INNOVATIONS IN DEVELOPING COUNTRIES FOR PEOPLE WITH DISABILITIES

Edited by

Brian O'Toole and Roy McConkey

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Contents

SECTION 3: DEVELOPING SERVICES

1

Towards the New Millennium

Roy McConkey and Brian O'Toole

Disability occurs in every society throughout the world and has done so down through the centuries. Common responses have been shame, prejudice and exclusion from community life. Amazingly though, as we move towards the year 2000, the world community is agreed on what our social policy should now be with regard to people with a disability. This has been enshrined in various declarations of rights, the most recent being this 1989 article on the rights of children:

> *A mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.*
>
> ***Article 23: United Nation's Convention of the Rights of the Child.***

And not only is there an agreement on what the **aims** of our social policy should be but there is agreement as to how it is going to be attained, namely by supporting families and local communities to cope with disabilities.

As we have discovered in industrialised countries, the millions of pounds which have been spent on services and the veritable army of professionals that have been recruited, have not resulted in fulfilling those rights. Our institutions, our special schools, our sheltered workshops have not created a full and decent life for people with disabilities. And so we look to the bold new approach of community care to fulfil that aspiration.

Likewise in developing countries, where 90% of the world's citizens with disabilities live, there is a realization that community based rehabilitation (CBR), as it has come to be known, is the only feasible way of providing any sort of help to people with a disability. Once again, the hope is that by training families and community personnel, a modicum of help can be given to all those in need. The finance will never be found to support a professional workforce.

This shift towards community based care is more than just a pragmatic response. Rather it is based on a very important new perspective that we have on handicaps. This involves making a distinction between a disability and a handicap. A *disability* may be a biological given of a person but *handicaps* are socially defined. Hence today we can state two truisms.

First, we can say that *"a disability need not be a handicap"*. We can point to young people with Down Syndrome who have attended ordinary schools, who are in employment and who have many friends around their town or village. They have a disability but it has not become a handicap to them.

The second truism is that *"handicaps are in the eye of the beholder"*. To often we see a person in a wheelchair and think of her inability to travel on public transport rather than considering that she might be a talented musician, artist or school teacher!

Both these truisms represent a remarkable shift in accepted wisdom about disability and most people have great difficulty accommodating to these new ways of thinking. This includes disability professionals as well as families, communities and even people with disabilities themselves! We have all grown up believing that handicaps were absolute characteristics of 'unfortunate' people.

This new thinking creates a whole new role for services to people with disabilities and for the people engaged in them. Our functions are two-fold; *to develop people's talents* - and not just their cognitive ability but also their physical, social, artistic and emotional talents. And secondly that our role is to *create opportunities for people with disabilities,* to open doors for them.

Innovations in Developing Countries

This volume explores how these twin aims can become a reality in developing countries. The authors have been drawn from Africa, Asia and America so as to give a global perspective and all have been actively involved in developing and sustaining services for children and adults with a range of disabilities - physical, sensorial and intellectual.

For most people this has been an uphill struggle as they have battled against scarce resources, antagonistic attitudes and governmental indifference. Hard decisions have had to be made when faced with dilemmas such as:

- Is it better to give a little help to many people with disabilities, or to give a quality service to a few?
- Is it better to provide direct services or do you try to mobilise the families and community to help themselves?
- Do you set up a special service solely for people with disabilities or do you try to work through existing services which are available in the community?
- Do you focus on only one type of disability or do you try and help

people with various disabilities within a defined community?

- Do you base the service within an identifiable, often purpose-built centre or do you base it in existing community facilities and family homes?
- Do you restrict your help to certain areas or should you try to provide a regional or national service?

Response to Disability

These are dilemmas because each course of action has its particular advantages and disadvantages. Arguments abound in the literature and in conference halls but as yet we have little objective evidence to prove that any one approach produces better outcomes than another. Hence, decisions on these key issues have to be based on the opinions and beliefs of the service planners and policy makers.

In many developing countries this has proved disastrous! Outmoded Western models of rehabilitation services have been foisted on developing countries by international 'experts' and donor agencies. Finance is donated to build and equip rehabilitation centres which national budgets cannot afford to staff adequately or to maintain. Moreover such centres are invariably urban based and serve only a small minority of those needing help. If charges are levied, then only the more affluent people benefit.

Likewise, staffing models have replicated those found in the affluent west. Local people are given bursaries to train in Europe, North America or Japan in service settings far removed from the working conditions of home. They return ill-equipped to cope with local needs and not surprisingly many are enticed to emigrate to other countries where salaries and working conditions are better. Those who remain are frequently over-worked or trapped within hierarchical systems which give little credit to personal initiatives and innovation.

