at the community level as well as the members of CBR committees, on monitoring and evaluation, with particular emphasis on the necessity of being sensitive, non intrusive and listening carefully to disabled persons and their families, while collecting information.

It is important to have feedback mechanisms, so that information flows not only upwards, but also downwards towards the community level workers. This is to encourage the application of results obtained at the field level and to give the community workers a feeling of being, part of a team, a sense of belonging and a sense of pride in the outcome of their recording systems.

Information to be Collected

Assessment and progress of disabled persons:

This can be in relation to the disabled persons, with particular reference to their daily living skills. It is necessary to pay special attention to children and to develop ways of recording information for those below 6 years of age.

Regarding the disabled persons, information is also needed relative to education, vocational training, income generation, social integration and referral services.

Community/group activities:

For this, information is to be collected regarding: sensitisation activities; resources mobilised; meetings (numbers attending, topics, etc.); mutual support groups; parent groups; groups of disabled persons; and CBR committee meetings.

Management and staff issues:

Information is to be collected about the following: number of staff and committee members; their tasks and responsibilities; their training needs; training programmes. For this information:

The level of detail of information will vary from programme to programme.

Meetings of staff and committee (another way of monitoring/review) could be held at weekly or fortnightly intervals, depending upon the needs.

Reports could be generated on a monthly basis.

The information is to be collected by community level workers, the local CBR supervisor/co-ordinator and the CBR committee.

Evaluation at Community Level:

The evaluation at community level is to be carried out as a part of a comprehensive evaluation of the CBR programme.

Why should the evaluation be carried out?:

It is needed since the programme is community based and thus, the community level activities are the most crucial part of the programme. It is also required to get the feedback from the disabled persons, their families and from the community. Finally, it is useful for comparison with other projects.

What should be evaluated?:

Has the project made any difference to the disabled persons and their families? What is the level of awareness of communities and families? How are the attitudes of communities and families? How is the transfer of skills? How is the role and the involvement of CBR committee? What is the sustainability of the programme (e.g. resources mobilised, community participation, development and strengthening of local structures, costs, etc.)?

Who evaluates?:

It will depend upon the objectives of the evaluation. It can be internal or external or a combination of both. Ideally, it should be a joint evaluation, since the goal is to improve programmes and internal persons must be a part of the evaluation team. However, their efforts may need to be supported by technical expertise from outside.

When to evaluate?:

It will depend upon the objectives and the needs of the programme.

How to evaluate?:

According to the objectives, a plan has to be drawn up, to finalise the team, the tools, the sample, the data collection, analysis and report writing.

There is need for preparation of personnel involved in the CBR programme for evaluation, in terms of attitude change, demystification and training.

Evaluation at District/provincial Level

This level is defined as that between the community and the national levels. In this instance, the evaluation is seen as a comprehensive process to see how a CBR programme is progressing over a given period of time.

Why is evaluation needed?

The reasons vary, depending upon who wants the evaluation a donor agency, the government, the implementing agency, etc.

The main reason for the evaluation is to facilitate further development of the programme. The emphasis is on meeting various needs and not only the external needs.

Who is involved and what are the tasks for evaluation?

The people involved are the steering committee or the co-ordinating team and the CBR workers/cadres.

The tasks at this level are: developing plans and strategies for the district/province; training of district and community level personnel; creating awareness; mobilising resources; liaising with other agencies; technical supervision; management of referrals from community and national levels.

What to evaluate?

(a) Progress made by disabled persons:

This is to be determined through: information on functional improvement; schooling; social integration/relationships; skills and income. The means for collecting this information is through questionnaires, reports, interviews, observations, field visits, etc.

The type of questionnaires/reports would include: checklists (as in Vietnam) or master forms (as in Ghana) to collect information during regular field visits; quarterly reports to deal with turnover of local supervisors, number of disabled persons identified or already in the programme, main activities undertaken, activities of disabled persons' organisations, training activities, community activities, planned activities, etc.; half yearly reports regarding the different kinds of disabilities, improvements and other activities.

(b.) Quality of training programmes: pre and post training assessment needs to be carried out to determine: perceptions of people, attitude change, transfer of skills, use of relevant materials/manuals/reports etc. and community involvement.

What do we do with the evaluation outcome?

The outcome of the evaluation can be used to identify ways and means to build in key issues into the programme; to use these for further motivation to sustain programmes; to use the information for further planning.

What are the main problems related to evaluation?

The main problems are related to the inability to complete reporting forms/records and the poor reliability of information from the community level.

This needs to be overcome by the use of checklists, regular field visits, problem oriented support to the community level, to increase the reporting and recording competence at that level so that the information from that level is reliable and there is no need for the district level to duplicate the collection of information.

Evaluation at National Level

At the national level the following mechanisms are to be considered:

Monitoring: to assess progress, through statistics, reports and records from the intermediate level to be collected on a quarterly basis. **Self-assessment:** to assess effectiveness and efficiency. This is to be done by national governments, through the generation of reports, twice a year and through field visits and meetings.

Comprehensive evaluation: to collect additional information to assess impact, sustainability and relevance and to study in greater details, some specific activities of the programme (e.g. education, community participation, etc.). This can be done every 35 years, could be internal or external and could be done through surveys and interviews with key persons.

An example of monitoring information from Indonesia

Input (annual): number of disabled persons, kinds of disability, gender and age; number of persons in the CBR programme; number of regular meetings of CBR team.

Process (quarterly reports): kind of training given; number of participants; awareness campaigns and activities (number and types); media interventions.

Output (twice a year): number of volunteers or CBR cadres; coverage of target areas; number of disabled persons integrated into schools; number of disabled persons employed; number of disabled persons with improvement in daily living and autonomy, etc.

Outcome: This refers to the impact of the programme and can only be evaluated during comprehensive evaluation.

An example of self-evaluation from Mauritania

This is done every two months at the beginning of a CBR programme in an area and can gradually be reduced to twice a year. This is carried out by local authorities through visits to the organisations of disabled persons and through discussions with volunteers/CBR workers, local supervisors, intermediate supervisors and local CBR committee. Depending upon the problems identified during this, visits may also be undertaken for discussions with relevant specific professional groups.

An example of monitoring and evaluation from Guyana

At the onset of training in a new region, pre-training questionnaires are completed about the families involved in the programme and the volunteers who provide support to them. The same persons are again interviewed after 15-18 months in a post-training interview.

The progress of the disabled persons on the programme is monitored every 3 months using the ADLQ from the WHO manual. Each volunteer reports on a monthly basis to the Regional CBR co-ordinator concerning community activities, role of PWDs in the programme, referrals, etc. Every three months the Regional Co-ordinator summarises the data in their report to the National Co-ordinators.

Once a quarter, there is a meeting of all key persons involved in the CBR programme in each region. The meeting examines progress and achievements to date, challenges faced and plans for the next three months. In addition, all the Regional Co-ordinators meet with the National Co-ordinators on a quarterly basis to share information. In this way a mechanism is in place for the monitoring of the programme through the local, regional and national levels of the programme.

An example of ownership of the evaluation process from Swaziland

The Swaziland CBR team had included a formal evaluation into their initial three year project proposal. Plans were made to recruit an external evaluator. In the meantime the team began to make preparations by holding meetings to discuss key issues and by drafting questionnaires. The evaluation was important, both to convince the Ministry of Health of the worth and impact of the programme and to secure further funding.

A series of circumstances led to the unavailability of the external evaluator. The local CBR team had no other option, but to conduct the evaluation on their own.

The Ministry was very impressed with the final report and held it as a model evaluation. The team has a greater sense of ownership of the report and the process leading up to it, than if it had been led by an outsider. The results helped them to draw up a five year plan which was included in the Ministry's overall plan for the first time.

Comprehensive evaluation at national level steps to be followed

Study or review the existing data such as statistics, monitoring/progress reports, self-assessment reports, etc.

Define the evaluation questions in relation to the objectives of the programme.

Decide on the methodology of evaluation such as surveys, interviews, sample selections, etc.

The additional information to collect will focus on the main conditions needed to "succeed in developing a CBR programme" such as: referral systems, community participation, skilled manpower, available resources, social attitudes, involvement of governments in terms of national policies, legislation, etc.

All the information is to be collected from different sources and cross-checked or verified.

Analysis of information and the plans for reporting: (a) Use the criteria of evaluation to analyse all the main objectives of the programme to see if the programme is successful such as progress, effectiveness, efficiency and impact. (b) Verify if the CBR is an appropriate strategy, looking at aspects like sustainability and relevance. (c) Organise meetings with partners and decision makers to discuss the results and to define what decisions will be taken on their basis.

Conclusions

Monitoring, self-assessments and evaluations are complimentary processes. It is important to train people at different levels in defining specific objectives, collection of information and use of information to take decisions to improve programmes.

Taking decisions based on the lessons learned and planning for further action are the most important aspects of evaluation.

INDICATORS FOR CBR PROGRAMMES

INTRODUCTION

All the programmes of CBR carry out some kind of monitoring and evaluation of activities. This includes some indicators to assess and analyse the activities and functioning of the programme (process indicators), as well as, indicators to verify the effects of the programme on the target groups (outcome indicators). In addition, all programmes use some indicators related to the baseline situation of the target groups for the planning of activities, for example, the number of disabled persons in a population.

However, there is wide variation between the indicators used by CBR programmes in different countries and among different projects in the same countries. This lack of standardisation of indicators, makes it difficult to compare the activities of different CBR programmes at national and international levels.

More often, programmes use process indicators like number of training courses held or number of meetings held, which do not provide complete information about the quality of activities.

Outcome indicators, which can provide qualitative information about the effectiveness of the activities are used less frequently and where used, are mostly related to the medical component of the activities. This occurs also, for, although social and community activities are important components of the CBR programmes, it is difficult to find objective ways to measure such activities.

The group identified the following aspects related to the indicators, as being the most important:

Need for identifying some standard indicators, to be used by all CBR programmes, which are simple to measure and which reflect the multi-sectoral nature of CBR programmes.

Need for identifying one or a few key indicators, which can provide a general assessment of the effectiveness of CBR programmes.

Discussion Methodology

The participants were divided into two groups and were asked to analyse the possible indicators of CBR programmes. One group examined all the possible indicators related to the four major participants connected with the CBR programme (disabled persons, families of disabled persons, community and government). The second group discussed the same issue looking at the many sectors involved in CBR programmes (general information about disabled persons, medical aspects, education aspects, occupational aspects and community aspects).

Possible Indicators for the Major Participants of CBR Programmes

The group looked at the possible indicators related to the major participants of CBR programmes, that is: disabled persons, families of disabled persons, community and government. All the possible indicators were examined to see if they would be easy to collect, objective, and broad/multi-sectoral.

Indicators related to disabled persons:

No. of disabled persons improving in skills

*

Total no. of disabled persons in the programme

This indicator would give information about: dedication of family members; commitment of disabled persons; commitment of volunteers/local supervisors; general functioning and quality of programme, value of training.

Indicators related to the families of disabled persons:

No. D.P. & family members active as volunteers

* _____

No. of households with disabled persons

This indicator would provide information about: participation of disabled persons and their families in the programme; awareness of the programme in the target group.

Indicators about the community:

No. of volunteers who drop out

* _____

No. of volunteers trained

This indicator would provide information about quality of: community participation; training; awareness campaign; referral system support; CBR team work.

No. of pupils spending time with disabled children

* _____

No. of pupils

This indicator was suggested by Lesotho CBR programme to assess their "child to child" component of CBR programme. It was felt that the data needed for calculating this indicator would be difficult to collect and it would be subjective.

No. of D.P./parents involved in DPO/parent organ's

* _____

No. of households with disabled persons

This would provide information about empowerment of disabled persons; social and political participation; success of awareness campaigns.

No. of D.P. participating in family productive activity

*

No. of disabled persons

It was felt that the data needed to calculate this indicator would not be easy to collect and it may be difficult to separate productive from non-productive activities. This indicator would show: self-sufficiency; social participation; validity of programme.

No. of DP participating in relig/activ. at least 4 times p.a.

*

—

No. of disabled persons

This would provide information about social participation and integration in the community. Some of the participants questioned the usefulness of this indicator and felt that it was not appropriate.

No. of volunteers in CBR programme

*

Total population

This would show: commitment of community; level of awareness.

No. of D.P. active in social & political movements

*

No. of disabled persons

This would provide information about active involvement of disabled persons in the society; empowerment of disabled persons. However, some participants felt that it is not an appropriate indicator because of the difficulty in having objective data.

No. of married disabled persons

*

No. of disabled persons

This would provide information about equalisation opportunities; quality of life. For this indicator also, some participants questioned its usefulness.

Indicators about government:

No. of employed D.P. receiving a salary

* _____

No. of D.P. of employable age

This would provide information about self-sufficiency; integration; contribution of disabled persons in local government.

No. of community rehab. workers paid by government

* _____

No. of disabled persons

This would provide information about commitment of government institutions to the CBR programme; level of collaboration with existing infrastructures.

No.DP to CBR prog. by ref.system/no.DP to ref.system

* _____

No. of disabled persons

It was felt that the number of persons referred to the CBR programme by the referral system would be a better indicator for awareness and acceptance of the CBR programme. To assess the involvement and functioning of the referral system, more commonly, we measure the number of disabled persons referred to the referral system.

Life expectancy of D.P. in programme

* _____

Life expectancy of general population

This was felt to be a very broad indicator to assess the overall situation of disabled persons and about the equalisation of opportunities. It was however, felt that it would not be easy to measure.

Indicators based on Different Sectors involved in CBR Programmes

This discussion did not examine all the possible indicators related to the different sectors involved in CBR programmes and was limited to indicators: related to the outcome of CBR programmes; which would be easy to measure at national level; and which could provide the most significant information about the effectiveness of the activities of the concerned sector. It was felt that out of this group of indicators, it may be possible to identify some "key" indicators.

General indicators about disabled persons:

* About numbers of disabled persons

No. of D.P. in the country/province/area

Total pop. in the country/province/area

This information would be useful for the planning of services and resources. While the information about the number of disabled persons in a limited area can be considered reliable, at national level, often this information is expressed, mostly as an estimate. Lack of consensus about what constitutes a disability, often limits the use of this indicator for comparisons at international level. However, in many countries, the data needed for calculating this indicator is easily available from census figures.

* About age distribution of disabled persons

No. of disabled. children 0-5 age group in country/area

Total no. of D.P. in country/area

This would help in finding out if a specific age group of disabled persons receives proportionate amount of resources in a programme; and for planning of activities. Such indicators can be calculated for different age groups.

No. of disabled. children 0-5 age group in country/area

Total no. of children 0-5 age group in country/area

Such information can help in asking for a bigger share of resources for specific services/infrastructures for a specific group of disabled persons.

* About kind of disability

No. of persons with a specific disability. in country/area

Total no. persons in country/area

Again, such information can help in planning services and resources, so that these are distributed in an equitable manner.

Apart from the above-mentioned indicators, some other data were discussed such as geographical distribution, number of married disabled persons, etc. However, these other data were considered to be less important.

Indicators about CBR programmes:

It was felt that for the CBR communities, only process indicators (number of meetings, number of members, number of sectors involved, etc.) are feasible and these indicators did not provide qualitative information about the functioning of these committees. However, use of a check-list to control the participation of different sectors of the community in the CBR committees (for example, are DPOs present in the committee, are different government ministries represented in the committee) can be useful.

Indicators about the medical component of the CBR programme:

Progress in ADL of D.P. in the programme

*

Max. possible progress in ADL of D.P.

For measuring the progress in the activities of daily living of the disabled persons in the programme, the form provided in the WHO manual could be used, as this allows the grading of the progress numerically. Over a period of time, a positive change in this indicator will show the effectiveness of training the L.S./volunteer, commitment of L.S./volunteer; rapport between L.S./volunteer and the disabled person and family; effectiveness of referral system; etc. However, it must be kept in mind that many disabled persons will never achieve the maximum possible score and thus, after an initial increase, this indicator may not show any further change.

No. of D.P. with functional self-sufficiency

*

Total no. of D.P. in the programme

Once again, this can be measured numerically, by using the form from the assessment of functional self-sufficiency provided in the WHO manual (form II) and grading the responses.

No. of D.P. referred to district/province

*

Total no. of disabled persons

An increase in this indicator may show that there is awareness/collaboration with the referral system but may also mean that the quality of training provided to L.S./volunteers is not adequate, so that more persons are referred.

Indicators for the educational aspects:

Disabled children going to primary school

*

No. of disabled children of school age

The group felt that this was a broad indicator reflecting: community participation; teacher training; involvement of teachers; attitude change; functional self-sufficiency; provision of orthopaedic appliances; effectiveness of media campaigns, etc. However, information about going to school may not indicate if the disabled children are effectively integrated and do not merely sit in a corner in the class. Still, this may be used as a "minimum quality indicator" which means that the majority of good, multi-sectoral CBR programmes should be able to show an increase in the indicator value, over a period of time.

Some other variations of this indicator can also be useful, for example, number of disabled children who do not complete the primary school compared to the number of non-disabled children who do not complete it; number of children with mental disabilities going to primary school as compared to other disabled children, etc.

No. of disabled. children going to sec. school

*

No. of disabled children of sec. school age

This would better reflect the integration of school children in the education system, but this has to be compared with similar information from the non-disabled children of secondary school age. Again, variations of this indicator can consider: school drop-out rates; school-going patterns for specific types of disabilities; etc.

For both of the above indicators, calculation of disabled children completing the primary school may provide better information about the effectiveness and impact of the programme.

Indicators related to occupational aspects:

No. of economically self-sufficient disabled persons

*

Total no. of disabled persons

The main difficulty with this indicator is the definition of economic self-sufficiency.

No. of employed D.P.

*

Total no. of disabled. persons of employable age

Conclusions

A number of possible indicators were identified during the discussion. These need to be field-tested to see whether the data required to calculate an indicator are available easily, and if they are reliable. Then, it will be necessary to verify, if the changes in the value of an indicator are associated with a corresponding change in the programme. Lastly, the numerical values of the indicator will need to be standardised.

COUNTRY EXPERIENCES OF CBR

COMMUNITY BASED

REHABILITATION:

THE GUYANA EXPERIENCE

Brian O'Toole

1. Introduction: challenge to be faced

A neighbour came to my house eight years ago to ask if I knew of any help for her severely handicapped daughter. I have known the family for several years, our children played together, but I didn't know there was another child in the family who did not go out of the house. We only live a few kilometers from a modern rehabilitation centre. My neighbour had visited the centre on a number of

occasions, but now her daughter was simply too heavy to be carried on and off public transport to get her to the expert facilities. A group of us therefore got together to see if there was anything that could be done for children like Nalini throughout the country.

As we move towards a new century we may do well to think for a moment about how future historians will characterise this particular period of development. Will the final decade of the Twentieth Century be said to be the age of reports, slogans and rhetoric, or will it indeed lay the foundation of the New World Order? Within the field of Special Education and Rehabilitation will we be seen to conservatively follow our forefathers or will we begin to articulate a new model of service delivery?