Consequently tens of millions of disabled people in the developing world receive no assistance; unaware of the international statements of rights issued on their behalf.

Starting Points

Amidst this depressing reality, our authors do identify some rays of hope. A number of themes re-echo throughout their chapters.

Firstly, ordinary people can reduce the handicapping effects of a disability if given appropriate knowledge and skills: Family members, neighbours and schoolteachers - to name but three groups - are available in nearly every community throughout the world. The challenge is to find ways of engaging them in helping and to give them the information they need to do the job. This task is just as pertinent in developed countries that wish to establish community-based services, for instance promoting paid employment for young people with intellectual disabilities.

Insert Photo 1.1 here

Secondly, services should be built around the needs of the people with disabilities and the needs of their families: A 'bottom-up' rather than a 'top-down' approach is more likely to do the job it is set up to do. Moreover, such services are more sustainable within local resources. It goes without saying that people with disabilities and their families, along with community activists, should be active participants in the development and management of the services. These can start at a local level before expanding regionally or nationally. Once again, the theme of user participation is coming to the fore in Western services.

Thirdly, the negative attitudes and prejudices of able-bodied people can be overcome: Every human culture has found its own explanations for why some of its members are born with disabilities. Invariably, these involve some form of supernatural punishments which invoke a sense of guilt and shame. Consequently, people with disabilities and their families are spurned and excluded from community life. But attitudes can be changed, especially through the advocacy of local people and by bringing people into contact with their disabled peers. Accurate information about the causes of disability also assists.

In western countries too, this issue is topical. For example the British government is committed to spending over £2 million on a national disability awareness campaign during 1995.

Fourthly, services for people with disabilities should be integrated into community development schemes: 'Enabling communities to help themselves' has become the slogan for sustainable development with the goal of ensuring that everyone in the community benefits in some way and not just one particular group. This calls for a radical shift in emphasis in CBR away from word 'rehabilitation' to the word 'community'. Major issues then ensue; should CBR programmes be located within health service structures and should they be staffed by rehabilitation specialists with little training and experience of community development work? Community-based projects the world-over still struggle with trying to balance the 'special needs' which arise from a disability and the 'common needs' which are unmet in the wider community.

Fifthly, people with disabilities and/or their families must become economically independent: Disability and poverty are almost synonymous the world-over although the welfare benefit systems of the rich countries protect their disabled citizens from hunger and homelessness. In poorer countries it is even more crucial that people with disabilities and their families do not become dependent on 'charity' from developed countries. Rather the goal must be to move people 'through services' so that others can get a share of the available help. Thus far, this has proved an elusive goal although the logic behind the aim cannot be questioned.

Throughout this book you will read of many imaginative ways in which these five aspirations have become a reality. By sharing information across cultures and continents we hope to bolster the morale of those already struggling to maintain services while encouraging others to develop new initiatives. Perhaps too we might cause some people to think again about the way they work at present. All of us need to look to the distant horizon to ensure that we are travelling on the right path.

Present Constraints

Various authors pinpoint particular difficulties they have encountered in their work. We summarise them here simply to offer a reassurance that it is no shame to admit one's problems and to encourage greater efforts at finding workable solutions. Nor are these difficulties unique to the developing world.

- **Personal Conflicts:** No project is immune from arguments be they among or between members of management committees, paid staff, volunteers and consumers. Projects can become identified as belonging to one person or professional workers disparage the contributions of their colleagues; the list is apparently endless.

- **Misuse of Funds:** Certain people in the organisation may be tempted to help themselves to the goods or money which donors had intended to be used to help others.

- **Bad Practices:** A charitable ethos can end up condoning bad practice in services on the grounds that *something* is better than *nothing*. Hence people are left in urine-soaked beds; children are tied into chairs to prevent them wandering and corporal punishments are often used.

- **Motivation and Enthusiasm runs out:** Projects often begin in a wave of enthusiasm but as time goes on, fewer people have to take on more of the work. This then becomes a self-defeating spiral as workers become exhausted. Ultimately, projects collapse through lack of interest although the need for them remains. In these circumstances it can be harder to restart, as people are discouraged by the previous attempts.

- **Aims become distorted:** Another common phenomena is that the project's aims can become distorted over time. The workshop designed to train people for jobs in the community becomes a sheltered workshop from which no one leaves. The parent-run, community centre is taken over by a professional worker and becomes a special unit solely for disabled children.

- **Funds run out:** This is a recurring problem as so many disability projects still depend on overseas funding. More time may be spent applying for monies than in doing the work! There is also the danger that projects are designed to meet the requirements of funders rather than the needs of local people! An allied problem is an over-dependence on expatriate staff; when they leave, the project may collapse.

This book has no instant solutions for these common problems, except one. All projects need to constantly evaluate their work so that they can pinpoint the specific problems, take corrective action and crucially check that these have had the desired effect. Moreover this evaluation should ensure that the service remains true to its aims and philosophy. Sad to say, few service providers in either the developed or developing world have heeded this advice; claiming to be too busy doing the job and having no time for evaluation. Which is akin to driving a car without ever checking where you are going or the state it is in. The outcomes are however similar - crashes and breakdowns!

Strategies for Initiating Services

Based on their varied experiences, the authors recommend particular approaches which they have found beneficial. Although these often vary in the detail, they share some common characteristics which we have summarised as follows:

- **Consult consumers and communities:** Take time to listen to families and people with a disability, get to know them and their lifestyle; share in their daily lives. Likewise, meet people from the community. In this way you will begin to see the world through their eyes.

- **Build relationships:** Communities, by definition, are based around relationships of one form or another. Hence the central task is to ensure that people with disabilities and their families are knitted into the relationships which already exist or through the building of new ones. This often begins with just one person.

● **Develop your skills as a trainer:** It has been said that effective CBR is based on three things; training, training and training! The passing on of knowledge and skills to families, CBR workers and community helpers is the essence of the work. Yet too often this is done in ineffective ways and without checking on what the learners need or want to know!

● **Nurture the family's capacity to cope:** This has been most frequently done through regular visits to the family home by a worker. Meetings with other families are another useful source of building family confidence and giving support to one another.

● **Nurturing the community's capacity to cope:** Building links with significant people in the community is another key task. Primary Health Care workers can advise families at home; teachers in nursery and primary schools can become more receptive to having children and young people with disabilities in their class; local businesses may offer work experience placements to young adults; and minibus drivers may have more patience with wheel-chair users.

● **Community Ownership:** The management of the project should remain with the local community, usually in some form of elected committee made up of service users, people with disabilities and interested people from the community. It is an unresolved problem as to how best to nurture the functioning of these committees so that services survive beyond the set-up phase.

Role of Government

Given this emphasis on community, we might then reasonably ask what the role of government should be? We must accept for the time-being, that disability will NOT be a priority for government expenditure. It is therefore unrealistic to expect them to directly fund services. The energies of lobbyists are better directed at encouraging governments to set the context in which appropriate services can grow and develop. This would mean:

- Enacting legislation to safeguard the rights of people with disabilities. Two areas have been the focus of international lobbying; the right to education and the right to equal job opportunities.
- Defining the government's aspirations as to the sorts of services they would like to see made available in the country for people with disabilities. Such statements have usually emerged from a process of systematic consultation with all interested parties and are updated through the formation of government sponsored bodies, such as a National Council for Disability.
- Assigning ministerial responsibility for disability issues, either within a single ministry, or by setting up an inter-ministerial group. This should make sure that a co-ordinated approach

develops across interested ministries while at the same time ensuring that disability issues are brought to the attention of all ministers. Parallel structures need to be developed for local government.

- Developing national standards for services and evolving mechanisms to ensure that these standards are maintained. This would apply in the first instance to services provided by government, such as education, health and social welfare services.
- The training of significant professionals should embrace disability issues, namely teachers, nurses and doctors.

Sad to say, the majority of governments have yet to embark on such programmes but much can be learnt from the experiences of those which have done so.

International Aid

Almost without exception, the innovative schemes described in this book are supported in one form or another by monies donated by international aid agencies. In what sense then can such schemes ever be owned by the community when they are reliant on external funding and subject to the priorities set by the funders?

This issue is so novel that no clear paths have yet emerged to resolve the paradox. Past notions of disability as being akin to 'relief work' or 'chronic sickness' are outmoded and yet present funding arrangements are often still based on these models.

Among the proposals under consideration for new ways of working are the following:

- All development projects need to be aware of disability issues, be it in education, agriculture or housing. Too many aid agencies still compartmentalise their programmes to the detriment of people with disabilities.
- People with disabilities are included among the regional representatives of donor agencies. They should personally visit projects applying for funds.
- Aid is given primarily in the form of seconded personnel who are linked with local partners to ensure transfer of skills and continuity of provision.
- International agencies enter into agreements with governments, either centrally or locally, to develop joint projects which have been developed through consultation with local communities.
- Funding is phased so that it gradually tapers off. For example projects may receive 90% funding for the first two years which reduces over the next three years to 75%, then 50% and 25%.
- Funding is given on a matched basis. Monies raised in-country are matched by the donor agency. Expertise is made available to communities on income generation strategies.