The United Nations "Decade for the Disabled" has now drawn to a close. Much of the decade however was spent highlighting the inadequacies of existing service models in the area of rehabilitation, rather than examining innovative alternatives.

The challenge facing rehabilitation in the 1990s can be easily stated; parents of disabled children throughout the world are not getting enough help with the education, care and training of their children. Existing services may be meeting no more than 2% of those in need (Marchesi, 1994; Kisanji, 1993; Kohii, 1993). In the poorer countries, where an estimated 75% of the disabled population live, they often receive no assistance at all (Mendis, 1988). Whilst we can debate the precise number and percentages, it is clear that a disproportionate number of the world's disabled population live in developing countries. Disability imposes considerable social, economic, and emotional costs on disabled people, their families and the wider community. Without effective rehabilitation disabled people may lead unhappy, dependent lives and become burdens to themselves and to society.

As long as poverty and malnutrition, ignorance and superstition, conflict and war continue, the figure may well rise by the end of the century

(Mittler, 1993). The great majority will live their lives without dignity, in absolute poverty, victimised by beliefs that they are possessed by evil spirits or that their very presence is proof of divine punishment. However the problem is not only acute in developing countries: A recent report by the International League of Societies for Persons with Mental Handicap, "Education for all" (ILSMH, 1990), concludes that the mainstream school has denied participation to handicapped children throughout the world.

A radical reappraisal of the concept of staffing, the model of training and the nature of services offered is therefore urgently needed. Community Based Rehabilitation (CBR) has been offered as one contribution towards the reappraisal of services, particularly in the context of developing countries.

2. Inadequate response to the challenge

No nation can morally or practically ignore a challenge affecting such numbers of people. It is however becoming increasingly apparent that the present model of rehabilitation, based on institutional care, would absorb more than the total health and education budgets of most developing countries if serious attempts were made to meet the needs of all disabled people in this way. For practical reasons therefore more economical approaches will need to be explored to meet the magnitude of the task. Reports from all corners of the world suggest that, where rehabilitation services are available, they are concentrated predominately in urban areas which are often accessible only to a small and privileged section of the community. The plan was to establish special schools and rehabilitation facilities centrally, staffed by highly competent personnel with the hope of expanding them progressively as resources increased until the whole target population was covered. The reality has been very different. Services have become centred on urban areas accessible only to a small and privileged section of the community.

Against this background, it may be useful to remind ourselves that the vast majority of mankind are village people who live in rural communities which have remained unchanged for hundreds of years and who, as yet, remain totally unaware of the slogans and declarations being voiced on their behalf.

The present situation has been characterised by Miles (1991): the cries of the oppressed filter through as bloodless statistics... while the response trickles back as theoretical programmes.

In light of the millions of people in need, the prevailing model has come under severe criticism. The undue concentration on an urban elite, the adoption of unnecessarily high standards of training, the narrowness of specialisations, and the isolation from normal life are some of the criticisms levelled at this approach to rehabilitation. The situation is further complicated by the fact that those most in need of services are often the least likely to seek out help (McConkey, 1986). Some new approach is therefore required to make the services relevant and accessible to poor people in rural areas.

3. New model of development

One reason for the lack of progress in the fields of Special Education and Rehabilitation is that the professional roles which have been adopted in developing countries are inappropriate to the needs of those societies.

We have been seduced by the "modernisation mirage" which has fostered the illusion that Western skills, knowledge and attitudes should be diffused to developing peoples (Arbab, 1984). In some cases the mirage has become so vivid that many civil servants and rehabilitation workers in developing countries insist

that Western style institutions are the solution and anything else is humiliatingly second rate. Karey's (1986) comment that:

- special education in Africa is profoundly
- European in origin, practice and prejudice, in spite of Africanisation
- is relevant to much of the developing world.

In our blinkered desire to imitate the West we have lost sight of the true magnitude of the problem. The justification for this focus is the need to "maintain standards". However to the 98% of the families who are presently receiving little assistance the argument concerning "standards" has no relevance. For them the question becomes, quite simply, will any significant service reach them during their lifetime (Mittler and Serpell, 1986). Simple improvements to the existing service are not enough. A fundamental re-direction is necessary to meet the challenge.

As we move towards a new century there is a growing realisation of the need for a new concept of development. The prevailing top-down model of service delivery is becoming increasingly discredited. Often in the past, social service programmes were planned and implemented by bureaucratic institutions without any consultation and involvement of the intended consumers. There is an increasing realisation now that if those who are meant to be helped by the innovations do not participate actively with those who would promote the development process, change will be impossible.

One of the basic questions now becomes how can we guide individuals who, for so long, have traditionally been led by others, to take charge of their own affairs. We need to move away from regarding rehabilitation as a product to be dispensed, and towards offering rehabilitation as a process in which the villagers are intimately involved (O'Toole, 1990).

4. Potential of Community Based Rehabilitation

The gap between need and provision cannot be closed by developing, or even expanding, conventional services. Within the field of rehabilitation and special education there is an increasing realisation of a need for a new pattern of services characterised by fewer experts, less advanced forms of training and simplified methods of intervention. The challenge is to see how to provide the most essential assistance to high numbers of people and to do so using readily available resources.

The concept of Primary Health Care (PHC) entailed the acceptance of two important principles which had been vigorously resisted earlier. Firstly that it is more important to bring about even small improvements to the health of a large number of people than to provide the highest standard of care to a privileged few,

and secondly, that non-professionals, with limited training, can provide much-needed services. The World Health Organisation (WHO) provided the stimulus for incorporating rehabilitation into PHC in its Manual "Training the Disabled in the Community" (Helander et al., 1989) which is now in use in many countries throughout the world.

The goal of CBR is to demystify the rehabilitation process and give responsibility back to the individual, family and community. Most disabled people live in rural communities, rehabilitation is therefore best done in that environment with the child's care givers as the primary training agents. In WHO parlance, a "Local Supervisor" is recruited from the community and trained. The Local Supervisor could be a health worker, teacher, social worker or volunteer. The Local Supervisor shows a member of the family how to carry out the training programme. The family therefore needs to learn what to do to help and requires a system of support and encouragement. CBR attempts to use existing organisations and infrastructures for the provision of services. Simple tasks are delegated to auxiliaries or volunteers whose performance is monitored by an intermediate level supervisor. CBR therefore promotes a simplified model of rehabilitation which, in the WHO scheme, is described in a series of booklets. The basic premise of CBR is that the greatest resource in developing countries for helping disabled people lead lives which are fulfilled and productive is a well advised and supported family.

CBR is an attempt to generate an exponential increase in appropriate skills, distributed to where the needs are by utilising hitherto unexploited resources in the community. The goal is for rehabilitation to be perceived as part of community development whereby the community seeks to improve itself. Once the community takes on the responsibility for the rehabilitation of those members with disabilities, then the process could truly be called "community based". In such a process rehabilitation becomes one element of a broader community integration effort.

5. Does CBR work?

The philosophy of CBR is immediately persuasive, but can it be translated into practice? Do parents welcome a teaching or training role with their children? Is community involvement in the area of rehabilitation realistic? Are there people in rural villages who would wish to offer their services in such a programme? Is it possible to develop rehabilitation as a process, in which a number of people are involved, rather than as a product which is dispensed at the local level? Moreover it would be useful to see for whom such an approach is meaningful; which children, which families and which volunteers are effective.

The past decade and a half has seen some notable advances in terms of exploring new concepts of service delivery. There has been a wide variety of attempts to introduce CBR programmes.

Programmes such as the Zimcare project in Zimbabwe (Mariga, 1986), the AMREF programme in Kenya (Arnold, 1986), Project Projimo in Mexico (Werner, 1986), NORFI in Philippines (Vaidez, 1991), 3D Project in Jamaica (Thorburn, 1990) have all presented very valuable innovations. In the great majority of the above cases if it were not for the CBR programmes the disabled people concerned would have received no help from any other source.

Others are less optimistic about the achievements reported in the studies cited above, there may be as many other projects where the limitations of the approach have been emphasised. Overwork, poverty, severe social tensions and sheer exhaustion make parental involvement a challenging proposition in developing countries (Thorburn, 1990; Miles, 1990). Moreover such practical limitations are not only apparent in developing countries. Indeed for the poor in the West the progress of the handicapped child may be the least of the parents' worries (McConkey, 1986).

The overriding conclusion of the ILO in reviewing a decade of experience in the area of CBR has been the realisation of the difficulty of introducing effective CBR programmes which will endure beyond the time of external inputs (Momm and Konig, 1989). The ILO conclusion states they have no experience of a really effective CBR programme which could demonstrate its ability to carry on solely with local resources once external support ended. The main experience of the ILO, however, has been a respect for the difficulties inherent in introducing CBR programmes.

The real test of CBR has yet to come. Can CBR expand beyond a relatively small scale, home based teaching model into a nation-wide community care programme?. The logistics of organising and effectively supporting a widely dispersed cadre of workers needs to be examined. What happens when the protected subculture disappears and the temporary system is absorbed into the government system using local officials not so committed to the approach?

6. "Hopeful Steps,,: one response to the challenge

As one contribution in response to some of the above challenge has been developed in Guyana, South America. The name of the project "Hopeful Steps". The programme began in 1986 and now operates in five regions of the country. This paper will focus on an examination of the way in which the "Hopeful Steps" programme attempts to respond to the challenges presented above.

6.1 Guyana: the land

Guyana is located on the Atlantic Shoulder of the South American sub continent. it is bordered by Surinam on the West, Venezuela to the East and Brayil to the Sough. Guyana is a land of 83,000 sq. miles with an estimated population of 0.8 million. 90% if the population live on the narrow coastal region where the

population density is 25 people per square mile, by contrast the population density in the vast interior areas is less than one person per square mile.

Guyana achieved its political independence from Britain in 1966, and declared itself a Co-operative Republic along Socialist lines in 1970. The economy is based primarily on the production of sugar, gold, rice and bauxite. Guyana's economy is very vulnerable to fluctuations in world trade.

An examination of social and economic statistics on the country, prepared by UNICEF (1987) reveal both positive and negative trends. Infant mortality is declining, from 69 per thousand in 1960 to 33 per thousand in 1985, as is the crude death rate, from 10 per thousand in 1960 to 6 per thousand in 1985. Life expectancy has risen from 60 years in 1960 to 69 in 1985 and is now 12 years longer than the world average.

The picture is however balanced by other indicators. The GNP per capita is falling from the 1982 figure of US\$ 670 to a figure of US\$ 590 in 1984. The percentage of infants with low birth weight (i.e. less than 2,500 gms, is 18%. The percentage of the national budget allocated to health has been one of the lowest in the Caribbean (Moody, 1981; Hannay, 1978).

According to Inter-American Development Bank figures, quoted in one of the National Newspapers (Stabroek News, April 3rd, 1987), Guyana with a per capita income (Gross Domestic Product) of US\$ 720 is one of the poorest countries with IDB membership. Only two countries, Haiti and Honduras, were considered to be worse off. It should also be noted that the article was written before a devaluation significantly decreased the value of the currency.

6.2 Provision for children with special needs in Guyana

Guyana has only one special school which is based in the capital and serves the needs of hearing-impaired and intellectually impaired children. There is a long waiting list for entry to the school. There is also a centre for physically handicapped children in the capital. A unit for visually impaired children is attached to a mainstream school in the capital. There are two very small units, catering for disabled children in two of the towns in the rural areas. The capital with approximately 23% of the population has 90% of the provision in the area of special education. The disabled children once admitted to these institutions remain for many years and few new places are made available. The degree of population coverage and the annual admission rate are therefore very limited. The ratio of staff to children is very high. In summary therefore, there is a significant gap between needs and available services.

6.3 Pilot project phase

As one contribution towards examining the potential of the philosophy of CBR a pilot project was implemented in two rural areas of Guyana from 1986 to 1988. A

systematic survey was carried out in one a one area of 4500 people. 1.5% of the childhood population of the village were found to be in need of special help because of their disability. The available provision was however concentrated primarily in the major urban areas.

Before the programme began a series of meetings was held with Ministry of Education and Ministry of Health personnel, parent groups, community leaders and rehabilitation professionals. The training was offered as a course by the Institute of Adult and Continuing Education (IACE) of the University of Guyana. We were fortunate that the IACE was headed by Mr Samuel Small who shared a common vision with the co-ordinators of the "Hopeful Steps" project and from an early date was a key collaborator in the development of the programme. The CBR programme complemented the philosophy of IACE, which is to reach out into rural communities and help villagers to become more active participants in their own development process.

A series of radio programmes, newspaper articles and announcements in schools, shops and places of worship helped to prepare the wider community for the project. A public meeting to introduce the programme attracted more than 200 people in a rural village school (Nalini's mother was one of those attending). Sixty people applied to be trained to work as volunteers with disabled children and their families. From the outset it was clearly understood that the work was voluntary and that it would not lead to formal employment. 26 of the applicants were accepted as volunteers for the programme. They came from a wide variety of backgrounds including nurses, teachers, clerks, technicians, students, and housewives. Virtually all of them were women. About one fifth of the volunteers had a relative with a disability. They all lived in villages up to 16 kilometres out of the capital. For more than half of them, the desire to be of service to the community, and a concern for children in general, was the reason for their participation. The great majority of the volunteers earned very modest wages and most had large families of their own. The volunteers soon felt however that they were part of something important and challenging. The pilot project therefore confirmed that within the Guyanese context it was indeed feasible to recruit volunteers from within the community who could be effectively trained to be of service to people with disabilities.

A separate training programme was offered for 30 nursery school teachers. Preschool education is widely and freely available in Guyana. Children attend for the morning session and the teachers are "free" in the afternoons for "staff development and training". For this pilot project 8 years ago the Ministry of Education requested that teachers participate in the programme, unless they could offer a good reason not to. In reflecting on the innovation it is important to understand the changes that have taken place in the country over the past two years as the country has experienced the first change of government for more than two generations.

The initial contact with the Ministry of Education was formal, more recent work has evolved in the form of a far stronger partnership. Under the demands of the earlier system only about 20% of the teachers were significantly involved in the programme. To the majority of those not involved regarded the programme as an external imposition (in later years we were to draw from this experience and learn more effective ways to establishing a partnership with the existing infrastructure).

The project was, and is, jointly co-ordinated by Dr Brian O'Toole and Ms Geraldine Maison-Halls. Dr O'Toole is an Educational Psychologist who, by 1986, had already worked for eight years in the country in the area of Special Education. Ms Maison-Halls is a Senior Physiotherapist from Guyana who has worked as a consultant in the area of CBR for a number of international organisations. The co-ordinators formed an effective team and combined skills and contacts in the areas of health and education.

In the pilot study there were significant differences regarding the effectiveness of the volunteers as opposed to the nursery schools teachers in the role of helping people with disabilities.

The pilot project lasted for 18 months with the volunteers and teachers meeting twice per week to learn about ways in which they could help disabled children. the training programmes drew heavily on ideas from the WHO manual (Helander et al, 1989), the Zimcare materials from Zimbabwe (Mariga, 1986) the Portage materials (Revell and Blunden, 1980) and ideas contained "disabled Village Children" (Werner, 1987).

The majority of the volunteers soon became deeply involved in the project and were eager to meet together to discuss their anxieties, doubts and indeed to share their successes. A deep sense of belonging soon emerged and the volunteers came to regard the project as their own. By contrast it was clear that the nursery teachers as a group invested far less of themselves in the project.

Each of the volunteers worked with one or two disabled children. In each home someone was identified who would work along with the child. the volunteer suggested certain activities to this family member. The volunteer would try out an activity with the child, watched by the relative, the relative would then try out the activity, finally the volunteer and the relative would discuss the session.

The children in the project were identified by a combination of house to house visits, referrals by professionals and parents and by identification within their schools. Fifty three children therefore became part of the programme in this way. They had a variety of disabilities, including cerebral palsy, deafness, speech impairments and mental retardation. the effectiveness of the innovation will be considered in a later section.

Does the programme lead to any meaningful change in the child's performances? The child's progress was measured, on an on-going basis, by the participants and by independent evaluators using both an adapted form of the Portage Checklist and the Griffith Test of Mental Development. Significant gains were seen on these assessments. The interested reader is referred elsewhere (O'Toole, 1991) for a detailed analysis of these results. The results for the volunteers were, however, consistently better than for the nursery teachers. Independent evaluators judged 54% of the volunteers sample to "show progress" as compared with 37% of the nursery sample.

The degree of progress of the child did not seem to be dependent on the educational level or financial resources of the parents or the degree of the impairment. A more significant factor was simply the level of parental involvement in the project.

In the final analysis a project of this nature cannot be judged solely in terms of the child's progress on a standardised test or development checklist. One needs an appreciation of what the programme meant to the participants. The great majority of the parents found the programme very helpful. One commented:

before the programme I only saw what my child could not do.

Now I look at what he can do.

The children were regarded as happier, better behaved, more mobile and more motivated. An analysis of interview and questionnaire material revealed improved feelings on the part of mothers towards their children, a keener perception of the child's progress and an improved relationship with others in the home. The parents also felt that they observed changes in themselves, feeling more relaxed, prouder of the child, and more confident. One father stated: "This programme has served to unite the whole family".

The immediate challenge was presented by Nalini and her family. However the survey soon showed that there were many others in exactly the same situation. At least half of the parents enthusiastically embraced the role of greater involvement in the training of their child. For others, however, the role was unrealistic, their lives were too difficult and their concerns too many to get deeply involved in the project.

The response from the volunteers suggested that it was feasible to train volunteer from rural communities to work with disabled children. Throughout the pilot project phase however, it was clear that the volunteers were far more involved than the nursery teachers thereby questioning the infrastructure through which the project can be introduced and maintained.

The numbers involved in the pilot project were small, thereby making it difficult to make generalisations. Some of the most noticeable progress was with children wh

had learning or movement problems. In contrast, children with hearing problems made only modest gains, suggesting that such children may well need far more sophisticated services than those offered in the pilot project. The volunteers came from a wide variety of backgrounds. While some were no doubt helped by their professional backgrounds, others with no formal education or training won the respect of the family and the affection of the child. In the sense that the local rehabilitation committee assumed responsibility for the rural resource unit, the project truly became a community-based model of rehabilitation.

After two years of the project, Nalini was still unable to say any words, but her neighbours now knew she existed and her mother felt comforted by the progress she perceived in the child's mobility and her general behaviour. To an outsider, the gains may have appeared insignificant, however to Nalini's family, and to a number of others, it was a meaningful experience and presented a challenge of what could be achieved in the future. It was on the basis of this pilot project that a three-year expansion of the programme was developed beginning in 1989.

The pilot programme was financed by a small grant of C\$ 12,000 from the Canadian International Development Agency and by a research grant of US\$ 1,500 from the University of Guyana. An analysis of the pilot project and the philosophy of CBR generally was successfully presented by Brian O'Toole for the PhD degree at the Institute of Education, University of London (the interested reader is referred to the thesis for a far more in-depth analysis of the issues presented here, see O'Toole, 1989).

6.4 "Hopeful Steps": an expansion of the Guyana CBR programme

On the basis of the results from the pilot project a three-year expansion of the Guyana CBR programme began in 1989. The expansion was jointly funded by Amici di Raoul Follereau and the European community. The project was administered by Action on Disability and Development in UK and the National Rehabilitation Committee of Guyana. The training of volunteers from the community was continued through the Institute of Adult and Continuing Education of the University of Guyana. At the end of the three-year funding cycle Amici di Raoul Follereau (AIFO) assumed full responsibility for the funding and management for the expansion of the programme over the period 1993-1995.

In the initial expansion of the project the focus on the development and deployment of volunteers from the community was maintained and expanded. The focus of the CBR programme in the Corentyne and ECD regions therefore was on the use of volunteers from within the community. Volunteers were recruited from Plaisance to Mahaica on the ECD and from Fyrisch to Bush Lot in the Corentyne (see maps). The experience of the pilot project phase was repeated in these two areas. Three times as many people applied to be accepted on the training programme as could be accommodated. The drop-out rate over the course of two years was no more than 5%. The volunteers proved to be a remarkable cadre of individuals who gave generously of their time and their substance. Over

70% of the volunteers remained deeply involved in the programme three years later. The volunteers were generally accepted by the families and generated a high degree of wider community involvement.

In the course of the last two years there has been a change of government in the country. This change is the first for almost thirty years. The new appointments within the government have offered new opportunities for establishing more effective partnerships within the existing infrastructure. The previous regime was in no way averse to the innovations within the CBR programme, however the present Ministers of Health, Education and Labour are genuinely supportive and encouraging of the various initiatives within the programme. The community-based philosophy of the new government has therefore proved to be very fertile ground on which to build effective institutional partnerships.

An illustration of this is the Essequibo region. In collaboration with the Ministry of Education at the central level and the officers within the region, a CBR programme was developed to train nursery school teachers within the Essequibo Coast region. A series of discussions were held with ministry officials and with teachers of the region. In the pilot phase ministry officials were adamant that no certification would be awarded for the teachers involved. In the expansion that was no longer an issue and the teachers were rightly given IACE, University of Guyana certificates for their two years of involvement in the project. In the pilot project no more than 6 of the 30 teachers were involved in the development of the project. In the Essequibo nursery programme all 30 teachers have played a meaningful role in the project. They have now developed four regional Resource Units to begin to cater for some of the needs of the children with disabilities in this relatively isolated region of the country.

Another example of the widening collaboration won by the "Hopeful Steps" project has been the CBR developments in the Rupununi region of the country. This region is the home to almost half of the Amerindian population of the country. It represents a series of 42 very isolated and sparsely populated communities. The initial goal in this region was no more ambitious than the holding of a series of three one week workshops over a two-year period to make the people of this region aware of some of the needs of people with disabilities. Now, three years later, the project is very much richer. Over the course of 8 months a series of 5 one-week field trips were made by the author to the region. Over 15 villages were visited. Discussions were held with the local politicians, administrators, teachers, health workers, village tuschaus (or captains), village councils, and community leaders. The approach adopted was genuinely questioning, there was no script in hand. After these visits an initial one week workshop was held for all the Community Health Workers (CHWS) of the region. The CHWs are men and women from the villages of modest primary school educational background who then pursue a 4-month full-time training programme provided by the Ministry of Health. We were warned by "more experienced people" on the coast not to expect too much from this cadre of workers. On the contrary, 28 people attended this initial one-week training

programme. A number of them travelled 20-30 miles by bicycle, or on foot, to be present. Two travelled 120 miles each way by canoe to participate. Two others, from Gun Strip, walked and canoed for 13 days to attend. From that first workshop it was clear that this was an area of great potential peopled by a group with great commitment to their villages. Over the course of the past two years a total of 13 one week workshops have now been held in this isolated region. In each of the 42 villages there is now a team of three people who constitute the CBR team, comprised of the CHW, a school teacher and a village leader.

Once again the training is under the auspices of the Institute of Adult and Continuing Education (IACE) of the University of Guyana. This is the first time that the University has had a presence in the Rupununi region of the country.

The work in this region has emerged as a genuine community development project. An effective partnership has been forged with a number of groups. The Guyana Office of Social and Economic Development (GOSED) of the National Spiritual Assembly of the Bahai's of Guyana has an extensive Primary Health Care Programme in the Rupununi. The CBR programme has established firm links with this health innovation. An example of this partnership is in the "Facts for Life project". The book "Facts for Life", produced by WHO, UNICEF and UNESCO, contains essential health information that could literally save the lives of millions of people. The challenge however is how to ensure that those who need that information actually have access to it. The CBR-GOSED collaboration, with funding from UNICEF, has developed the following:

a series of illustrated pamphlets, translated into the two local languages, summarising the key information in the book;

a 50 minute video programme, filmed in the region, and shown throughout the Rupununi, depicting the major health messages;

an illustrated manual for teachers and health workers with practical suggestions as to how the information in the book can be communicated;

the development of a "Facts for Life Festival". All 42 villages have been invited to participate in the Festival. People of all ages group are writing poems, songs, skits, short stories and producing posters to communicate the essential health messages. The Festival has captured the imagination of the villagers, It has proved to be a way of allowing expression to their rich culture in a way that can communicate life saving messages. Five subregional festivals are now being planned. The winners from each sub region will then present their entries at the regional finals later this year. A video and a book will be produced to feature the winning entries.

Following one of the early workshops on CBR a request was received from the teachers present to develop a literacy training module as part of the CBR programme.

As a result a one-week workshop was held for 32 teachers in the Sand Creek region. All the practical arrangements were undertaken by the teachers themselves. An outcome of this workshop is a major collaboration with the Ministry of Education in this region to run a series of these workshops, over a two-year period, for all the teachers in the region. A series of specially commissioned reading books have been developed by the CBR team to meet this request. UNICEF sponsorship now facilitates the production of a children's literacy newsletter, written by the children of the region. The books have been procured by various Bahai's communities in Canada, the shipping from Canada to the Rupununi is paid by CIDA, UNICEF and AIFO. GOSED and CBR are now collaborating in the establishment of the libraries and training for resource people to manage the libraries. This project has facilitated a strong partnership between GOSED, CBR and the Ministry of Education officials in the Rupununi. An outcome of these on-going consultations has been the development of a plan to introduce a series of nursery schools in the villages.

Partnerships have also been formed with other groups. The Social Impact Amelioration Project (SIMAP) is an NGO established to offset some of the hardships of the Structural Adjustment Programme which is now in place in the country. The bulk of their activities are focused on the coast. However SIMAP approached the CBR project to be the catalysts and intermediaries to develop their programme in this region. As a result visits were made to 6 villages to meet with the Tuschaus, Village Councils and villagers to learn of their needs and to formulate funding proposals. Proposals have now been submitted for the improvement of water supply in these villages. The CBR team's role has been the development of these proposals, networking with the funders on the coast and monitoring the implementation of the project.

UNICEF are embarking on a fairly major integrated development programme in this region for the first time and have approached the CBR team to be collaborators in the process.

As a result of the austerity and isolation of the area only a handful of NGOs are operating in the region. As a consequence the CBR programme receives requests in areas seemingly outside its expertise. In one workshop the participants asked if new innovations in the field of agriculture could be included in subsequent workshops. A partnership has now been formed with the Inter-American Institute for Co-operation in Agriculture (ICCA) to provide resources people to be included in the seminars offered in the region.

The "Hopeful Steps" programme began two years ago with very modest goals. The vision has however expanded significantly over this period. To help facilitate this expanded vision Voluntary Service Overseas (VSO) from UK have provided two full-time volunteers for a two-year attachment to the Rupununi programme. The Dutch couple, with training in nursing and occupation therapy, have provided tremendous support to the programme.

The seeds are therefore established for the development of an integrated model of development in this region. This direction has emerged out of on-going consultations over the two years of operation in the region. The various innovations were not designed from Georgetown but arose out of an attempt to respond to the expressed needs of the community. Throughout our time in this region we have attempted to appreciate, respect and understand the rich culture of the Macushi and Wapashana people of the region. We were guests in their region. The Rupununi is an area in the process of change. A road is being built through the heartland of the region, linking Manaus in Brazil with the coast of Guyana. The CBR team felt that one contribution they could make to the region was to help document the culture of the people. A number of attempts have been made to achieve this goal. Daniel Janke, a professional musician from Canada, gave freely of his time and expertise to produce a video and an audio tape that documented the music and oral tradition of the peoples of the Rupununi. Laureen Pierre has written a series of stories, translated into the local languages, which present CBR themes within the folklore of the people. Pamela O'Toole produced a video and educational training materials on the rainforest to help the children on the coast appreciate the majesty and potential of this region of Guyana. This has been complemented by a series of story books on appreciating water as resource. A short video was produced by the CBR team showing the pioneering work of the Rupununi Weavers who have rekindled the craft skills of the people in a dramatic and effective manner. In all of these initiatives we were fortunate that our funder, AIFO, appreciated the important role of CBR as an integral part of a wider process of community development. If the "Hopeful Steps" programme had adopted a narrow disability focus from the inception the programme would have been dismissed as an irrelevance.

When the programme began 21/2 years ago, we were informed that there were no disabled people in the region. We knew this was not the case but to have argued the fact would have been futile. Instead we began by building an approach to training that would enhance the development of all of the children of the region. Having won the respect of the people of the region the focus has now widened to encompass the needs of the disabled people within the region. A comprehensive survey of disabled people of the entire region is near completion. A plan of action to respond to the needs of the people identified by the survey is emerging.

The Rupununi, the most isolated and remote of the regions in which the CBR programme is operating, is therefore proving to be an excellent environment in which to increase our understanding of the role CBR initiatives may play in a wider community development innovation.

As the "Hopeful Steps" programme expands we are mindful of the need to balance expansion and consolidation. Within each of the regions in which the programme operates a Regional CBR Committee has now been established. A series of meetings were held throughout the various regional programmes to write a Constitution for the Committees. The Constitution is now written and has been submitted to the Ministry of Co-operatives for ratification. A National CBR

Committee will soon be formed comprised of two members from each of the four Regional Committees and one from Rupununi. The Regional Committees are assuming more and more of the management functions of the programme. These Committees will help to ensure the maintenance and continuity of the programme. We began to appreciate that many of the social and emotional needs of parents could be most effectively met by participation in an informal voluntary association with other parents. The Committees provide a network of families who offer mutual support and who are beginning to assume an advocacy role. It is important to recognise that this structure has evolved out of the project and was not pre-conceived from the beginning as the way to manage the innovation.

6.5 Development of training materials

In the first few years of the project the coordinators drew on material from the following sources: Zimcare in Zimbabwe (Mariga, 1986), Portage (Reville and Blunden, 1980), WHO "Training the Disabled in the Community" (Helander et al, 1989) and David Werner's "Disabled Village Children" (1987). As the programme evolved we felt the need for locally produced training materials that would reflect our own particular needs and culture.

In response to this the Canadian International Development Agency (CIDA) and UNICEF co-operated with our funder, AIFO, to allow Dr. Roy McConkey to pay four visits to Guyana. Dr McConkey played a key role in the development of the training materials. The "Hopeful Steps" programme owes him a great deal for what he has contributed in inspiring the programme.

A major focus in the expansion of the project has been the development of training materials produced and developed in Guyana. We were encouraged by the level of commitment and dedication shown by the volunteers in the pilot project. Moreover whilst for some of the families overwork, poverty, severe social tensions and sheer exhaustion made the goal of parental involvement unrealistic, there were as many others who were willing and eager to assume the role if they received the necessary help and guidance. In the majority of cases the parents wanted to help although they often did not know how to proceed. The volunteers and parents appeared to learn by seeing and doing rather than from following lectures or reading textbooks. What they valued most was practical information that they could relate to and apply to their own situation. There was therefore a need to record examples of good teaching carried out under similar conditions to those experienced by the families. In a similar way it became clear that there was a need to develop a curriculum of training for the CBR workers. In the initial three year expansion period therefore, an attempt was made to respond to these needs.

6.5.1 Development of video training packages

A decision was made to develop a series of video programmes to be used as training materials. These programmes were filmed in a local village setting

thereby reflecting the viewer's world. This also appeared to offer a more efficient use of professional manpower as it facilitated the production of ready made programmes that could then be used in outlying areas where it might be difficult to get scarce professional resources to visit.

Television is still a relatively new medium in Guyana, it was only a few years ago that programmes were first broadcasted in the country. Despite the very limited means of many people in the rural areas of the country, for good or ill, television and VCRs are now present in every village. Moreover in our work in the interior of the country it was also possible to use solar or battery powered facilities. The technology is therefore present.

The novelty of the medium also created various problems as programmes tend to be received in a passive manner. The video training course was therefore developed in an interactive style. The video programmes were complemented and supplemented by course books with series of activities and exercises. The video course then became an integral part of the training curriculum for the volunteers on the "Hopeful Steps" CBR programme.

The materials have now been used extensively by the co-ordinators of the "Hopeful Steps" programme to expand the service into other rural areas. When asked to evaluate the training programmes the participants have repeatedly placed the video training materials at the top of their list regarding what they have found of most value in the course. The materials were originally intended for use within Guyana. However we have now received requests from CBR programmes in 44 countries for copies of the videos. This, in itself has been a powerful motivating force for the families that we work with as they see the growing international interest in the approach they have helped to develop.

6.5.2 Overview of the courses

(a) "Hopeful Steps"

This course is intended for Home Visitors who are working with children who have disabilities. It is intended to help the Home Visitors assess the needs of the disabled child and develop an appropriate teaching programme. The aim of this course is to help the volunteer Home Visitors to:

increase their understanding of children with disabilities and to learn more about ways they could help them;

learn how to assess what children can do already and what is the next appropriate skill to develop;

select appropriate teaching ideas to help the child progress to higher levels of development;

exchange ideas with others on the programme to see how each child can learn to do more for himself or herself.

This video course is divided into the following five units:

(i) Introduction to the video course:

This unit explains the aims and objectives of the programme. The first video unit offers an overview of the Guyana CBR programme and introduces some of the people who participate. They talk about why they volunteered for the project and what they feel they have gained from the experience. Parents also talk about their children, we hear about some of their hopes and their dreams and what they feel they have gained from their participation. The video also offers examples of how the wider community can become involved in the process.

In this first programme the new CBR volunteer is encouraged to reflect on what they hope to achieve on the programme, why they chose to participate, what they hope to learn, what they think they can offer the family and how, at the end, they think they can evaluate what the experience has meant to them, the child and the family. This first section helps to demonstrate the necessary qualities which need to be developed in an interaction of this nature and helps to ensure that the intervention is not pursued in a mechanical fashion.

(ii) Unit 2: Learning to move:

This unit focuses on the importance of movement in young children and suggests some ways that the volunteer can help the child learn and practice the skills they need. The objective of this section is to help the child develop the skills necessary for them to be able to sit, crawl, stand, walk and run.

(iii) Unit 3: Learning to think:

This unit is designed to help the volunteers think of ways in which children with disabilities could become more skilled in their thinking and thereby learn more about their world.

(iv) Unit 4: Learning to talk:

Being able to communicate with others and socialise is very important for children to learn. This unit examines these skills in more detail and suggests ways in which they can be promoted.

(v) Unit 5: Learning to be independent:

Often parents feel they have to do everything for their disabled child. Each child has the capacity to do more for him or herself in terms of looking after his or her

own feeding, dressing and toileting. This unit explores ways in which these skills can be developed.

Units 2 - 5 are broken down into the following five sections:

(a) Assessment Sheets

A simple illustrated sheet which identifies the steps the child goes through in learning the various skills in each area. The volunteer and parent complete this simple assessment together.

(b) Teaching Ideas

An illustrated page of activities is offered for each of the various goals on the assessment sheet. If for example the child was just beginning to crawl then the volunteer would select the card; "Learning to move: Goal 4: child crawls". The volunteer and parent would then discuss ways in which this goal could be achieved by incorporating some of the suggestions from the card into the child's daily activities. The teaching ideas are also included in a separate manual for parents to provide stimulus material for the development of a teaching programme for the child.

(c) Video

A 20 minute video illustrates the theme of each unit.

(d) Video Record Sheet

To ensure that the participants do not simply view the video passively they are given a series of activities which encourage them to reflect on issues raised in the video. These activities also offer the opportunity to consider the assessment and teaching ideas in relation to the child with whom they are working.

(e) Review Sheets:

This provides a simple one page summary of the key points from the unit and the relevant video programme.

"Community Action on Disability"

This video course is intended as resource material for trainers conducting introductory courses in CBR. The philosophy of CBR has evolved over recent years beyond a narrow focus on disability alone. As such CBR workers need to be equipped with a broader range of skills if the wider goals of rehabilitation are to be achieved. These skills include methods to facilitate the involvement of families, ideas for influencing community attitudes and strategies for effectively integrating children with disabilities into mainstream school.

The course "Community Action on disability" consists of eight units each focusing on a different dimension of the CBR workers' role. Each unit consists of a 15 minute video programme, filmed in Guyana, along with suggestion for group activities for use during training sessions. The videos are complimented by a 60 page illustrated tutor's manual.

The "Community Action on Disability" package provides material for eight, three-hour training sessions. It is envisaged that the "Hopeful Steps" video series would complement this training package and therefore provide five further three-hour training sessions.

This video series has been prepared for use by trainers who may have relatively little experience in training others. It is hoped therefore that these video series can also provide the basis of a curriculum for the training of CBR workers.

The "Community Actin on Disability" video series provides:

special recorded video programmes which illustrate the various role that CBR workers could perform;

a series of learning activities for use with groups in training sessions;

Reference to further resource material to expand each unit;

suggested take home activities to perform after the training sessions as a way of consolidating the learning.

The aims of the "Community Actin on Disability" video course are to:

offer a curriculum for the training of the Home Visitors in CBR programmes and assist in the development of new cadres of workers;

promote an interactive model of learning - "learning by doing" rather than the passive receipt of material;

nurture the abilities of the CBR workers in the helping process;

facilitate a "multiplier effect" by providing resource material to allow less specialised personnel to conduct CBR training courses.

The following is a summary of the contents of the "Community Action on Disability" video course:

Unit 1: "Hopeful Steps": this programme provides an overview of the concept of CBR and the various roles CBR workers are asked to play.

Unit 2: "Community Workers": this programme examines the motivation of CBR workers, their role within the family and the wider community.

Unit 3: "identifying Handicaps": this offers an introduction to common disabilities and simple screening tests. This segment of the video is complemented by two illustrated manuals. The "identification of Disabilities" manual provides guidance on how to carry out the simple screening tests featured in the film. The "Introduction to Disabilities" manual offers a simple overview of the major disabilities that are likely to be encountered in the CBR field.

Unit 4: "Training Strategies": this offers a selection of appropriate teaching ideas and ways of helping the child progress to higher levels of development.

Unit 5: "Family Involvement": this programme analyses the demands made on families and offers suggestions for involving other family members in the process.