Names and Labels

Finally, a word about words as they invariably betray our perceptions and prejudices. A lively debate presently rages over the appropriate labels to describe people who have a disability. Disabled activists promote the use of the term, *'disabled people'* to emphasise that society has disabled them from living a full life. Others prefer the term *'people with disabilities'* which they feel emphasises that they are people first and their disability is secondary. Throughout the book you will find both terms used as chosen by the authors.

Similarly, the world's nations have been grouped into *'developed'* countries and those who are said to be *'developing'*. The latter term is especially ironic when so many poor countries are in fact becoming poorer! However alternative labels are equally unsuitable. Once again, the choice of labels has been determined by the authors of each chapter.

Of course these debates only arise because of our need to divide the world into 'them' and 'us'. Is it too much to expect that such divisions will become less significant in the new millennium?

Acknowledgement

Photograph by Liz Lee and taken at Lilongwe Cheshire Project,

Malawi

Roy McConkey is Director of Training and Research with the Brothers of Charity Services in Scotland. A psychologist by training, he has worked in England and Ireland before moving to his present post. He has completed many overseas assignments sponsored by UNESCO, the Leonard Cheshire Foundation International, Canadian International Development Agency and Irish Foreign Aid.

Brian O'Toole is a British educationalist psychologist who has worked in Guyana for 17 years. Initially he spent six years introducing and developing the Special Education programme at the University of Guyana. For the past nine years he has directed the Guyana Community Based Rehabilitation Programme. He has worked as a consultant in rehabilitation for PAHO-WHO, UNESCO, UNICEF and Save the Children UK and Norway.

Further Reading

The ideas summarised in this chapter and which re-occur throughout the book, are expanded on more fully in the following publications.

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2
Strengthening the Role of Disabled People in Community Based Rehabilitation Programmes

David Werner

I write to you, not as a health worker or rehabilitation professional, but from the perspective of someone with a disability. This is because we disabled people - like other disadvantaged groups - need a louder voice in the discussions and decisions that affect us.

I cannot, of course, speak for all disabled people because - like *non-disabled* persons - each of us is unique. We come from different cultures, different socio-economic classes, different histories of oppression and/or opportunity. Also, we have different kinds and degrees of disability. This sometimes divides us or breeds misunderstanding, even among ourselves. Each of us perceives the world based on our own vision, experience, and bias.

Yet we disabled people - everywhere on Earth, I think - do have something unusual in common. We have been *judged*, and to a greater or lesser extent *defined*, by our impairments rather than by our abilities or potentials.

What we all have in common is our difference. Many of our strengths are the fruit of our weakness. Even the experience of being marginalised - pushed out, if you like, from the mainstream of humanity - gives us an unusual perspective on the human saga: an *outsider's insight* from the vantage point of the disadvantaged. Be it with a limp, a cane, a wheelchair, or simply an off-beat dream, we march to a different drummer. And surely, today's world sorely needs a breaking of the ranks and questioning of the *status quo*.

This paper is based in an address given at a workshop on CBR held in Solo, Indonesia, November 1994 and is reprinted here by kind permission of the conference organisers and HealthWrights, Palo Alto, California

Rehabilitation of the Person or Society

To look creatively for solutions, it is essential that we view disability within the context of the local community as well as within the fabric of humanity as a whole. The needs of disabled people are related to the world that surrounds them; the culture, the attitudes and beliefs of family and community, local economic constraints and resources. Too often professionals working with disabled persons forget this synergy of factors. They tend to approach disability out of context, as an individual deficiency; treating it as a purely medical or technological problem.

The official response to disability is to provide something called REHABILITATION. Some disabled activists dislike the term *rehabilitation*, viewing it as an attempt to normalize or re-form the disabled person to fit into the existing society, rather than to require society to appreciate and adapt to the differences of the disabled person. In the words of Joshua Malinga, a leader of Disabled Persons International in Zimbabwe, "*It is society that needs to be rehabilitated*."

I appreciate this viewpoint. Nevertheless, I feel that for certain disabled persons, many of the activities and procedures known as *rehabilitation* can be important, especially if they help those persons to empower themselves, become more independent, and demand their rights.

But we must remember that disabled people - like other human beings - have certain vital needs, some of which clearly come before conventional *rehabilitation*. I am thinking of basic needs for *survival*.

In the rich countries of the North, activists in the *Independent Living Movement* have gained a lot of ground in their demands for *equal rights* and accessibility. But because these disabled activists mostly come from middle class backgrounds, they take certain things for granted. When they talk about *accessibility*, usually they mean such things as ramps, elevators and public transportation.

But for disabled people in the South - as for many non-disabled people - the main accessibility issues are how to access enough food, clean water, decent shelter and primary health care. Ramps and lifts for wheelchair accessibility are of low priority for persons who don't have a wheelchair - nor enough to eat.