Unit 6: "Community Involvement". this explores common attitudes to people with disabilities and offers suggestions for influencing negative attitudes.

Unit 7: "Working with Teachers": this programme explores the challenge of integrating children with disabilities into mainstream school.

The "Hopeful Steps" programme is now working on a new package of materials for the mainstream school teacher to facilitate the creation of inclusive schools.

Unit 8: "Community Networks": this programme analyses the process of forming local committees to enhance the sense of ownership of the project.

"A New Tomorrow"

This video training course consists of eight, 12 minute programmes, filmed in the Rupununi region. The package is complemented by an illustrated teaching manual which offers teaching ideas.

This video package has been developed for CHWs and teachers who work with children in the Amerindian areas of the country. The objectives of this course are:

increase the participants understanding of child development;

learn how to assess what children can do already and what is the next appropriate skill to focus on developing;

select appropriate teaching ideas to help the child progress to higher levels of development;

learn how to make simple playthings out of readily available materials to stimulate the child's development.

The package is composed of 10 programmes each of 12-15 minute duration. The programmes are as follows:

- (a) Introduction to the region: this film provides an overview of the area and offers some insights into the traditional practices of the people of the region.
- (b) "Growing Up": focuses on the importance of movement in young children and offers suggestions of ways in which children can learn and practice the skills they need.
- (c) "Playing with babies": illustrates the ways in which babies learn by looking, touching and listening.
- (d) "Learning about objects": provides ways in which children could become more skilled in their thinking and thereby learn more about the world.
- (e) "Solving problems": offers ideas to help the child solve simple problems and thereby stimulate their capacity to think and reflect.
- (f) "Learning to talk": presents ways to promote communications skills.
- (g) "Introducing numbers": suggests methods of teaching basic mathematical skills.
- (h) "Early literacy skills": explains how a start can be made in developing literacy skills.
- (i) "Children sharing": this film suggests ways in which the role of siblings can be widened from simple care-taking activities to promoting the child's wider development.
- (j) "Making playthings": this film introduces a number of simple toys that can be made out of readily available materials.

As with the other packages, each unit contains an assessment sheet, a video record sheet and a review of key points.

This package of materials is complemented by two further publications. A manual on "Puppet Making" which has been very valuable in providing step by step instructions on how to make puppets, how to build a stage, make scenery, write scripts and manage a production. Puppet making workshops have now been held throughout the country. In turn, the CBR workers have presented over 40 shows in schools, cinemas, and public halls to a total of over 10,000 people as one contribution towards improving attitudes within the community to people with

disabilities. A video of their efforts was featured on national television as a result of sponsorship from a variety of local business from the community.

A second manual is "Easy to Make Toys" which features a series of toys that can be made, at little or no expense, from readily available materials.

The approach to the development of the training materials is premised on the idea that video offers an effective medium for instruction. When accompanied by exercises and activity sheets, it provides an interactive medium of learning which can be effective both in sharing information and in influencing attitudes. A bonus may be that the materials have been developed by a team of people so that the end product is genuinely regarded as a collaborative effort. Initial scepticism concerning the relevance and appropriateness of the medium of video in the context of developing countries can be countered by the requests from 42 countries for the various video programmes. The materials are now translated into Spanish, French and Arabic.

As we reflect on the evolution and development of the "Hopeful Steps" programme we can see the production of the video raining packages as a significant element. The materials were produced with a specific target audience in mind and reflect the culture of the intended consumers. The packages have been produced at low cost with equipment and expertise that is available within our own programme. The development of the materials has created a sense of solidarity on the part of professionals, the volunteers and the families as they worked together towards a common goal. The programmes have now been featured on a number of occasions on national television. In addition, through sales of videos, the participants are becoming aware of the international interest in their efforts.

Certain terms are ever present in the burgeoning CBR and development literature. The word "empowerment" is common in development literature. The word "empowerment" is common in development literature; often however the term is more spoken about than demonstrated. The production of the training materials has provided an avenue of service for people from very varied backgrounds and has offered a tangible means for demonstrating community action in the area of rehabilitation.

The term "community involvement" is also repeatedly exhorted in the literature and yet few effective examples are readily available of how it translates into practice. Many of us working in the field of CBR may be qualified in technical skills, however we are often naive in terms of social, political and organisational skills. We need to develop a wider role, helping the community examine their own problems and letting them realise they have within themselves the capacity to meet many of their needs.

It was understood however that to be effective as a tool for development, the innovation would need a well informed and well prepared community. From the

outset therefore time was invested in promoting local awareness of the programme. Extensive coverage in the newspapers, radio and local television did much to enhance the prestige of the CBR initiative and nurture the involvement of the community in the process.

This process of keeping the community informed of the developments within the project was nurtured through the publication of a quarterly CBR Newsletter, distributed to over 500 people throughout the country.

7. Work within an existing infrastructure

The early years of the programme relied on volunteer manpower from the rural communities. A number of the volunteers reported that the CBR experience had impacted on their lives, increasing their self confidence, self respect and feeling of personal significance. They realised that they could contribute something of real value to others. As Werner (1976) notes, if volunteers are taught a respectable range of skills, if they are challenged to think, to take initiative, they can become agents for change, awakening their neighbours and fellow villagers to their human potential and ultimately their human rights. More research is needed into the qualities needed to be effective as a Home Visitor. In our experience (O'Toole, 1991) there was no significant correlation between the educational background, income, or occupation of the Home Visitor and their overall effectiveness. Volunteers from the community can clearly be effective in the role of Home Visitor. More imagination is now called for in terms of the deployment and recruitment of community based volunteers, within their time constraints, linked on a person to person basis.

Whilst we plan to continue our use of volunteers we are also aware of the need to work more effectively within the existing government infrastructure. CBR has been presented, in theory, as an inter-disciplinary approach. In practice the majority of innovations have been conceived within the health system. However the potential contribution of the most extensive rural service, the school system, has yet to be fully explored. Of the 51 countries responding to the international study, "Consultation on Special Education" (UNESCO, 1988) 34 acknowledge that they were providing for no more than 1% of those in need. Just as there have been radical changes within the health service in the movement towards Primary Health Care, so too there needs to be a fundamental change in the philosophy of provision for children with special needs within the education system.

A significant contribution is being made in this respect by the UNESCO project, "Special Needs in the Classroom", (Ainscow, 1993) which responds to the challenge of accommodating diversity among pupils within ordinary schools. Through this initiative UNESCO aims to develop materials and approaches for use in teacher training. This has helped to conceptualise the special needs task as a process of general school improvement and develop the teachers' capacities. The UNESCO materials help to facilitate the process of integrating children with special needs into ordinary, mainstream schools.

As yet however there is little international experience to draw on in terms of CBR provision within an educational perspective. The Kenyan (Arnold, 1986) and Zimbabwe (Mariga, 1986) experiences have been with special schools becoming involved in outreach work. Experience within the mainstream school system is far more limited. The pilot experience in Guyana (O'Toole, 1991) of working with nursery teachers recorded only modest success. The challenge therefore is how to incorporate CBR into an existing government infrastructure, in order to expand coverage in an economically viable manner.

The challenge from our pilot project was how to move beyond providing a service for 40 to 50 children and to begin to formulate a Plan of Action that could respond, in some form, to all of the needs identified within a region. This has proved a major challenge in the expansion phase of the "Hopeful Steps" project.

A number of innovations are underway in Guyana in collaboration with the Ministry of Education, these include:

nursery school teachers are being trained in CBR in one region of Guyana, Essequibo Coast, as part of their on-going workshop sessions. The Ministry also allows the teachers one session per week to work in the homes of children with disabilities.

in two regions, Berbice and ECD, the original CBR volunteers have now undergone an additional 20 hours of training and formed themselves into teams of five. They are now in the process of presenting a series of 10-hour modules on CBR to teacher, health workers and parents. Over 160 teachers have now completed the 10-hour course.

The University of Guyana has requested the CBR team to offer a 45 hour module on CBR which will be a core course for all teachers in training. They have also requested the CBR team to re-introduce the two-year Certificate in Special Education programme at the University.

a draft copy of the new Education Plan for Guyana from the Minister of Education features a proposed partnership with the CBR programme.

a collaboration with Mount Royal College in Canada will focus on training practising teachers in the development of a more inclusive school philosophy.

Whilst the intention in many parts of the World is to meet special educational needs in mainstream schools (Piji and Meijer, 1991), the reality is often very different, with a high proportion of children with special needs being excluded from mainstream education (Ainscow, 1991; Fulcher, 1989). The rhetoric and the slogans now call for an inclusive model of education. For this to be viable we need to examine what support the mainstream class teacher can be given in terms of personnel, training and special resources. Work now needs to be done on how the entire staff of a school could be prepared for the task of including children with

special needs into the mainstream school. We need to move beyond the skill and initiative of individual teachers and see how the integration process could be regarded as an integral part of a broad-based programme. The UNESCO pack (Ainscow, 1993) offers some keys as to how this may be achieved. CBR and Inclusive Education are complementary philosophies and the "Hopeful Steps" programme may present an early attempt at effectively integrating these two movements.

Of all the resources available, the other children in the school offer the greatest potential for real change in the lives of disabled children. Activities within the Child to Child framework have illustrated the value of simple and practical approaches for improving the lives of children. Within the "Hopeful Steps" programme thought is now being invested into how to develop this rich potential for peer tutoring.

The initiatives in Guyana within the school infrastructure are mirrored in the health services. The original CBR volunteers are now in the process of collaborating with the Regional Health Worker. A module on CBR has been accepted for inclusion in the training of doctors at the University of Guyana. A module for nurses is under review.

A programme that therefore began on a modest scale with volunteers has now expanded and is forging meaningful links with the existing infrastructure.

8. Need for on-going training and support

The "Hopeful Steps" programme appreciates the need for on-going support, even once the initial 120 hours of training are complete. The pilot project phase clearly illustrated the danger of thinking that the placement of a disabled child into mainstream school was enough and highlighted that this was only the beginning of the process and revealed the need for on-going support of both the teachers and the other children in the school.

"Hopeful Steps" is also encouraging a process of reflection as to what constitutes effective training. A significant element no doubt is influencing the attitudes and expectations of the families and nurturing the belief that the child is capable of learning and worth helping. If attitude change is indeed a key variable, this significantly determines the type of training programme suitable for the Home Visitors.

Adequate and appropriate training is a crucial first step. Support and supervision are equally essential. It is clear that a key to improved services depends on a more innovative approach to manpower utilisation and preparation. Within the programme we have endeavoured to provide a supportive model of supervision where the goal of the support is to promote the confidence of the Home Visitor and develop the respect of the family for the volunteers. The role of the "supervisor" is to help the volunteers, the disabled people and their families to

identify their own needs and then to assist them in formulating creative responses to the challenges they face. In response to this nurturing model the self confidence and self worth of participants grows as they realise they can contribute something of value to others. Such people can in turn become agents for change, awakening people to their potential and to their human rights.

9. "Trainer of Trainers"

The programme therefore was based purely on volunteer manpower for the Home Visitors for the first years of the programme. Their original 120-hour training programme grew to over 150-hours as they requested additional elements to enhance their repertoire of skills. As mentioned above however it was appreciated that for the programme to continue to grow and expand a more effective partnership with the existing infrastructure was necessary.

Of the original 96 volunteers who were trained in Berbice, ECD and Essequibo Coast, 73 opted to undertake an extra 20 hour module to prepare them for the role of trainers of others. Following this additional training the "volunteers" formed themselves into teams of 4 or 5 and then offered a series of 10-hour modules on CBR for teachers, parents and health workers in their regions. Initially the plan was that the CBR "supervisors" would take charge of these 10 hour modules and the volunteer teams would be used as resource persons to supplement the inputs of the more experienced trainers. However it soon became apparent that the teams had invested considerable time and resources in this process and that they were quite capable of presenting the 10-hour modules on their own. In consultation with our funders, AIFO, these volunteer teams were given a modest stipend for this training function. This was the first time in three years of voluntary work that they were receiving any payment for their services.

The CBR co-ordinators prepared a training manual for these 10-hour modules. The manual offered a very detailed overview of each of the sessions. The illustration below gives an example of the guidance offered.

The newly formed teams began by using the guides as a virtual script, however, as their confidence grew they introduced other material into the sessions. In most cases however the video series, "Community Action on Disability" provides a valuable skeleton on which to build the module.

The considerable time invested in the development of training materials and human resources is now paying dividends. Two new IACE CBR training courses are now being prepared in ECD and Berbice. Each course is for 120 hours. The courses are managed and presented by resource people who have been trained through the early years of the CBR programme. The National CBR co-ordinators play no more than a monitoring role in these courses. Once again the various materials that have been produced on the programme form the backbone of the training course.

The element of "Training of Trainers", will be further developed this August (1994) when the first in a series of Annual Trainer of Trainers courses is run for a one month period. Approximately 30 people are expected to attend. This will include 10 people from the interior and 10 from other parts of the Caribbean. The WHO is in the process of pioneering CBR in other territories in the Caribbean and plans to send a team from three pilot countries, St Lucia, Trinidad and Tobago and the Bahamas, to take part in the one-month workshop. Discussions are in process between the University of Guyana and a leading European University to make this one-month course into a regional CBR training base for the Caribbean.

The developments in the field of the "Training of Trainers" has been most significant as it offers pointers towards how the programme can become sustainable. It has provided a key path of service for volunteers who have remained fiercely loyal to the programme far beyond their initial 2-year commitment. The initial volunteers are emerging as articulate role models for the new volunteers that enter the programme.

10. Relationship between CBR and more traditional forms of provision

In the early days of CBR the approach was sometimes viewed as an alternative to the institutional model of rehabilitation. For many years, the literature on CBR has tended to be emotive. Now the two approaches are more wisely regarded as complementary. Institutions offer accumulated experience, opportunities for in-service training, scope for innovations, and much needed family relief. A key element of the "Hopeful Steps" programme has been the development of community based resource centres run by the Regional CBR Committees and which provide a valuable training base for both parents and professionals. Seven of these centres have now been established in the country. They provide a link between the community worker and the professionals and between the disciplines of health and education. The sustainability and technical quality of the innovation may well depend on this intermediate link. Paradoxically, those countries where services are only now being developed may offer the environment for the emergence of a more collaborative pattern of services, drawing on the strengths of both CBR and the merits of more transitional approaches.

11. Effectiveness of the intervention

Parents obviously have very different degrees of capability, time and energy in dealing with their children. There will be those for whom a parental involvement role is unrealistic because of unemployment, poverty and ingrained negative attitudes. However there are many others, from comparable backgrounds, who are eager to become involved once given the necessary support, information and guidance. The challenge therefore is not to add one more demand on an already overburdened family but to assist in improving the quality of the interaction

between parents and children in the time which is available. At the same time however we should surely respect the rights of families in choosing whether or not they feel that participation in the CBR approach is of relevance to their own experience. There is surely no universal prescription for appropriate involvement; it is a question of striking a balance between encouraging parents to take advantage of the opportunities the CBR programme offers, without however putting them under pressure to conform to other people's expectations.

A detailed evaluation of the "Hopeful Steps" programme has recently been completed by a team of independent evaluators. The interested reader is referred to this document (Miles, Pierre and Gautron, 1994). These researchers recorded the emotional and psychological support the parents claimed to receive from the home Visitors. The value of CBR may lie as much in the relationship between service agents and family members as in the specifics of the practical intervention that they propose. Parents report feeling more relaxed, less depressed, happier, more confident and more aware of the child's potential as a result of the CBR programme. Their goals became more long term and more realistic. Aspirations changed from wanting the child to be "normal" to seeking help in specific problem areas.

Does CBR work? If so how? For who is the approach most effective? How could CBR work better? What types of parents, with what types of children, benefit from which aspects of a CBR programme? Such questions are not easy to answer, in part because of a lack of suitable methods for evaluating "success". In the evaluation of Project Projimo (Werner, 1986) 60% of the disabled children had clearly benefited from the programme. Many of the remaining 40% had also progressed, but in more subtle ways. In evaluating CBR programmes, there is a danger in focusing only on what can be readily measured, while intangible feelings of increased hope, improved human relationships, and self worth are often overlooked. We still lack the tools to assess social, affective and interpersonal change. We need to rethink the concept of "success" and develop better methods for evaluating the quality of life of the disabled child and their family. It is surely the process of intervention that we need to understand, and not just the results.

12. Constraints

What are some of the constraints under which the "Hopeful Steps" programme operates? It is all too easy, with the benefit of hindsight, to paint a coherent path of evolution to the project.

The economic reality of recent years in Guyana has encouraged professionals to look to North America for more lucrative assignments. At the time of writing there are only three practising physiotherapists in government service. There are no speech or occupational therapists. There are no psychological services. There are only a handful of teachers with qualifications in Special Education. Working within the existing infrastructure is therefore a challenging prospect.

The prevailing economic climate gives rehabilitation a low priority on the national agenda. Rehabilitation facilities and referral services are almost non-existent in rural areas. The economic challenges for survival have also taken their toll on the community of disabled people. The organisations of disabled people have yet to appreciate the considerable potential they possess for effecting meaningful change. For a number of years their energies have been deflected by an unsuccessful maj . or income generation project.

The "Hopeful Steps" project is officially under the auspices of the National Rehabilitation Committee, an umbrella group of the various disability groups. The Committee however is not functioning.

The pilot project revealed a number of challenges. One of the "successes" of this phase of the project was the creation of a community-run Resource Unit in one of the rural areas. The Unit, housed in a building loaned by the local Hindu community and renovated by local businessmen, began with a high degree of community involvement. It was initially managed by a local village health committee with volunteer teachers from the community. As the unit grew it gained the support of the Ministry of Education who gave three teachers and the patronage of an expatriate women's group. In the process however the community lost ownership of the innovation and external agents became the project spokes people. An interesting "success" of the pilot project was the development of the regional CBR committee. Their first goal was the establishment of a centre for their children. The initial centre was community managed. Now, as visions widen, the desire, on the part of some, is to build a larger institution. An irony of empowerment can of course be that the demands of the villagers are not those we may in "our wisdom" see as most appropriate.

13. Key features of the "Hopeful Steps" programme

The two co-ordinators of the programme, a physiotherapist and an educational psychologist, had strong ties within both the fields of education and health. One is Guyanese, the other has lived in Guyana for 16 years. Both have worked as consultants in the field of CBR for a variety of UN agencies and NGOs.

"Hopeful Steps" began as a small pilot project to explore the merits and the potential of the approach. The programme was not designed to prove the efficacy of this approach as opposed to another. The coordinators embraced the philosophy in a genuinely questioning fashion.

From the beginning, the hope was to develop a management style which would allow the lofty concepts of community participation and empowerment to be facilitated. There was no predetermined script for the project, many of the most creative features of the programme emerged from the participants over the course of time. This openness is perhaps best seen in the Rupununi where a modest beginning in the area of early stimulation has now emerged into an integrated development programme involving several hundred people.