In today's world - with its development strategies and structural adjustment policies that favour the rich at the expense of the disadvantaged - such basic needs are becoming more and more difficult to meet for all poor and marginalised people. This includes disabled people, most of whom are also poor and marginalised. It is therefore important that we disabled people do not look at either our marginalisation or our need for rehabilitation - which I prefer to call *enablement* - as separate from the struggles for enablement of other marginalised groups.

Rehabilitation as Enablement

Given these considerations, we can then ask: *what kind of 'rehabilitation efforts' would be most appropriate from the perspective of disabled people?* Clearly they are ones which will help us to empower ourselves, so that we can join with other disadvantaged and socially concerned groups, both locally and globally, to work towards changing the power structures that deny us our basic rights to meet our needs and potentials.

So what kind of rehabilitation efforts now exist in developing countries? Current programmes embrace a wide spectrum, falling between two poles: *top down* and *bottom up*, or put another way, between those that try to *normalize* disabled people and those that help to *liberate* them.

Unfortunately, most services for disabled people remain very institutionalized and top-down. Delivered by costly professionals in hospitals or large urban centres, they reach only a tiny portion of those in need. Many of these palatial urban centres are equipped with all the most modern, expensive therapeutic equipment, imported from the North. Too often, however, much of the therapy executed on disabled clients tends to be at best ritualistic and at worst, counter-productive. Even special seating is often thoughtlessly standardized. Children of all sizes and disabilities are strapped into oversized chairs that increase, rather than help correct spasticity and deformity. In some of these institutions you get the feeling that disabled people are lovingly dehumanized, on the assembly line of an elaborate robotics factory.

Fortunately, during the last 10 or 15 years, things have begun to change. Forward-looking planners have begun to realize that the needs of the vast majority of disabled persons can only be met by *deinstitutionalising* services, so as to place rehabilitation skills in the people's hands. There has been a growing effort by national and international agencies - and by a few of the more socially conscious disabled people's organizations - to reach the countless disabled people whose needs and potentials remain unmet.

The most exciting and potentially revolutionary of these approaches - loosely dubbed ***community based rehabilitation*** or ***CBR*** - attempts to move the focus of rehabilitation from the extravagant *"rehabilitation palaces"* into under-served communities and homes.

Community Based Rehabilitation

In spite of the World Health Organization's early attempts to rigidly standardize the approach, the term *CBR* covers a wide range of initiatives. At one end of the spectrum are ***large CBR programmes launched by government***. Although these programmes do reach out to many more people, they still tend to be structured from the top down, in ways that *normalize* rather than *empower*. Rehabilitation measures usually follow a set of oversimplified, prepackaged lesson plans. In practice they tend to be even more ritualistic and ineffective than in the large urban rehabilitation centres. The whole approach is very hierarchical. The *district supervisor* supervises the *local supervisor* who supervises the *home supervisor* who supervises the *disabled person*, who is definitely the 'low man' on the totem pole. Thus disabled people become the objects, not the subjects, of their rehabilitation. They are trained to jump through hoops and are graded for their performance.

Of course, some good things do happen in these programmes, especially when there is creative leadership that dares to go outside the norms. This sometimes happens when disabled persons themselves take the reins and begin to restructure the programme on their terms.

At the opposite end of the CBR spectrum are ***small community programmes run by the disabled persons, or by families of disabled children.*** These tend to be woefully disorganized yet very exciting. Every programme is different. In the best ones, disabled persons become peer counsellors and skilled technicians. They may make low-cost wheelchairs, orthopaedic appliances, prosthetics, and a wide range of rehabilitation aids. We have found that the quality of their work is often as good as or superior to that of many highly trained rehabilitation professionals; especially in the care they take in making sure appliances and therapy really match the needs and wishes of each individual.

This is not to say there is no role for rehabilitation professionals in these programmes. Even in Community Rehabilitation Programmes run and controlled by disabled persons, the co-operation of competent professionals for teaching and back-up is essential. Indeed, the lack of adequate professional support and referral is one of the biggest obstacles to successful community based rehabilitation.

In some of the most outstanding CBR programmes, a vital role in their success has been played by exceptional rehabilitation professionals - ones who are willing to go into the community, share their knowledge, and learn from the people *as equals*. But even more important to the success is the *leadership of disabled persons themselves*. I want to emphasize, that when given the opportunity, ***disabled persons - even with limited formal education - often make excellent rehabilitation workers and community health workers***. We discovered this in Mexico, completely by accident. Let me tell you about it.

Project PROJIMO

For much of the last 27 years I have worked with villagers in Western Mexico. Together we have looked for solutions to health-related needs. A villager-run, primary health care programme, known as Project Piaxtla, gradually evolved. Villagers wishing to participate would choose someone from their community to take a 6 week training course as a *village health worker*.

In the selection of health workers, a curious thing happened. Some villages chose a disabled person. This was not because they thought a disabled person would make an especially good health worker, but rather because they were the persons most available. Unable to do hard physical farm work, and often unmarried because of local taboos, disabled persons were among the few persons with free time to take the training course.

As the years went by, some of these disabled health workers proved to be among the most outstanding. This is understandable, because by becoming health workers disabled villagers were able to move from a marginalised to a centrally important role in their community. Because of what they had been through themselves, they had more empathy for other disadvantaged persons and tended to reach out to those in greatest need. So in a way, through health work, their weaknesses led to their strengths.

In time, some of these disabled health workers became leaders in the village health programme. They became concerned that their programme did relatively little for disabled persons, especially children. So, in 1981, the health workers met with families in the village of Ajoya, and started a programme called PROJIMO: Programme of Rehabilitation Organised by Disabled Youth of Western Mexico.

PROJIMO is run and almost entirely staffed by disabled villagers. Although most have little or no formal schooling, they have achieved recognition for a wide range of skills. These include peer counselling, medical and nursing care as needed, physical and occupational therapy, as well as self-care and skills training. The team makes high quality low-cost orthopaedic appliances, artificial limbs, wheelchairs and many other aids and equipment. Most of these skills they have learned through hands-on, problem-solving apprenticeship during short-term visits by friendly rehabilitation professionals, many of them disabled themselves.

The collective of disabled young people at PROJIMO, have begun to assert their rights as they have gained respect and self-confidence. They have pressured the local community to build ramps for access into public buildings and stores, and they have pushed for the admittance of disabled children into normal school.

One time the soldiers came into town and arrested a village health worker on charges of treating a fugitive whom they had shot. As the soldiers threw the health worker into their truck to take him away, the able-bodied villagers peaked from their doorways. But they dared not protest, for the soldiers can be quite brutal. However the disabled group from PROJIMO did not hesitate. On crutches and in wheelchairs, the young men and women surrounded the truck and refused to move until the soldiers released the health worker. Put off their guard, the soldiers gave in.

Although the modest centre is located in a small, remote village, disabled young people have come to it from 10 states of Mexico. The programme has gained the respect of the director of the government-run centre for Rehabilitation and Special Education (CREE) in the state capital. CREE has contracted with PROJIMO for prosthetics and orthopaedic appliances.

At present, the PROJIMO team of disabled villagers has a contract with UNICEF to make low-cost, high quality wheelchairs for disability programmes in other states.

The PROJIMO team has also functioned as advisors and facilitators in neighbouring states, where disabled persons themselves have been recruited to take the lead in setting up and managing CBR programmes. Today a growing network of non-government, community based programmes with strong leadership by disabled people and/or their families exists through Mexico and much of Central America.

For the last two years, PROJIMO has led a series of short courses for disabled leaders from different community programmes in Mexico and Central America, focusing on themes ranging from limb-making to massage therapy; from disability rights to sexuality of disabled persons, as well as integration into schools and peer counselling among disabled persons and among parents. These courses and workshops have expanded out of PROJIMO and are conducted by the larger, grassroots network of community programmes.

Although this network is made up completely of non-government programmes, the disabled team members of PROJIMO have also willingly collaborated with government efforts. But they deeply value their freedom and the control of their own programme - so much so that they turned down an offer to work at the CREE centre in their own state for three times their present, very modest salaries.

Finding Solutions from My Own Disability

My conviction that disabled persons - including children - should be involved in the planning and decision-making of their own rehabilitation also comes from painful personal experience. I have an inherited, progressive muscular atrophy. As a child I had very weak feet and ankles, so an orthopaedist prescribed arch supports. I hated them because they made it harder for me to walk. They bent my weak ankles outwardly just enough so that I was constantly spraining my ankles. I would take them out of my shoes and hide them. But my parents would find out and both they and the orthopaedist would scold me.

Later I was prescribed heavy metal braces which, although they protected my ankles, made walking so awkward and tiring that I finally abandoned them.

It was not until many years later, when I began to work with the team of disabled villagers in PROJIMO, that I realised that as a child my disapproval of the arch supports made sense. They did me more harm than good.

Only since I began to work with PROJIMO, and could actually take part in the design and improvement of my own braces, do I now finally have top-quality orthopaedic appliances that really answer my needs. They are plastic AFOs but with unique features adapted specifically to my needs. With these braces I can walk better than I could 30 years ago, although without them I can barely walk. They have given me a new degree of freedom and ability.