A strength of the programme has been the partnerships established with a number of agencies. Over the course of the project a strong partnership has now been established with both the Ministry of Education and the Ministry of Health. The partnership is at both the central and regional level. Other partnerships have been formed in the Rupununi with, the Bahai's development agency, GOSED, with SIMAP in the area of water and sanitation, with ICCA on agricultural education and UNICEF for primary health care.

Through out the programme we have been fortunate to benefit from the wisdom and experience of a series of consultants which of whom contributed significantly. This includes Dr McConkey in the area of the development of materials, the Merritts on puppet making, Brigitte Goutron on methods of evaluation, Dr Pupulin of WHO on management, Dr Deepak and Mr Trevisan of AIFO on methods of expansion and consolidation and Dr Neumann of Health for Humanity on community development.

The pilot project provided the basis of the writer's Phd from the Institute of Education, University of London, Professor Weddell and Dr Norwich provided key insights into the whole philosophy of innovation in education. The analysis demanded of a research programme helped to provide an appropriate questioning environment in which to examine key elements of the process of CBR.

A key feature of the programme has been a true partnership with our funders, Amici di Raoul Follereau. The partnership is based on mutual respect and the desire to achieve a common goal. They have been a constant source of encouragement and support throughout the period.

As we look towards the future we consider ways to consolidate the gains which have been won and seek realistic ways in which the efforts can be expanded. A combination of a number of forces including: the spirit of the Guyanese people, the support of the government and its ministries at the highest level, the success of the training of trainers model, a growing partnership with the philosophy of inclusive schools, the emergence of a clear management structure make us optimistic regarding the gradual evolution of a National CBR programme. Only the next few years will reveal whether this is a gallous hope or a realistic aspiration.

14. Conclusion

Few CBR programmes have moved beyond small scale projects to large scale innovations. As yet few governments have made any significant commitments and investments to establish national CBR services. Most CBR programmes are regarded as "additional programmes". Moreover attempts made within existing infrastructures have often become little more than a minor facet of existing service provision to which no particular priority is given.

However despite these limitations, in its best examples, CBR has demonstrated what can be achieved, at low cost; creating not only better opportunities for people with disabilities, but a sense of hope on the part of families that they can play a significant role in the development process. Communities have become more aware of disabled people in their midst and, at times, have played a major role in planning ways to meet their needs.

CBR offers a new approach to rehabilitation to policy makers, professionals, planners and community leaders and to people with disabilities themselves.

Looking back at first decade of CBR progress has been slow and uneven. It is significant, however, that some of the most creative examples of parent-professional collaboration have come from some of the poorest nations. It may be that the developed world should look south for innovative approaches to working with disabled people. As we move closer to a new century it becomes evident that the challenge of disability has yet to be met. It is however quite, clear that traditional approaches can do no more than scratch the surface. A radical reappraisal of our respective roles in rehabilitation and education of people with disabilities is required, CBR offers such a role, If however we lack the vision and courage to tread new paths, then the danger is that more conferences will be held, more declarations will be written, more slogans devised and still 98% of the disabled population will remain totally unaware of the international concern being voiced on their behalf.

ACKNOWLEDGEMENTS

We gratefully acknowledge appreciation to the funders of this project: the European Community and Amici di Raoul Follereau. Additional financial assistance has been provided by the Canadian International Development Agency and UNICEF. The project is co-ordinated by the National Rehabilitation Committee of Guyana. The training in Guyana is facilitated by the Institute of Adult and Continuing Education of the University of Guyana.

COMMUNITY BASED REHABILITATION:

THE MAURITANIA EXPERIENCE

Tambo Camara

AIFO consultant

PEOPLE WITH DISABILITIES IN MAURITANIA

The issues surrounding disability in Mauritania can be considered in three distinct phases each related to the social and economic development the country.

FROM THE COLONIAL PERIOD TO TEN YEARS AFTER INDEPENDENCE (1970)

Urban centres were not very developed. The majority of the population lived in rural areas carrying out cattle-breeding activities and subsistence agriculture.

The social system was one of hierarchic classes each with its own place and role. Within this social system people with disabilities were not seen as a specific issue and in most cases they were integrated into their community without any problems.

In fact, in traditional society, there wasn't a direct relationship between individual production and individual consumption both being totally organised at family, camp or village level.

Traditionally, people with disabilities were integrated within this collective production / consumption system.

In this traditional structure there were different activities to be carried out and within those activities there were always useful, necessary and feasible activities for people with disabilities, for example: keeping an eye on the village or on the children while the others are working in the fields, looking after their cattle or making exchanges.

Even though people with disabilities were exempted from working they were never excluded from collective consumption or decision making unless they were affected by some mental disabilities.

PEOPLE WITH DISABILITIES IN THE SEVENTIES

In the Seventies, Mauritania was entering a new period, a period of drought and increasing desertification. The cattle were decimated, transhumance, very important to livestock breeders, slowly disappeared and many lands under cultivation were abandoned.

Desolation was everywhere, famine caused malnutrition and infectious diseases increased. In this very serious situation, rural populations had very few alternatives. They could either leave or wait for emergency aids planned by the Government to help affected populations.

Rural areas were slowly abandoned and rural populations migrated to towns or abroad. At first young people left and then all the other members of the rural community, all looking for new resources to survive. Women, old people, children and people with disabilities were left behind or were the last to leave.

Mauritania passed through an immense rural exodus, unequalled by any other in the Sahel region.

Since then, the economic burden of people without economic self-sufficiency has become a problem, and people with disabilities are amongst this group.

In the above-mentioned traditionally structured society the problem of unproductive people was absorbed by traditional clan solidarity; in the new social and economic context resulting from drought, it has changed visibly. It resulted in the disappearance of the social rules which had assured people with disabilities a certain integration into the community.

Furthermore, all the pressures and tensions previously managed by traditional society rose to the surface under the form of conflicts and dissolution of social rules leading to the exploitation of "the poor" by "the rich". Traditional Élités whose power and prestige was based on traditional values were gradually replaced by Élités whose power derived from their financial standing, land properties, money, etc., and often from their relationship with economic systems outside the traditional local economic system. These new Élités didn't follow the traditional habit of taking charge of people with disabilities.

As a result, disabled people became a burden and a disadvantaged social group whose survival depended on its own capacity to make a living.

Due to lack of professional qualifications and referral support they simply became assisted people, mainly beggars. In a period of social and economic crisis this had the blessing of the ruling class, whose priority was to satisfy the needs of the majority, relegating disabled people and their families to the class of under-privileged.

On 29th June 1976 the "Union Nationale des Handicapés Physiques et Mentaux - UNHPM (National Union of People with physical and mental disabilities) was founded, a non-governmental organization (NGO) of disabled people.

ORIGINS OF UNHPM

From its foundation to the implementation of Community Based Rehabilitation (CBR) programme in Mauritania

In response to the pressures caused by the social and economic upheaval in the country, a group of people with disabilities decided to find a human and lasting solution to the issue of disabled people in Mauritania.

Disabled people were being totally ignored by national development programmes and the barriers caused by the impairment itself was preventing them from taking part in the development process. Furthermore, disabled people had no access to ordinary vocational training structures and were left feeling useless, frustrated and without hope.

The Ministry of Social Affairs was charged to manage this issue. There were no means or special programmes available merely the traditional relief concept which only favoured a few privileged disabled people .

When natural resources are appearing more and more insufficient for the demand of both industrialized countries and poor countries, it makes sense to utilize all human resources in a better way. Disabled people, no matter what their physical and/or mental disabilities, are human resources to be utilized as per their potential and capabilities.

Unfortunately, in this new Mauritania, people with disabilities are considered unproductive, capable only of begging and totally dependant on others. Yet human beings are at the beginning and at the end of all development systems: to bring back human dignity to people with disabilities they shouldn't be considered as an isolated issue but should be considered in their overall dimension, at national and even world-wide level.

In practice, people with disabilities are abandoned to their families in a social background full of prejudices and unfavourable stereotypes. And the issues of disability are still unknown to a large part of the public, despite the great development of technology and communications in particular.

Disabled people form an important social group. Despite the many differences between them (due to type of impairment and/or national sensibility), they are united in their need of a world made for and with each one of them.

With these considerations as their starting point, the group decided to found a legally constituted national organization of disabled people in order that they might have a say in matters concerning them and to make society understand and help people with disabilities as human beings and citizens.

Through the support of the Ministry of Social Affairs, the "Union Nationale des Handicapés Physiques et Mentaux" (UNHPM) - expression of the will of disabled people of Mauritania, was officially recognized on 29th June 1976 as an NGO according to legal statute no.64098 as modified.

UNHPM defined its philosophy and objectives by formulating the following plan of action.

UNHPM STRATEGY

UNHPM strategy is based on the principle of self-defence and self-representation to inform about disability issues and to implement adequate strategies to solve related problems and ensure a full social and economic integration of people with disabilities.

OBJECTIVE

To help the Government and the community create better conditions for the progressive and full integration of people with disabilities in all aspects of life.

To reach this goal UNHPM should carry out the following activities:

Heighten public awareness nationally, including the awareness of disabled people and their families, to the issue of disability and the need to find adequate solutions to the aspirations of disabled people.

Gather together all categories of disabled people through a common sense of solidarity and set up training structures.

Let people appreciate the many capabilities of disabled people through the establishment of small training and employment projects.

Solicit relevant authorities to carry out a logical policy of global rehabilitation, aimed at preparing disabled people to benefit from human rights and perform their duty as equal citizens.

STRUCTURAL SET UP

In 1985, during UNHPM's national meeting, the following statutory declarations were adopted:

At national level UNHPM consists of:

National Congress: the highest authority which plans the general activities of the organization. It can decide about the dissolution of the organization according to the laws, it appoints the members of the National Bureau, it approves plans of action, etc.

National Board: gives suggestions on programmes and projects, at the request of the National Bureau.

National Bureau: is elected by the Congress and is in charge of the implementation of its various plans of action. It can be helped in this task by some technical committees and its Standing committee which is based in Nouakchott.

At peripheral level UNHPM is represented by:

A Regional Union at each Wilaya (region) level whose main authority is the Regional Assembly which appoints the Regional Bureau.

A District Union at each Moughataa (district) level, with a District Assembly as main authority and a District Bureau.

Its branches can reach urban and rural centres, according to the number of disabled people living in those areas.

PLAN OF ACTION

The proposed plan of action is aimed at transforming the unfavourable situation of people with disabilities into a situation more responsive to the social and economic needs of its members. It has three main objectives:

Strengthening of the organization;

Increasing the participation of disabled people in the activities of the community;

Attaining human rights for people with disabilities.

During the last 15 years, UNHPM strategies have always been aimed at an improvement in the quality of life of people with disabilities. The following are the key elements in the different plans of action:

Information and heightened public awareness;

Development of the organization;

Social and economic development in its components;

Education and training;

Income generating activities;

Co-operation.

UNHPM global strategy is not to act as the substitute of the Government or of the community in the implementation of activities aimed at resolving issues concerning disabled people, but on the contrary, to educate the community and its authorities about their roles and responsibilities in this respect.

In this context, and in compliance with the above-mentioned objectives, the following activities have been carried out:

ACTIVITIES CARRIED OUT

Early activities can be considered in three phases leading up to the late eighties when the CBR programme was started.

First phase: activities were mainly focused on the development of the organization and on information activities/increasing public awareness.

a) The organization of development is the process that gives orderly structure to an association and enables it to implement its objectives. According to these concepts - planning, organization, co-ordination, monitoring - UNHPM carried out the following activities:

Opened a permanent office in Nouakchott;

Decentralized the association by forming regional unions in the 12 regions of the country;

Set up a national committee of disabled women;

Organized, periodically, general assemblies and meetings;

Employed permanent staff etc.

b) Information activities/increasing public awareness:

Information was directed in particular towards disabled people and their families, the community, national/community leaders and the donors;

Awareness raising activities were organized in order to enhance a change of attitudes towards integration and the role of disabled people, taking into consideration their physical and intellectual capabilities;

An additional objective was to reach a change in the negative attitudes of the community towards disabled people and to promote the start of new social relationships, mutual help and solidarity, on the basis of mutual understanding. This campaign was carried out both, through the mass media and the organization of meetings, conferences, committees, etc.

Second phase:

a) Educational activities:

i) During this phase many social and economic development activities were carried out stressing the capabilities of disabled people. Initially these activities were aimed at families with disabled children, helping them to solve school-related problems or prosthesis-related problems;

ii) In co-operation with the Government, two special education centres were established; the former Centre for Braille Teaching and Rehabilitation of the Blind (CEBRA) which became the National Institute for the Blind (INAV), and the Teaching Centre for the Deaf.

iii) The first national workshop which started a special integrated education in Mauritania was also organized .

b) Training activities: three kinds of activity were carried out:

i) Integration of disabled people into the general training system;

ii) Training centres established and managed by UNHPM:

training centre for French and Arab speaking secretaries;

training centre for sewing, embroidery and tailoring;

technical high school (computer and book-keeping).

iii) Short training courses:

training workshops for UNHPM leaders on association management and on planning, follow-up and evaluation of the development projects.

training workshops for craftsmen on the production and sale of cooking stoves.

workshop on horticulture and co-operative management.

c) Employment related activities:

i) Help for disabled people seeking more work opportunities through practical refresher courses.

ii) Implementation of community projects:

cultivation of lands in Aioun, Boghé, Sélibaby, Kaédi.

co-operatives for sewing activities in Nouakchott, Kaédi.

co-operatives for the production of cooking stoves in Nouakchott.

iii) Aid to small projects for income generating activities.

All these activities were carried out through the support of the "Direction des Affaires et de la Solidarité Nationale" and most particularly, through the financial support and co-operation of international organizations such as: Godwill Industries of America, PACT, CNFLRH, Oxfam U.K., USA Embassy in Nouakchott, Canadian Embassy in Dakar, USAID for Africa, AGFUND, French Association Raoul Follereau, etc.

Third phase: in this phase the Government should have undertaken its role and responsibilities to integrate disabled people and protect their fundamental rights by implementing the following process:

Declaration of a national policy for disabled people;

Formulation and adoption of a national plan of action;

Formulation and adoption of legislative texts to promote and protect disabled people;

Setting up of a national department for disabled people; or, a national co-ordinating standing committee;

Set up a national fund to support projects in favour of disabled people,

However, apart from the National Orthopaedic and Rehabilitation Centre, the support to the budget of training schools and some specific activities - nothing really significant and lasting was carried out.

CONCLUSIONS FOR A NEW STRATEGY

Looking at the results obtained at the end of so many years of activity it is nice to say or to hear that we've come a long way since UNHPM first started! What seemed a dream at the beginning is now a reality: at school blind children can read, write and cope with the work in a regular grade-one class; deaf and mute children can communicate in writing with their parents and friends; disabled people can access vocational training and employment opportunities.

But what have we really achieved? Certainly, the fact of having provided new opportunities for disabled people and their parents and to have helped give them hope for the future are important achievements. But we have also led leaders and observers to raise some questions:

How many disabled people benefit from this miracle - is it only ten or so?

How much did it cost - isn't it almost impossible to estimate?

How many have been left out - does it amount to tens of thousands?

What strategy has been adopted for a better integration of disabled people - have those living in rural areas been left out?

We have had to admit to ourselves that we still have a long way to go to identify the specific needs and skills of disabled people and their organizations and arrive at a time when our Government will be politically engaged in multi sectoral and community programmes. In fact, despite UNHPM efforts and the valuable support of our national and foreign partners, disabled people have never been a priority in the development programmes of the Government of Mauritania. Government activity was carried out only via the Department for Social Affairs

(MSAS) which, due to lack of funds and manpower, took charge only of traditional assistance activities and a few UNHPM proposals.

In fact, of the total 100,000 disabled people in the country, only 300 or 400 benefited from the activities of the Department of Social Affairs and UNHPM, carried out over a period of more than ten years.

This has led us to change our strategies for implementing the involvement of our Government in favour of disabled people and, especially, to develop activities for a greater number particularly those living in rural areas.

COMMUNITY-BASED REHABILITATION IN MAURITANIA

In Mauritania in the early eighties, the traditional concept of institution-based rehabilitation was prevalent through the National Institute for Orthopaedics. Functional-rehabilitation subordinated services for disabled people to institutions which did not have enough trained staff. To this unfavourable situation should be added:

The majority of disabled people are very poor and without any possibility of access to the expensive services provided by the National Institute.

In the National Institute only functional rehabilitation activities are carried out.

Increasing pressure from disabled people and their national organization, made MSAS more conscious of the issues concerning disabled people, and the need to address them adequately.

It was in this context that Dr. Helander, then head of Rehabilitation Unit of WHO and promoter of the community-based rehabilitation method, was invited to visit Mauritania.

Following his visits to Nouakchott and other areas of the country he had the opportunity to verify both the high number of disabled children needing rehabilitation; and the presence of UNHPM in all the regions of the country and its co-operation with national and regional authorities;

Reaching the conclusion that CBR activities could be a valuable alternative new rehabilitation approach for disabled people in Mauritania, Dr. Helander convinced all national authorities and UNHPM to initiate CBR activity in Mauritania. As a result UNHPM and WHO were requested to prepare a joint programme. One year later, in February 1989, a CBR programme was initiated in Mauritania, first through the intervention of CNFLRH (French Liaison Committee for the Rehabilitation of Disabled People) and then through the support of the Associazione Italiana Amici di Raoul Follereau (AIFO) and the technical supervision of WHO.

OBJECTIVES OF THE CBR PROGRAMME IN MAURITANIA

- i) To initiate a CBR programme and to adapt it to local needs.
- ii) To implement the CBR programme in Mauritania by the year 2000 in order to cover the whole country through community involvement.
- iii) To ensure rehabilitation services for disabled people, such as:

Daily living activities (communication and mobility, etc.)

School and literacy activities

Employment and/or income generating activities for a better integration of disabled people into active life.

INITIAL PHASE OF CBR PROGRAMME

During the initial phase of the CBR programme in Mauritania, all possibilities for its implementation were carefully evaluated.

Partners

Local partners and foreign partners should complement each other in what they represent, in the activities they carry out and in the implementation of the programme. They were:

a) At national level :

The Government of Mauritania represented by the Ministry of Health and the Ministry for Social Affairs, promoter and joint-administrator of the programme through the Department for Social Affairs;

The "Union Nationale des Handicapées Physiques et Mentales (UNHPM), joint-administrator of the programme;

Local communities, beneficiaries and basic administrators of the project.

b) At international level:

The "Associazione Italiana Amici di Raoul Follereau" (AIFO), a Non Governmental Organisation for international health co-operation took the role of supporter and funder of the programme;

The World Health Organization (WHO) undertook to carry out the monitoring and provide technical support to the project.

Constitutional framework

Agreement protocols and financial regulations were signed by the partners and an administrative structure was set up, managed by an organizing committee.

GENERAL PRINCIPLES AND ACTIVITIES CARRIED OUT

General principles: intervention is based upon the following principles:

Community Based Rehabilitation (CBR) is an alternative approach to meet the needs of disabled people;

CBR is a social-based and multi sectoral approach;

Disabled people have the main role in CBR which is a programme aiming at the strengthening of disabled people organizations. CBR projects should share responsibilities with community leaders and other authorities;

CBR projects implement the re-development of traditional community systems, integrating the community's more disadvantaged members - disabled people;

The transfer of competence to the community in order to improve the quality of services;

The involvement of disabled people in decision-making processes and the promotion of opportunities where they can take an active role in their own rehabilitation.

Activities: starting from February 1989 the following activities have been carried out:

First phase (early activities for launching the CBR programme):

The objectives of early starting phases of CBR projects were to conduct:

- i) Training courses on rehabilitation techniques for personnel in order to initiate CBR activities in the selected areas of the programme, through the WHO manual.
- ii) Awareness campaigns on CBR for local authorities and the community.

These were carried out in 4 areas (Nouakchott, Aleg, Boghé and Kaédi) with the help of an expatriate consultant. In each area one person was identified and trained to become the CBR supervisor, except for Nouakchott where two supervisors were trained.

Essentially two kinds of activities were carried out:

i) Information activities and increasing public awareness, through national mass-media ("Chaab" newspaper, radio, TV) visits and meetings, conferences, etc.

ii) Training activities, through experts in different sectors (medical, social, administrative, educational, carpentry, etc.)

In the initial phase, as the CBR programme took its first steps, the general trend was towards enthusiasm. Disabled people and their families, who had till then been largely overlooked, started to hope and the community looked for the hidden aspects of the programme. A programme co-ordinator was identified. Surveys were carried out and 93 disabled people were registered. In Boghé and Aleg some people joined CBR committees. Volunteers were selected and trained and income-generating activities for disabled people were identified. At the end of this phase (end of 1989), the number of registered disabled people had gone up to 112.

In this early phase, the CBR programme also collaborated with the leprosy programme, helping in the detection of 60 cases of leprosy. An evaluation of this phase was carried out in collaboration with WHO, with very positive results.

Second phase (1990):

The second year of the CBR programme focused on consolidation of activities, with the following objectives:

Strengthening of the CBR programme

Continuation of campaigns to increase awareness in the community.

Involvement of the authorities in CBR activities.

Provision of additional training and specialized skills for local supervisors.

In the second phase the following activities were carried out:

A technical commission prepared a plan, aiming at the consolidation of activities started in the first phase. Thus CBR activities were extended around the pilot areas where the project was initially started. This was done by creating local committees, by involving community volunteers, and by carrying out public awareness campaigns.

At a national level, efforts were made to involve other NGOs and agencies present in the country, to make them aware about the issues surrounding disability issues and to ask for their collaboration in the CBR programme.

New volunteers were recruited into the programme and support was provided to all the CBR volunteers through field visits and supervision. At the end of 1990, the programme covered all of Aleg, Boghé and Kaédi.

Activities for public awareness were strengthened through advertisements and interviews in newspapers, magazines, radio and TV broadcasts. Specific awareness campaigns were directed at teachers. These promoted the integration of disabled children in local schools.

Different income-generating activities were started such as, vegetable gardens, small trades, tailoring, etc. In collaboration with local craftsmen in Kaédi and Boghé, for example shoe-makers, simple orthopaedic aids were produced.

In spite of all these positive achievements, events out of our control influenced the project. There was massive repatriation of Mauritanian refugees from Senegal and among them there were many disabled people. The project responded with extra efforts to provide care for the disabled refugees under an emergency programme.

During this phase, a second evaluation of the CBR programme was carried out jointly by WHO-AIFO. As a result of this, it was decided to try to increase the involvement of DRASS and to improve the quality of the programme in Aleg by providing a social worker to support the supervisor. At the same time, supplementary training was suggested for the team in Nouakchott.

At the end of 1990, the CBR programme involved 44 community volunteers and 334 disabled people in the 4 project areas and refugee camps.

At that time 2 different factors were developing: one was negative - the increasing interference of Department of Social Affairs in project activities; and the other was positive - the proposal to use this project as a training-base for Francophone Africa.

Third phase (1991 - 1992):

The third phase starting in 1991, had the objective of extending the CBR programme to new areas in the north and east of the country; and consolidating the activities already started in the four areas in the south of Mauritania.

This phase started with the difficulties between DRASS and the expatriate consultant, who was forced to cut short her visit in the country and was not allowed to visit the project areas. Thus for the whole of 1991, the support of an external consultant was missing. In spite of this, the project managed to achieve many positive results:

Training courses for CBR supervisors - three interregional training seminars were organized, two of which were in the new areas of Brakna and ZouÉratt.

New CBR activities were started in Brakna and Gorgol regions.

Intermediate level co-ordinating personnel (between national co-ordinator and regional programme level) were identified and trained. These were to help in new areas where CBR projects were being started.

A national seminar on the educational needs of children with disability was held in collaboration with the Ministry of Education.

In collaboration with the national psychiatrist referral services, training courses were held in the regions of Brakna and Gorgol for people with mental disabilities.

As a result of all these activities, in March 1992, there were three intermediate supervisors, 29 local supervisors and 73 volunteers, working with the CBR programme. Out of the 13 regions in the country, CBR programmes had been started in 13 areas in 7 regions, reaching to 1,200 disabled people. There were 25 micro projects going on, dealing with income-generating activities. Disabled people were participating actively in all activities of the programme and at all levels. Community attitudes towards the CBR programme were changing from sceptical to supportive.

The fourth phase (1992 - 93)- Problems on the horizon:

The second half of 1992 saw a number of situations which almost brought the programme to a standstill. At the end of this phase, the CBR programme had completely changed its basic characteristics: the participation of UNHPM in the management of the project became secondary while the Department of Social Affairs assumed a more prominent role. These changes can be briefly summarized as follows:

The Department of Social Affairs wanted more say in the running of the CBR programme. At their insistence the funding organization, AIFO, signed an agreement with the Government of Mauritania, giving a direct role to the Department of Social Affairs in the running of CBR programme.

Increasing difficulties were occurring within UNHPM while at the same time the project co-ordinator appointed by the Ministry of Health for the first three years of the project was getting involved in politics. The first multi-party elections resulted in two important changes. Firstly, UNHPM was fragmenting and as a result its role in CBR became less active. Secondly, after a gap of almost one year, the Government nominated a new project co-ordinator, a medical doctor who took charge of the continuation of CBR programme, in a very active way.

Problems between Mauritania and Senegal, which had resulted in Mauritanian refugees returning from Senegal, caused more problems in the south of Mauritania where CBR projects had been started in four regions. As a result, many people working with the programme and trained as volunteers and

supervisors were forced to move away, bringing programme activities to a standstill.

A lack of external support following the forced withdrawal of the expatriate consultant, adversely affected both the training courses and the activities in the north and east of Mauritania, where new CBR projects had been started.

The new co-ordinator faced a critical situation: Since June 1992 the situation facing UNHPM had been so serious that the project could not be implemented. The many interventions sought to save UNHPM and the results they obtained were useless. Only in March 1993, after a visit from AIFO, was a compromise found. It allowed the renewal of activities in the short term and consequently, after a delay of three months, the organization of the UNHPM national congress. This brought to an end a conflict which had been so disadvantageous for disabled people in Mauritania.

Two main factions of UNHPM had signed an agreement of compromise during AIFO's visit and it seemed that UNHPM would be able to continue its work for the disabled people of Mauritania. However, the peace was short-lasting and after three months, the fighting recommenced.

The Government decided to intervene and created a governmental commission which elected a National Bureau of UNHPM since UNHPM members themselves were unable to reach a consensus.

UNHPM has remained fractioned following this intervention and today is still not able to represent or defend the rights of disabled people.

The CBR programme, however, recommenced its activities in November 1993 under the responsibility of an AIFO expatriate consultant and the co-operation of the national co-ordinator.

Suggestions:

Disabled people are the subjects of CBR. They are not simply the beneficiaries but should play a leading role in all CBR activities aiming at their development and integration. In this context, the CBR programme in Mauritania was successful in involving the disabled people in their national organizations.

LIMITS AND OBSTACLES TO THE CBR PROGRAMME IN MAURITANIA:

a) Lack of political support:

In Mauritania, the political authorities didn't see disability issues as a priority and the CBR programme was implemented in this context. The programme was

not developed according to a national plan or to a specific programme leading to the problems outlined above:

b) Inadequate co-operation between the Government and AIFO:

The lack of a clear policy prevented the development of good co-operation between the Government and the NGOs in the implementation of joint programmes.

c) Instability of UNHPM:

As previously mentioned, UNHPM promoted and administered the CBR programme.

With the advent of democracy in Mauritania, UNHPM went through a crisis of instability because its main objective stopped being the CBR programme and became its own survival. All these events damaged CBR activities in the country.

d) Inadequate training of staff:

The training of rehabilitation workers was inadequate for the good development of the programme. The cancellation of the third training session for local supervisors, as mentioned above, meant that the consultant in-charge did not participate in the training.

With regard to the objectives, training activities were aimed at creating new professionals instead of preparing local supervisors who could strengthen the traditional values of the community, which are the basis of CBR approach. This was also a mistake.

As for the content of the training sessions, in theory, the WHO manual had seemed enough, but in practice the opportunity to have practical training about its use in the field was lacking.

Training methods were good both in theory and in practice but they neglected that extra-knowledge component which would have allowed the supervisors to play a leading role within the community, and thereby bring about the necessary changes.

e) Strengthening of the programme:

The strengthening of the programme was carried out on two levels.

First, the strengthening of the programme overlooked the transfer of techniques, competences and habits suitable to the need of the community.

A CBR approach implies the improvement of the traditional system of the community in order to make the CBR programme a community programme and not a Governmental one.

The trend, specially in the last phase of the programme, was to train a team of technical workers at the service of the community instead of training the community itself to play a leading role in the integration of the programme into its habits and daily activities.

Secondly, there was a tendency to forget that it was a pilot project, with a limited field of activities. In other words, the programme should have been carefully tested in a pilot area before gradually extending it, should it prove successful, to other areas. This was not the case, because the programme tried to reach the majority of the areas as soon as possible before the foreign funding ended, even though the results attained at various levels in the areas covered by the project were inadequate and not so encouraging.

f) Inadequate funding to support the strengthening of the programme and to come up to rehabilitation workers' expectations:

Initially, the budget of the funding agency didn't take into consideration the many volunteers trained by local supervisors and motivated by promises. This was not a good strategy because promises were broken and as a consequence many volunteers left to the detriment of the programme. In the beginning, costs for only 6 people were included in the budget (the co-ordinator and 5 local supervisors) although the programme also included the recruitment and the training of new local supervisors who wanted to receive the same allowances.

g) Inadequate co-ordination:

Given the geographical extension of the programme, its co-ordination was not effective (1 co-ordinator and 1 vehicle) and the local supervisors were not adequately trained to work with the co-ordinator in the seven regions covered by the programme.

This situation got worse due to the lack of vehicles for the supervisors and the lack of regular meetings.

h) Changes in the political structure:

The first protocol concerning the funding of the CBR programme was signed by AIFO and UNHPM and it had the advantage of limiting the responsibilities of Government representatives to financial decision-making. The balance was broken when the signature of the new protocol passed from UNHPM to the Government (MSAS). In fact this transfer was regarded as a simple transfer of competences and responsibilities from UNHPM to the Government.

I) Inadequate evaluation techniques:

The evaluation of the programme did not effectively promote its development. The evaluation activities were inadequate and not suited to the different human resources involved in the programme (disabled people, families, local communities, referral services, associations, etc.).

RECOMMENDATIONS:

AIFO should:

Listen and observe: These are very important aspects in the relationship with local partners.

Consider as equal all the members of the CBR team in order to avoid disparities which could damage the activities of the programme.

Promote not only medical interventions, as part of the CBR programmes for disabled people living in the poorest communities, but also projects for an integrated development of the community itself.

The Government should:

Act as a mediator within the CBR programme by organizing a national congress in order to reconcile all disabled people.

AIFO and the Government should:

Encourage, support and include in their priorities the creation of a national movement representing all disabled people.

Stress competences, commitment and availability rather than feelings, in the selection of people in charge both of the programme and the UNHPM.

In addition, CBR workers should be helped by disabled people in order to facilitate the approach so that the results attained can be a challenge for disabled people and their families.

CBR workers should receive assistance with personal problems or transport problems which could affect their competence and availability.

One of the main objectives in the training of CBR workers is to provide them with the competences and skills needed to carry out the programme in the field and within the community.

A successful CBR programme not only involves disabled people but should also be able to find within the community and for the community its own sources of finance.

VOICES FROM THE CBR PROGRAMME IN MAURITANIA

A) Mohamed Abdallahi ould Cheikh, Local supervisor in Dar-Naim:

I am a professional nurse, and my family was quite well off. In the fulfilment of my duties I have had the opportunity to work in the Ksar prison in Nouakchott, where life conditions were extremely bad (lack of hygiene, narrow rooms, bad food, etc.). While I was trying to improve the life conditions of the prisoners, I heard about the CBR programme whose project leaders were selecting some paramedical workers for the Nouakchott district. I became enthusiastic about the programme and I committed myself to it in order to help improve the quality of life of disabled people, another disadvantaged social group in need of help. As time passed by I could appreciate CBR as an active method for the integration of disabled people in their community. I have also realized that traditional social values, which are the basis of CBR, are changing; mutual help and social solidarity are being substituted by profit. The implementation and the success of CBR activities in Mauritania, or better in Nouakchott, need the intervention of competent, disinterested and available people in order to carry out its fundamental principles. As a simple local supervisor I am not in a position to give impulse to the management but I think that the programme should perform both the selection of staff and the mobilization of the community in a lasting way.

To conclude I would say that the programme shouldn't make differences between people, it needs everybody, particularly those who were there at the start and have now been set apart.

B) Mohamed ould Hamid, CBR volunteer in Boghé from 1989 to 1990

In my opinion CBR is very important because it's the only programme in Mauritania which allows disabled people to live a human life. This is why, as a disabled person who had the opportunity to attend school, but was not able to continue my studies or find a job, I have decided to help the disabled people in my town. With this decision, I certainly wanted to give my help, but I also was hoping to be selected as a supervisor, with a salary. After one year, without any hope of promotion, I realized that my prospects were elsewhere. So I left Boghé to Nouakchott looking for a professional training or an employment which could give me the possibility of earning a living. In Nouakchott I worked with the UNHPM team and I have had the opportunity to appreciate the role played by UNHPM in the implementation and in the development of the CBR programme.

The programme has certainly had some difficulties due to the serious problems of UNHPM but I still think that CBR can help disabled people and therefore should

be encouraged and supported, in particular by disabled people, within a strong organization.

Finally, CBR started its activities in Mauritania by working for disabled people and if disabled people are excluded from it, what's CBR good for?

C) Lehboussould el Id, former director of UNHPM:

The success of the CBR programme in Mauritania is mainly due to the following:

a) The existence of a national organization of disabled people, well organized, active in the whole country, and a programme with objectives, supported by competent, motivated and available workers.

b) A population characterized by tolerance, human solidarity and acceptance of all the other members of the community.

c) The moral support of MSAS to UNHPM which was realized in the following fields:

- signature of protocol agreements concerning the financial and administrative management of training schools;

- appointment of UNHPM as member of various Boards of Administration of public institutions and Government-controlled agencies involved in activities for the disabled people: CNORF, Islamic Foundation of Oghafs, CBR/P.

- involvement of UNHPM in the preparation of seminars organized by the department and concerning the disabled people.

Following the events which upset the national movement of disabled people (1992) many things changed both in the attitudes of those responsible for administration and also the structure itself. This change of attitude had serious effects at the national administrative level and in the attitude of the population towards disabled people.

The CBR programme is struggling in this critical situation as characterized by:

Disagreement in the ranks of disabled people

The politicization of the structure of the national NGO

An estrangement from the fundamental objectives

An inability to promote public awareness in the community and bring about a real change of attitude, and a return to the traditional system where all disabled people are integrated members of the community.

Even though the programme started again under the management of a consultant, we fear that after her departure, the institutional set-up she established, may lose its effectiveness if the national organization is not re-established.

Comments: we notice nowadays a disagreement between the leaders of "UNHPM new era" and the CBR group concerning the leadership of the programme and the selection of the representative of the disabled people within the local committees of the CBR programme. In particular, this selection is not made by the disabled people of the involved area but is imposed by the leaders of UNHPM/RN. This conflict of competences doesn't facilitate the development of the programme through the participation of a responsible UNHPM.

Conclusions: for the success of the CBR programme in Mauritania, what is necessary is peace and compliance within the national movement of disabled people.

D) Mrs Aissata Ngaidé, midwife and local supervisor in Riadh-Nouakchott:

I started working for CBR in 1991 to help disabled people. After my training period, I couldn't work much in the field due to the many problems of the National Bureau of UNHPM. My motivations and my confidence in the programme are unchanged, even if I know that it will be difficult to reach a good level of information and cooperation within the community. Disabled children accept us well because of what we try to do for them, but their families expect simply assistance from us because they are very poor. But through the support of the local committee, particularly certain members of it (prefect, mayor and imam), we think that progressively the community will co-operate with us and will also be able to contribute to the local funding of the programme.

For our work to become more effective we need:

good training,

the means to make or to buy prothesis for our patients,

and some funds to help them start income generating activities.

E) Mrs Boya Faye, volunteer nurse in Riadh:

I am still the only volunteer in this area. I started my activity with "Terres des Hommes". At the same time I was seeing Mrs Aissata Ngaidé offering her assistance to disabled people within the CBR programme. I asked her if she wanted me to help and in this way I became a CBR volunteer. I think that other people like me exist in this area, who would accept to work without a salary, because it's human and noble to help those who are in need.

F) Salek, young paraplegic:

I lived in Senegal with my parents, there I had my wheel chair which allowed me to attend school and after school I used to go to a watchmaker to learn his work. In 1989, following the problems between Senegal and Mauritania I found myself repatriated with my parents to Mauritania, without my chair. Since then I always stayed at home. Now, the local supervisor has given me a wheel chair and I am free because, in spite of the sand, I always find somebody who can help me. What I would like to find now are some funds to open a workshop for watch repairs, because I would never like to be a beggar.

COMMUNITY BASED REHABILITATION

THE MONGOLIA EXPERIENCE

Lorenzo Carraro

Note: Mauritania CBR programme is a multi-sectoral CBR programme with two distinct approaches to respond to the two specific situations existing in the country. Thus in the urban areas with higher population density, like Ulaan Baator city, the CBR approach can be considered as a classical CBR approach involving the "communities". In the rural areas, where about 65% of the Mongolian population lives, very low population density means that small groups of persons, often part of one extended family live together and the CBR approach involves the family and not the whole community. In the urban areas, volunteers are also involved in the programme which is not possible in the rural areas. The project also involves collaboration with Ministry of Education to promote schooling for children with disabilities. The Project also involves Ministry of Labour and Social Welfare for vocational training. The organizations of disabled persons are involved in management of rotating credit funds for income-generation. This article deals mainly with the role played by personnel working for the Health Ministry, as the writer is a consultant physiotherapist with the project.