For this reason I am committed to ensuring that other disabled persons participate as fully as possible in the assessment of their own needs and in the design, innovation, and evaluation of their own therapy and equipment.

Programmes Staffed by Disabled Persons

There are many reasons why a Community Based Rehabilitation Programme should be run and staffed mostly by local disabled persons:

1. Having an impairment themselves, disabled workers tend to be ***more sensitive to the needs and feelings of other disabled persons***, and to relate to them more as equals.

2. Because of this sense of equality, disabled workers are more likely to ***involve those who come for rehabilitation in the problem solving process***. This permits the disabled person, even children, to play an important role in evaluating their own needs and in figuring out what therapy or assistive equipment might be effective. Disabled people then become the subjects, not the objects of rehabilitation.

3. Because of the insight which the workers gain from their own disability, the rehabilitation aids and therapy they provide often

are ***better at meeting the real needs*** - and felt needs of the user. I should point out that in the United States and Europe, some of the real breakthroughs in design of wheelchairs, prosthetics, and orthopaedic appliances have been achieved by disabled wheelchair riders, amputees, and brace users who were dissatisfied with the equipment provided to them, and set out the improvements needed.

4. Perhaps most important of all, is the ***role model*** that disabled leaders and crafts-persons present to disabled children and their families. In Mexico, as in many parts of the world, most parents deeply love their disabled children. But they overprotect them. They do everything for them and don't let them do much for themselves. They may not let them play with other children, or go to school. They expect them to be helpless and dependent.

   When such a family arrives at a place like PROJIMO these attitudes are turned around. They see villagers in wheelchairs and on crutches running the programme, providing medical and nursing care, performing a wide range of skilled services, earning their living, raising families, enjoying life and doing more to help other people than most non-disabled persons do. It gives both the parents and their child a whole new sense of what is possible. And that is the first big step of rehabilitation - or *enablement* - and ultimately of *empowerment*.

5. Having disabled persons with limited formal education as leaders and highly skilled technicians helps to ***demystify*** the rehabilitation process in two ways. Firstly, it shows that first hand experience and personal commitment can sometimes outweigh years of rote learning and official diplomas. Secondly, it moves disabled persons - both providers and clients - from the role of passive recipients to ***active participants*** in the rehabilitation or enablement process. Thus the example that a competent disabled rehabilitation worker provides not only engenders a new, more open and liberating point of view to the disabled child and family, but also to society as a whole. This includes non-disabled rehabilitation professionals, whose attitudes are often the hardest to change.

6. Finally, providing hands-on skills training and leadership opportunities to disabled persons in the field of rehabilitation and disability rights provides ***employment*** of such people in an area where their disability can also be an outstanding qualification in community health work. I hope the day will soon come where planners and administrators recognise the positive side of disability and - other qualifications being equal -

give preference to disabled candidates in job training and leadership roles, especially in relation to work with disabled people.

Disability Rights

I believe that disabled person have a right to play a leading role in organisations and activities that are committed to their well-being. In this context, we should compare *disability rights* with *women's rights*. Most of us would find it unconscionable today, that an organisation committed to the concerns of women should be directed and staffed by men. Yet when it comes to disability, our consciousness is still underdeveloped. In many countries organisations for "the disabled" - especially rehabilitation centres and programmes - are still mainly directed and staffed by non-disabled persons.

Women in most countries are now demanding their right to leadership in the institutions that represent their concerns. It is high time for disabled people everywhere to make similar demands. It is time for planners and administrators to provide the necessary opportunity, encouragement and appropriate skills training. And, most urgently of all, it is time for non-disabled professionals to recognise the right of disabled persons to self control, and therefore to gracefully step to one side, into a role where they, as professionals, are no longer *on top* but rather *on tap*.

Strengthening the Role of Disabled Persons

But much remains to be done. I list below a number of shifts in policies and approaches that decision makers, funding agencies, and organisations of disabled people might make to help strengthen the role and leadership of disabled persons in community based rehabilitation.

1. Organisations of disabled people and the families of disabled children: In order to achieve a democratic and potentially liberating restructuring of rehabilitation services, disabled people need to organise and pressure for full participation and leadership in all stages of the CBR process.

In the industrialised countries of the North, during the last 15 or 20 years disabled people have made substantial advances in terms of opportunities and more equal rights. But changes in legislation and public attitude have come about through a long struggle and organised demand by disabled people themselves. Today, in poorer countries in the South, disabled people are just beginning to organise. In Mauritania, under the leadership of Tambo Camara, such organisations have played a key role initiating CBR programmes with strong input by disabled persons. It is important that such bottom-up approaches be encouraged and supported.