INTRODUCTION

'It's strange to see how in some countries history is rewritten at regular intervals, so that all things considered imperishable until then shatter and disappear in a very short time and leave behind hardly a trace.

Mongolia is one of these countries, where the old pillars of consolidated and official knowledge started to totter and fall in a short period of time. Now there are only a few such things left, seen by the population as life-boats in a stormy sea. The more these forever things are considered indestructible and firm, the louder the complaints when they disappear definitively. Then there is nothing else to do except to search among the ruins only to find unpronounceable names and let the busts of the old regime and its personages sink into the mud. It seems

that the moment of great changes has come and as it wouldn't be in good taste to raise too much dust, at last it is permitted to polish and display what is really worthwhile.

I quote these words because more than any other thing they describe the atmosphere I found during my first visit to Mongolia in the summer of 1992. Although in Mongolia the process of change has been bloodless, in a short time entire political and economical structures, unchanged since the 1920s have been erased.

Since 1991, the political and administrative structure in Mongolia has changed completely. In that year, on the wave of popular protest after 70 years of communist regime and very binding relationships with the Soviet Union, the first pluralist elections in the history of Mongolia were held. These elections were held again in July 1992, following the approval of the new constitution, to ensure and fulfil the opening democratic processes.

It is important to keep these events in mind because they have inevitably conditioned the start of the community-based rehabilitation project.

PART ONE: THE COUNTRY

1. Origin of the project

In August 1991, at the request of Government of Mongolia, a joint feasibility mission was carried out by the World Health Organization (Rehabilitation Unit) and the Italian NGO Amici di Raoul Follereau (AIFO). The objective of the mission was to evaluate the overall situation of disabilities in the country. This was to be done through verification of the quality of rehabilitation services, the possibility of starting a community-based rehabilitation project, and through the finding of possible solutions to the need for orthopaedic aids.

As a consequence of that visit, the Ministry of Health of Mongolia, decided to start a community-based rehabilitation project as an integrated part of the general health structure, in order to strengthen the rehabilitation services.

The World Health Organization (WHO) co-operated with the Ministry of Health in working out the project proposal and continues to provide technical and scientific supervision. AIFO co-operates in the implementation of the project itself.

The introduction of this project should not be considered separately but rather as a component of the whole health policy of the country. Since 1988, the Government has been making an effort to bring Primary Health Care (PHC) to the rural population by strengthening and improving rural health services. The expansion and strengthening of general health services, especially rural health services, is part of the 'Health for all by the year 2000' strategy.

Unfortunately, the Government's plans were interrupted because of radical political changes in the country and the ensuing serious economic crisis.

2. Geographical area

Mongolia is situated in the centre of the Asiatic continent and covers an area of 1,566,500 square Km (Superimposed on Europe, Mongolia would extend from Amsterdam to Moscow and from Copenhagen to Venice). To the North, Mongolia borders with the former Soviet Union and to the South with the Popular Republic of China. The country is characterized by great contrasts. In the North there are high mountains covered with forests, great lakes and rivers, while in the South there is the Gobi desert and a landscape characterized by highlands. To think of Mongolia as a totally desert region, made green by few blades of grass, is completely wrong. In fact, the vegetation of the country is extremely different due to its vastness and its resulting environmental differences. In particular during the short summer, the ground is covered with rich pastures strewn with flowers - mountain flora so rare and protected in Europe. How can I explain my feelings during jeep journeys across boundless pastures strewn with edelweiss?

The country has a strongly continental climate, with four different seasons. During winter (from October to February) the temperature can drop as low as 35 degrees below zero. The highest temperatures occur in July where, in the Gobi desert temperatures of 40-45 degrees are recorded. Spring is characterized by great sandstorms and powerful winds. In May, the vegetation turns green once again.

Mongolia has a population of about 2,199,570 (1972) with a density of 1.33 inhabitants per Km².

As shown from these data, Mongolia is scarcely inhabited and apart from the population living in the Capital and in the Provincial capitals, its inhabitants are spread over a vast territory. About half of the population live outside urban areas and nomads are numerous among those living in the steppes.

The Capital, Ulaan Baatar, has a population of about 600,000 and is the political, economic and cultural centre of Mongolia. Other important towns, besides the chief towns of the provinces, are Erdenet, Darkhan and Choir. Impressive public buildings, made even more severe by great arcades, delimit the very heart of the town - a big quadrangular square dedicated to the hero of the revolution. The outskirts of Ulaan Baatar are characterized by long rows of prefabricated buildings, just like all the outskirts in the world.

Mongolians are essentially nomads and in their culture the concept of 'town' as we consider it, doesn't exist. They still carry signs of those who ruled the country over the last seventy years, but if you go out of the town just few kilometres you can find the real Mongolia, characterized by endless open spaces.

Shamanism was the original religion of the native population - typical religious beliefs of a nomadic and bellicose people. Traces of this religion are still found in certain rituals, especially during feast days. Now the prevailing religion is a sort of lamaist-buddhism, while the Kazazhi, a minority group living in the north-eastern part of the country, are Muslims. At present, there is a great revival of interest in religion. As a consequence of liberalization, human spiritual needs, suppressed for such a long time, are now strongly bursting out. Stalinism had a great influence in Mongolia and in the 1930s and 1940s resulted in the massacre of many lamas and the destruction of almost all the monasteries. In the 1930s, the use of traditional medicine was also suppressed along with all other religious practices. These beliefs and medical practices, based on the Buddhist traditions, were practised mainly by lamas.

Recently, there is renewed interest in traditional medicine, together with a revival of Buddhism, as the old traditions are seen as evidence of the Mongol identity. There are also increased contacts with Indian and Chinese traditional medicine. Small manufacturing industries are the only evidence of industrial development, while agriculture, mainly cattle-breeding, is still one of the main economic activities of the country, involving most of the population and supplying raw materials to manufacturing industries. Cattle-breeding is more than a simple income generating activity for Mongol people, it forms part of their deepest cultural roots.

The Mongol people have a passionate relationship with animals, especially with horses, that cannot be compared with other nationalities. During the public holiday period (Naadam) people come from distant places to the hills surrounding Ulaan Baatar, every year bringing with them about 40,000 horses. They breed not only horses but also rams, goats, sheep, cows, elks, camels and yaks. The number of cattle in Mongolia is estimated to be about 120 animals per inhabitant, one of the highest rates in the world. Animal breeders rarely stop in the same place for long. The very dry climate prevents pastures from growing forcing shepherds to continuous displacement. They use their animals both as a means of transport and to cart their goods. Usually, nomads carry all their goods with them and their speed at putting up a tent even in the most adverse weather conditions is proverbial. The history of the Mongol round-tent dates back to 2,500-3,000 years BC and it can be considered as the only typical Mongol construction. It is made of a round thin wooden load-bearing structure, tied up with horsehair cord, and covered with felt and canvas. Its main feature is that it is suitable for both the constant displacements and the continental climate of the country. In fact, it's easy to take down, light to carry, warm in winter, cool in summer and wind-proof. Even in urban settlements, these tents can be found grouped together and protected by wooden fences.

3. Economic situation

In the past, the industrial development of the country was subordinated to the colonial relationship it had with the Soviet Union. Through development plans

worked out directly by Comecom, the Soviets supplied technicians, technology, machinery and spare parts. They determined economic goals and strategies and fixed a ceiling price for imported primary goods; in exchange for this Mongolia gave its territory as a military outpost.

At the end of 1989 the country had a big foreign debt corresponding to 450% of its gross national product (GNP). In the following years (1991-1992) the fall of the Soviet socialist system and the radical political-economic changes which happened in Mongolia (pluralistic political system, denationalization and free market) resulted in immediate repercussions and further economic imbalance. Suddenly, the Government's balance of payments couldn't be based on the compensation agreements signed with traditional allies. As a consequence foodstuffs, fuel and spare parts for industry had to be paid in foreign currency which was lacking in Mongolia. Previously about 90% of export trade was with socialist countries who paid with goods and not foreign currency. As has been the case for other former-communist countries, the sudden liberalization provoked a sharp imbalance leading to a dramatic deterioration in living conditions. In a three year period (1990-1993) Mongolia went from a situation of apparently no poverty to a one where more than a quarter of the population was living below poverty line (\$4.35 per person per month). The number of people living in poor conditions continues to increase rapidly: during the first ten months of 1993 there was an increase of more than 60%. In addition to the difficulties resulting from the economic crisis, Mongolia has also had to face a series of problems related to its geographical situation, including the unpredictable and rigorous climate and major transport difficulties. The combination of these problems and a scanty population scattered over a very large territory have presented the Government with an enormous task.

4. Health situation

From the 1940's, the health structure of the country was developed under the influence of the Soviet Union and was characterized by strict centralized planning. This included the employment of feldshers, as paramedical staff among nomad peoples, a high number of specialized doctors and the absence of the family doctor figure (family doctors were only introduced at the beginning of the 1990s).

Thus, a health system was established which, even though it had limitations and problems, was free and accessible to the majority of the population. Almost all women, for instance, gave birth in a hospital, under medical care and maternal mortality was 1.4 per 1,000 live births. While such services contributed to improve the populations' general conditions of health, their quality was not, however, as good as expected.

While access to health services is sufficiently adequate for the population living in urban areas, it is insufficient at the somon (rural district) level.

Those living in rural areas, mainly nomads, have little access to health services and what access they have is dependent on transport and communication facilities at local level, and on the number of health staff available. The effects of the economic crisis during the period of transition are mainly felt at this level. In fact, in rural areas the maternal mortality rate has rapidly increased (over 85%) in the last two years due a lack of beds in rural hospitals for women in labour, lack of transport and other problems. For instance, the number of doctors working at somon (rural district) level is now 21% below the minimum level established by the Government.

4.1 Health structure.

Since 1994 the administrative structure has covered 21 provinces (aimaks) and the Capital. Each province is divided in to rural districts (somons), which are sub-divided into 'bags'. At present there are 324 somons and 1590 bags. The capital is divided into 12 districts. The health system structure complies with the administrative structure and will also work as a referral system for the CBR project.

Health services start at the rural community level (bag) where feldshers work. Each bag has one feldsher working both from a fixed place and following the Nomads' migrations. The feldsher has to visit all the families periodically, give medication, and is responsible for prevention and health education activities. The feldshers refer the patients to the district (somon) hospital in cases of need.

A typical district (somon) hospital may have up to three doctors (one specialist in internal medicine, one paediatrician, and one obstetrician) supported by two to four feldshers, one chemist and two to four nurses. There are up to 15 beds, but no laboratory or surgery services. Paediatric and maternity services are usually present. Patients who cannot be treated at the somon level are hospitalized in the district hospital or in the Capital.

Hospitals in the provincial capital cities are at a higher (aimak) level with specialized services including surgery, odontology, radiology and a laboratory. There are about 250 beds available.

In the Capital, national hospitals are at the highest level where complete medical and surgical assistance can be found. In urban areas (the Capital and provincial capitals) health assistance is provided in the district clinics. These clinics used to have three doctors (1 specialist in internal medicine, 1 paediatrician and 1 gynaecologist) but these have recently been replaced by 'family doctors'. The majority of the district clinics in the Capital have a doctor specialising in rehabilitation.

5. Rehabilitation

The total number of people with disabilities in the country is not known. The only data available, from the Ministry of Labour, are related to people employed by the State and aged between 16 to 60 years. Data on the unemployed population or those working in the private sector are not available. Furthermore, those under 16 years or over 60 years of age constitute about 50% of the total population. According to an estimate of the Ministry of Labour there are about 47,000 people with disabilities in the country, with 24,320 of them having long term disabilities.

At national level, the total number of patients registered as oligophrenics is 20,000 (50% older than 16 years). To sum up, the total number of disabled people currently known is 3% of the total population. Exact data concerning children with disabilities are not available. According to an estimate by certain international organizations (UNDP, UNICEF) working in the country, 20,000 to 30,000 children have some disability.

At present, children with disabilities don't get compulsory education and their access to schools is mostly limited to children with particular disabilities (blind, deaf-mutes, etc.). In almost all cases education is carried out in special schools or in special classes situated only in the Capital, in the biggest towns and in the provincial capitals. Only 10-15% of children with disabilities receive any education.

Children with walking disabilities attend ordinary school only if they are self-sufficient and if they have normal intellectual faculties. Only 3% of the 25,000 children with walking difficulties and with mental insufficiency attend school. Attendance among children with visual and communication difficulties is 40%. Another aspect of the situation which is deteriorating, is the fact that 20% of disabled children drop out of school, according to an official estimate (1993). The Ministry of Education states that 30% of children attending special schools drop out, corresponding to approximately 7% of the total number of school-age children. The integration of disabled children into the school system is of particular interest in this country and there are many aspects shared with the community-based rehabilitation project.

5.1 Rehabilitation structures.

There aren't any formal rehabilitation services at community (bag) level and district (somon) level. There are rehabilitation services in provincial hospitals and in the various hospital in the Capital.

In the whole country there are no specialized services for rehabilitation, except a geriatric centre in the Capital (200 beds) and an occupational therapy centre for psychiatric patients (400 beds) 100 km from the Capital. There are also some thermal baths in the country where some physiotherapy activities (mud-baths, hydrotherapy, massage, acupuncture) are carried out. In 1992, the geriatric centre in Ulaan Baatar was used to refer people for rehabilitation activities. But, not only is the centre in bad condition and an inconvenient location (old building

in the outskirts of Ulaan Baatar with bad public transport connections), it does not have the necessary equipment.

Apart from these last two examples, physiotherapy services are available in out-patient clinics or in other wards for hospitalized patients (surgery, paediatrics, orthopaedics, etc.). Such services are usually under the charge of a 'specialist' in rehabilitation (one specialist had received only three months specific training) and other 'specialists' among feldshers and nurses. Physiotherapy, acupuncture, traditional medicine, massage are the most common specializations.

6. Conclusions

From a general point of view, at national and district level there is a good distribution of health services but the quality is not very good. Professional training of the staff is almost exclusively based on acupuncture, massage, instrumental-passive therapies, carried out in a undifferentiated and generic way for all kind of diseases and pathologies, from rheumatics to medullary lesions, from cerebral palsy in children to Hemiplegia in adults. Rehabilitation has been influenced by traditional medicine deriving from Tibetan Lamaism and by Soviet and Chinese medicine. What is missing is, first of all, the idea of a global rehabilitation approach aiming at reducing the impact of disability by helping the individual to improve his self-sufficiency, that is, his/her capacity to move, to communicate and to perform daily activities. There are also insufficient activities aimed at the social reintegration of the disabled person.

About half of the Mongolian population lives isolated in rural areas where there are no rehabilitation structures. A disabled person has to be referred to provincial and national centres for treatment; but these services are very difficult to reach due to bad weather conditions (a very long and cold winter), few roads, lack of transports, communication difficulties and long distances (somon and aimak can be more than 100 km apart).

As far as medical rehabilitation is considered, only a small percentage of disabled people (5-10%) get any regular treatment (usually two short courses consisting of 10/15 visits per year).

In August 91, a WHO/AIFO joint mission reached the conclusion that the existing system was not able to respond to all the primary needs of disabled people, but that conditions permitted the establishment of a CBR programme. The widespread distribution of the health staff both at urban and rural level, in particular the presence of people working at community level like family doctors and feldshers could become an advantage for starting CBR activities.

PART TWO: PROJECT DESCRIPTION

1. Introduction

Many people consider CBR to be a rehabilitation approach good only for developing countries. The fact that most CBR projects are in these countries and that their costs are much less compared to the cost of an 'institution based' approach, has undoubtedly contributed to this interpretation.

The formulation of the community-based rehabilitation concept by WHO is a serious attempt to 'deinstitutionalise' and demystify rehabilitation activities . Unfortunately, this concept has often been misunderstood giving rise to controversy. Deinstitutionalisation and simplification of the rehabilitation approach doesn't make it superficial. To involve and train the family and the community doesn't mean that the entire management of all disability issues will be delegated to them. What characterizes and differentiates the various approaches (from institution-based to home-based) is not 'where' the rehabilitation is carried out, but the different role and involvement of people with disabilities, their family members, and the community.

I feel that CBR is a more realistic and honest approach to rehabilitation for various reasons.

First of all the role of the disabled person is changed, because he is no longer considered a 'patient needing treatment', but has an active role, taking part in his own rehabilitation process, including decision making. Rehabilitation should be related to the context of the individuals involved; this implies the removal of the social, physical, and environmental barriers which cause handicaps. It should not be seen as 'normalization' or 'taking care', but should mean facilitation of integration. There cannot be a conflict between rehabilitation and integration - that is, first rehabilitation and then integration. The role of rehabilitation workers is also different within a CBR context; instead of being care-givers they should be resource people - available to support disabled people in reaching their objectives. This doesn't mean that the workers have to become passive and unqualified: in fact to be a resource person implies a higher level of professional competence.

Community-based rehabilitation starts from the concept that the community must be directly involved in the rehabilitation process; only when the community takes charge of all the issues affecting its disabled members will their needs be understood. Community involvement means reaching a higher number of people with disabilities and enabling them to stay in their social/family background and, through simple interventions supporting their integration as active members of the community.

CBR doesn't mean giving a medical role to the family/community but on the contrary, to quote Prof. A. Milani Comparetti, it means: 'to introduce quality therapy into the daily routine activities of the disabled person and his/her family'.

If CBR is to be made possible and the community is to take charge of all the issues concerning its disabled members, it is important to transfer information

concerning disability and rehabilitation to people with disabilities, to their families and to the community where they live. The community should be involved in each phase of the programme: planning, implementation and evaluation. Acting to reduce the impact of disability should be seen as an integrated part of the development of the community itself; as part of a process which allows the community to have more control over its own development and to have a better awareness of its own resources and capacities to solve problems. In many countries, including Mongolia, disability issues are often seen as development problem by governments and agencies, but not as a priority. New employment opportunities, primary health care, infant mortality, etc. are considered priorities, while rehabilitation and disability issues are often seen as taking resources away from other development activities. The importance of CBR is not well understood in terms of promotion of community development and an opportunity to improve the level of community awareness.

2. Main objectives of the project

a. To start a CBR programme at national level through the existing health structures, with the aim of giving rehabilitation opportunities to at least 60/70% of people with disabilities.

The project also aims to improve the quality of existing medical rehabilitation structures at national and provincial level, so that these can support all activities (e.g. training, supervision, etc.) carried out at community level. Finally, it aims to strengthen the production of prothesis and orthopaedic aids in the existing national orthopaedic workshop, both quantitatively and qualitatively.

b. To identify a team of people who would ensure training, supervision, evaluation and epidemiological/statistical data collection activities at national level.

The above team would be in charge of the supervision and training of doctors: both rehabilitation specialists working in each province, and doctors working in hospitals in the Capital and in district out-patient clinics. These doctors would be 'key' members of the programme, as they in turn would give training and supervision support to district (somon) doctors and feldshers (community paramedics) in rural areas and to family doctors in urban areas (see annexed).

Feldshers and family doctors should start their activity by screening the whole population in their areas with the aim of identifying the disabled people.

In the second phase, people with disabilities and their communities will be involved in a transfer of information, using the WHO manual on CBR.

c. To promote community participation in all the phases of the project, from planning to evaluation, through community resources and local support teams.

d. To promote the integration of children with disabilities in local schools; and to provide training and work opportunities (for instance, through subsidized credit funds and co-operatives, etc.) for adults with disabilities.

(Note: As can be seen from these objectives, the main emphasis of the first phase of the programme was on medical component of CBR).

3. Beneficiaries of the project and their involvement

Although people with disabilities comprise between 6-8% of the total population (the project aims to reach 60-70% of them), not all need specific medical rehabilitation activities. Children and young adults with disabilities will be the main beneficiaries of the programme. Many disabled people are already well integrated into society, while old people with long standing disabilities may receive only minimal benefit from such activities. Many times, however, even a small benefit may make a significant difference to the quality of life.

When a disabled person becomes more self-sufficient the impact on the family life of all the family members is usually considerable - but it is especially important for mothers with disabled children. The promotion of self-help groups among people with similar problems, volunteer involvement and other ways of increasing social support, will also help to improve family life. This is an important consideration in Mongolia. In 1993 estimates showed 36,813 families headed by a woman. Out of these 30,973 (84.1%) were single women (separated or widows). This figure is almost a 50% increase on 1991 figures, and further increases are anticipated.

The community also benefits: taking care of people with disabilities, helping people with disabilities to become more self-sufficient, increasing community awareness of disability issues - all these factors contribute to global community development.

4. Start of the community based rehabilitation (CBR) programme

The programme started in 1992 and its first step was to select three doctors from the national team, specialists in rehabilitation, to be trained as trainers. They were trained for six months (January to June 1992), in Poland and Vietnam. In Poland they attended courses concerning the rehabilitation of people with mobility disabilities. In Vietnam, they were joined by the national CBR co-ordinator appointed by the Ministry of Health and received field training from staff and managers working in the local CBR programme (Poland and Vietnam were chosen because Russian is spoken in both countries).

The translation and printing of the WHO manual, 'Training in the Community for People with disabilities,' in Mongolian was also planned. The manual gives information and suggestions about the development of the capacities of disabled people to support them in becoming more self-sufficient. This clear and practical

information also takes into consideration the individual in his/her global aspects within a socio-environmental context. Of course the manual will not be the only teaching material used. Other texts on specific disabilities will also be translated and printed (e.g. cerebral palsy in children, poliomyelitis, etc.). All these training materials are very important in Mongolia considering the lack of rehabilitation texts available in Mongolian.

In Ulaan Bataar, I met Ann Goerdt (Rehabilitation Unit, WHO, Geneva) who was there to help start this new CBR programme. Her competence was of great help when planning the courses schedule.

When we arrived, the programme co-ordinator and the three national-level teachers had already started the first course for doctors specialising in rehabilitation in the Capital and in the aimaks (Provinces). Initially, the course was intended to last three weeks, this was later extended to four. In the original project, jointly prepared with WHO, a course lasting three months was foreseen. This was changed for several reasons: firstly, the teaching-doctors felt that they were not sufficiently well prepared to conduct a three-month course; in addition, the economic situation of the country had got much worse since the previous year when the project was planned; other difficulties included:

- a. travelling by plane is the only way to reach the Capital from the aimaks - this was very difficult due to a great fuel shortage;
- b. lack of food - food could only be bought with a special card (the alternative was black market or shops where things could be paid in dollars) and doctors coming from aimaks couldn't use their cards in the capital;
- c cost of life - food, rent, transport - greatly increased making a per-diem (difficult to) foresee in the project, (the official dollar exchange rate was still controlled).

Another important reason was that the WHO manual was not yet available in Mongolian. (Initially the delay was due to lack of paper, then the main reason was the lack of printer developer.)

The delay in the printing of the manual greatly influenced the qualitative development of the course. The training at peripheral level directed at the feldshers also had to be carried out without the manual. Yet the manual is a vital tool, giving basic information on data collection, screening, rehabilitation of disabled people and community involvement in the project. In a country where English is not well known, it's difficult to transfer this information via English versions of the manual.

These difficulties were offset to some extent, however, by the motivation and interest of the three teaching doctors and the course participants. The teachers translated the manual into Mongolian using a Russian/English dictionary. So

although during the course part of the time was spent in translation this was also seen as confirmation of their motivation and interest.

We shouldn't forget that for many years Mongolia was an isolated country with Soviet culture as the only term of comparison. For the doctors coming from the aimaks this was the only opportunity to attend refresher courses after their graduation. Apart from their commitment and interest they were also very well prepared professionally.

Another important aspect is that in Mongolia the majority of doctors and health workers are women who, besides their daily professional work, also have to look for food and take care of their families and children. Notwithstanding this, the women were always graceful and decent. During my first mission, which lasted from August to December 1992, my main activities were to co-operate with the three teaching-doctors and the national project co-ordinator to revise the duration of the programme training courses (see annexes), and take an active part in the teaching activities.

5. Community involvement

The importance of active community involvement in the rehabilitation process has already been stressed. The drive to increase community awareness was aimed at the transferral information on the objectives of the new programme to: community leaders (formal or informal), workers at different levels, people with disabilities, and the population in general. This was the most important activity in the initial phase of the programme. In the Capital a national seminar was organized in order to reach this objective. It covered the meaning of rehabilitation in general and the meaning of CBR in particular; as well as the definition of disability/handicap; the importance of education, employment and social integration of people with disabilities; and so on. Health workers, administrative officers, representatives from institutions and organizations coming both from the Capital and from the provinces attended the seminar. Conferences on the same subjects with similar objectives were planned for each provincial capital before the start of training courses for doctors from aimaks (provinces) and somons (districts). Finally, the continuous use of the mass media - newspapers, television and radio in particular since this is listened to even in the most remote areas of the country - was equally important.

Community awareness activities and the involvement of the population as a whole should lead to the creation of 'CBR committees' at community level.

The (tasks) roles identified for these committees were:

- to identify people with disabilities in their community;
- to talk with disabled people about their problems and the most suitable ways to solve them;

- to give information to community members about the various kinds of disabilities, how they are caused and how to prevent them;
- to make the various community services - health, education, transports, etc. - more accessible to disabled people;
- to promote the integration of children with disabilities in local schools;
- to organize vocational training and find work opportunities for adults with disabilities;
- to discuss and evaluate the programme developments through recurrent meetings;

In other words, these committees co-operate and support fieldshers and family doctors in implementing the CBR programme at local community level.

Let me give you a practical example of how all these activities were carried out in one province (aimak) of about 60,000 inhabitants, divided into 18 somons. In 1993 the joint WHO/AIFO evaluation mission visited Bulgan aimak together with the local responsible of the project. They met the Governor, the health-service authorities and other authorities. The aim of the visit was to inform them about the project, in particular to tell them about the forthcoming training courses for somon doctors and family doctors in the aimak capital and to ask them to support the programme.

After this visit one doctor was selected from the aimak to take part in the two month training course in Ulaan Bataar. When he went back to the aimak he started the screening of disabled people in one area, as suggested, and gave them some information from the WHO manual. In February 1994, before starting the training course, a seminar was organized in the aimak chief town with the participation of somon and family doctors, representatives from the Ministry of Labour and Education, Red Cross workers, women, young people and disabled people organizations, etc. Apart from discussing the project the course participants also had to find appropriate words in Mongolian for 'impairment', 'disability', and 'handicap'. This was important for the correct screening of disabled people. During another meeting it was also decided that the aimak association of disabled people, could become a 'CBR committee', given its existing involvement and interest in the project. In order to avoid any waste of energy and resources it was deemed better to involve those existing local organizations and groups, which are already motivated and active in the CBR project.

6. Data collection

As the exact number of disabled people in the country was not known, discussions were held during training courses on how to carry out data collection and population surveys. This was based on the WHO manual specific forms

prepared for the purpose. Data is collected and analysed at national level by the national CBR team (the co-ordinator and 4 teachers).

It was difficult to find synonyms for words like 'impairment', 'disability' and 'handicap' in Mongolian. In particular the word 'disability', which should be used to classify registered people, may be often confused with 'invalidity'. This word, which is derived from Russian, refers to people receiving state benefits.

I realised that there was confusion between these two words through the help of a translator and by analysing the screening results in some areas. These showed that identified disabled people aged between 16 and 60, corresponded to those people who received state benefits. Another clear indicator was the great difference between data collected from one aimak to another or the comparison of screenings repeated in the same areas using different people, where identified people went from 3% to 19%.

Apart from the semantic problem mentioned above differences in data were derived from the way the screening was carried out by the workers - mainly doctors and paramedics - working in that area. Their professional training teaches them to classify by diagnosis not by degree of disability.

7. Objectives attained

Even though training courses were delayed due to the unavailability of WHO manuals in Mongolian, it doesn't mean that training activities and initiatives to start the CBR project in the country stopped. In October 1994, the majority of doctors specialists in rehabilitation completed their training, both in different regions and in the Capital. These doctors will train district doctors (somon) in their provinces. They will be helped in this task by national trainers. Family doctors and feldshers will start their training only when the WHO manual is printed before the end of the year. Basic staff training, in order to start the project in the whole country, and a survey of population should be carried out within 1997.

As a result of activities carried out by the project team to increase public awareness the CBR programme is now starting to be well known not only among health workers but also among the population as a whole.

Mongolia is a very big country, with great transport difficulties and remote inhabited centres but during my last visit (in the winter of 1995) last winter, I received the impression that people knew this project.

It's difficult to identify people's precise expectations because each person has different terms of comparison. Mongolians are a nomadic people, they live simple lives but at the same time they are very proud, self-reliant and used to a hard life. I remember last winter while visiting a district (somon) in an aimak in the North of the country I was asked to visit a disabled person. It was a woman of about

thirty years, a primary school teacher, who became paraplegic after a street accident two years previously. Her mother helped her during this period and valuable technical solutions were suggested to her by an expert in that field. She avoided bedsores and severe contractures by remaining mobile and was even able to walk inside her home thanks to wood splints tied to her lower limbs and home made crutches (see picture).

Her mother has asked me to visit her daughter simply for reassurance that what she had done was correct and to know whether there was anything more she could do. My suggestion was to make a pair of shoes with a supporting metallic structure for the leg so that the woman could put them on by herself. These were made with the help of the aimak doctor and the involvement of the local shoemaker and blacksmith who were given explanations and designs. The nearest orthopaedic hospital was in the Capital about 1,000 Km away. This is, of course, only one example among many others.

8. Present situation

Last year a paediatrician, who had been working with me as an interpreter since the beginning of the project, joined the national team (one co-ordinator and three specialists in rehabilitation) in charge of all the activities related to the project at national level. In addition to her knowledge of English, her professional competence in the field of child disabilities has been very useful to the project. Local aimak level project responsible who are carrying out training courses for somon doctors, are also discussing with other institutions and organizations matter of interest to the CBR programme: the school integration of children with disabilities.

As mentioned earlier, education in Mongolia is not compulsory for children with disabilities and at present they have very few opportunities to attend school.

In fact, I never met a disabled child in Mongolia who was attending school.

The present Government policy about children was sanctioned in the 'National Plan of Action for the Development of Children in the 1990s' (NPA 1991). This act, among other objectives, foresees interventions in various fields such as health, nutrition and education and the needs of children living in particular situations (disabled children, orphans, etc.).

The present trend in education is to attempt to ensure eight years of compulsory education from the age of eight. For children with disabilities the main objective is that of assuring access to ordinary school for at least 80% of them. For pre-school education, NA gives general guidelines for children's development within family structures and seeks to assure more nursery places for poor families, along with the opening of private structures, but does not regulate the existing kindergartens and nurseries. For seventy years, the Government had been taking care of the education of the individuals (the first kindergarten in Mongolia was

opened in 1930), with the aforementioned act, education becomes the responsibility of the family. These restrictions, were the result of the economic crisis rather than due to political will.

To implement school integration of disabled children the Ministry of Education started to revise the programmes of the teacher training school in September 1993, by introducing basic knowledge on disabilities in children (the teachers at national level of the CBR programme could also be used for this purpose) and on teaching methodologies. A refresher course for existing teachers is also planned. And one teacher in each school will get further training so that he/she can work as support teacher for disabled children. In addition, the existing team of teachers who were previously trained in the former Soviet Union or in East Europe to work exclusively in special schools will get more detailed training. Their work as trainers, apart from those working in the Capital, is planned at provincial level. The Ministry of Education is supported in this reform of the school system by a Danish NGO, Danish International Development Assistance (DANIDA).

The Government and DANIDA have the following objectives:

- to promote changes in the attitudes of the population and school workers by increasing awareness about the potential of disabled children;
- to reform school programmes introducing up-to-date methodologies, teaching materials, new competences, etc.;
- to develop through the children's families non-formal teaching methods and materials for promoting education of children living in the more remote parts of the country.

At present pre-school education in Mongolia is not receiving adequate attention, leaving the more vulnerable groups, such as women and children, in extremely disadvantaged situations. In Mongolia, according to official estimates, 5-9% of families are headed by a women and about 50,000 children live with only one parent. Without any structure to take care of their children such parents cannot go to work and if they don't have a job they don't get any social insurance. At present only 10% of pre-school age children attend kindergartens and nurseries - available mainly in towns and provincial capitals. Much of the provision at somon level has been cut due to high maintenance costs. Without adequate pre-school provision attempts to integrate children with minor disabilities (the majority in this case), become very difficult. The increasing number of such children and the rise of previously unknown categories such as street children (at present there are about 1,000) are the source of great concern to the authorities. The National Centre for Children (NCC), which has branches in each province, is responsible for the implementation of the objectives sanctioned by NA and its activities are carried out in co-operation with UNICEF. Another organization co-operating with NCC is Save the Children Fund, UK (SCF). The representative of this

organization reached Mongolia in February 1994, and is now actively working for pre-school education. Presupposing that the NA objectives concerning pre-school education could be better attained by making the community at large assume more of the responsibilities currently regarded as the family, SCF's proposals imply that the government should promote not only private kindergartens but should also help to establish pre-school centres in urban areas leaving pre-school education in rural areas to the family.

SCF suggests the establishment of some kindergartens in the Capital at district and sub-district level, using tents (ger) built by the parents involved in this initiative, trained volunteers would be used as staff. I think that this a very good proposal because it would help reintegration of children with disabilities by allowing them to stay within their communities. In order to not to waste the existing human and structural resources, the staff working in state kindergartens, duly trained through refresher courses, should train and supervise the volunteers of these community kindergartens, and reorganize existing structures to support training activities and as use existing buildings as social centres. In other words, the aim is that of changing from a policy of state control, through a process of popular decentralization and mobilization process, to a participatory system. The collaboration between institutions and organizations (private and public) which was proposed during my latest mission (February-March 1994) is important because it will help to establish some common co-operation methodologies. For instance, from this discussion resulted that each project was collecting different data on disability separately.

It is fundamental to define a common strategy between different projects to avoid superimpositions and to establish a real co-operation. To reach an effective co-ordination and to benefit from project synergies, a seminar is going to be planned to be held in Ulaan Bataar next October. This seminar should be a good opportunity to define a long-term common strategy (through working groups, if necessary).

At present, the 'National Centre for Children' has a liaison role among the different institutions and organizations working in the field of disabilities in children:

- a. AIFO is co-operating with the Ministry of Health to start a Community-based rehabilitation programme (including a population screening to identify all disabled people),
- b. DANIDA is co-operating with the Ministry of Education for the training of teachers,
- c. UNICEF is co-operating with the National Children's Centre in their co-ordinating tasks,

d. Save the Children Fund is co-operating with the National Children Centre in pre-school education.

This is also an important phase for the CBR project co-ordinators, so that they learn to assume their responsibilities personally and go beyond the narrow health field to understand that the rehabilitation process is not only restricted to medical aspects but has to be part of a more extended project aiming at social integration into community.

9. Difficulties, limitations, etc.

It's too early to make an objective project evaluation at this stage. What I can do is to point out its characteristics, its difficulties and limitations.

One of its primary characteristics is that it is a national project. CBR programmes usually start as small scale pilot projects which are then extended if necessary. Those carried out on large scale or at national level, particularly in such big countries, are very few. But in Mongolia given the existing administrative set up and resource distribution it would not have been possible to plan the project any other way.

The Ministry of Health is responsible for the project and all rehabilitation activities are carried out at different levels by health staff (doctors and feldshers); in Mongolia, unlike in some other projects, participation of volunteers has not been planned in a specific way. We are aware that if the only involvement and change is at health structure level, there is a risk of altering the main characteristics of CBR, or it could lead to a restrictively strict medical approach to disability issues to the detriment of the social component. Re-education therapy - the intervention to develop a disabled person's potentiality, is only one aspect of the rehabilitation process, which should also include social and political aspects. All these aspects are linked and only with an integrated approach can a CBR programme attain its objective of reintegrating disabled people into the community. Otherwise, we can only restore ability and functions leaving individuals without any possibility to carry out social activities and benefit from their human rights.

Another problem may be that CBR could be considered as an additional programme, an alternative to the institutional rehabilitation model, and not complementary to it. Institutions are important if they support the community activity (referral system), through training, supervision, diagnosis, follow-up and so on. This support shouldn't come only from the health system but also from social, occupational and educational fields.

Finally, over centralized project management might indirectly lead to a lack of community involvement in the different phases of the programme. The different activities must be discussed with the community leaders, disabled people, family

members, and the organizations representing disabled people. A CBR programme dropped from the top is a contradiction in terms.

1. Conclusions

Although, theoretical discussions about CBR are easy, some questions may be asked about the practical feasibility of CBR projects.

Firstly, how realistic is community involvement in the field of rehabilitation?

I think that the experiences of existing CBR projects answer this question, in particular when the intervention on disability is considered as a part of a whole process aiming at giving to the community more control on its own development.

Another question might be, is it right to give more responsibilities to parents and family members, especially when these people are already living in extremely poor conditions?

It is for this reason that the role of referral services in supporting the parents and family members is so important. Proper support enables parents to understand their children's needs and provides them with a better awareness of their child's potential, helping them to set goals and finding support for other families facing similar difficulties.

We discussed the above mentioned matters with the project co-ordinators.

I'm aware that this maybe too technical a presentation, unfortunately this is my limitation. It has always been difficult for me to right down my experiences. If I could explain myself better, I would surely say not only more about the project but also about the proud and simple people of Mongolia, whose hospitality deserves a chapter apart. They have so long been forced to adopt a foreign language and foreign concepts and are now rediscovering their historical conscience and the pride of being a people with very ancient and glorious traditions.

I would like to conclude by thanking the Government of Mongolia, and the Ministry of Health in particular, for its interest and support to this project. Their support was particularly appreciated given the very difficult transition period of the country.