2. Redefinition of goals: Our present rehabilitation efforts, while important, are but a drop in the bucket. The structural violence in today's world is producing disability much faster than it can be dealt with. The most basic needs of millions of disabled persons will not be met until the social forces that are increasing levels of poverty, malnutrition, unemployment, homelessness, repression, and violation of human rights, are confronted and transformed. Therefore, *the long term value of any rehabilitation or development effort must be evaluated in terms of how much it empowers marginalised groups and moves us towards fairer, more fully democratic social structures.*

It is important that disabled persons themselves contribute to rethinking the underlying goal of "rehabilitation". Too often the tacit objective of rehabilitation - especially when approached from the *top down* - is to ***normalise*** disabled persons into the existing unfair and discriminatory society. By contrast, the goal of the alternative, bottom-up approach is to ***empower*** disabled persons to joining in an organised struggle of all disadvantaged and marginalised groups, to *change our present society* into one that is fairer, more truly democratic, and more accepting of human differences.

The goal of this alternative approach to rehabilitation - or *enablement* - is not to force open doors which society has closed against disabled persons. Rather it is to tear down the walls of inequality, to work towards a social order that provides all people - weak and strong, rich or poor, male or female, black, brown or white - with equal respect, equal opportunities, and equal rights.

3. Restructuring rehabilitation services from a *top-down* to a *bottom-up* approach: Too often so-called "community-based rehabilitation" is, in practice, more of an extension programme into poor communities than one that is based, planned, and managed within the community itself. The skills pyramid needs to be turned on its side so that disabled persons and family members become the front line workers, so that mid-level rehabilitation workers become facilitators and back-up persons rather than "supervisors" (which means those who *look down from above*) and the rehabilitation professionals are ***on tap*** and not **on top.**

When selecting rehabilitation workers (at all levels, but especially at the community level) *disability must be rated as a key qualification*. Give it equal or greater weight than other qualifications. Actively look for and encourage disabled candidates for such posts. Provide special or additional training for disabled persons in the areas where they may be weak or less qualified (including organisational and management skills).

4. Re-educating professionals: They need to recognise and contribute to the development of the full potential of disabled persons, to involve their disabled clients as partners in defining and resolving their needs, and to encourage their participation and leadership in the planning, administration, delivery and evaluation of rehabilitation services.

5. Encourage and support the active participation of organisations of disabled people in launching and leading CBR initiatives: Funding agencies and organisations should give *preferential funding* to CBR programmes which are started or run by disabled groups, or which maintain a certain quota of disabled people at all levels, including technical and decision-making posts. Be sure programmes include a plan and timetable for training disabled persons to move into such posts.

6. Set up small community centres: Here disabled persons and family members can come together, exchange information and experiences, and provide assistance and advice to one another. For example, a mother who has cared for her child with cerebral palsy for many years, and has learned many skills and *tricks* in caring for her, can provide valuable advice to the mother of a new-born with cerebral palsy.

The standard CBR approach, devoted mostly to home visits, often does not do enough to promote information sharing between and among disabled persons and their families. The creation of a small community centre can help facilitate this process, especially when it is run by disabled persons and/or their family members themselves.

7. Work toward moving referral and technical services closer to the communities served by CBR: In many CBR programmes a wide, often unbridged gap separates the very basic front-line home-based CBR services and the distant, urban referral services. The result is that a great many disabled persons go without the rehabilitation and technical aids they need. To solve this problem, such activities as brace-making, prosthetics, wheelchair making, more advanced clinical assessment, testing of vision and hearing, non-surgical correction of contractures, and/or various types of skills training, can be carried out in the above mentioned community centres.

To carry out all these more highly skilled rehabilitation functions, local disabled persons can be trained in specially designed "hands-on" courses. These workers can be given modest but fair salaries, proportionate to what other semi-skilled workers earn in the community. The money for these salaries could be taken from that saved by not having to refer so many persons to the distant, expensive, urban rehabilitation centres. Such decentralisation of referral and technical services could in the long run be more economical and supply badly needed, and possibly more appropriate, services and appliances. At the same time it provides meaningful work for promising, young disabled person.

8. Encourage decentralised and egalitarian organisations of disabled people: The two most exciting and potentially liberating advances for the rights and well-being of disabled people in the last two decades have been firstly, the growing organisations run by disabled persons, together with the Independent Living Movement, and secondly, the Community Based Rehabilitation Movement. Each has its strengths and weaknesses.

- The strength of the organisations of disabled persons and the Independent Living Movement is that they are run and controlled completely by disabled people who actively demand respect and equal opportunities in society. The weakness of organisations of disabled persons, in the South as in the North, is that both its membership and its agenda are urban-based and largely middle class. The poorest and most marginalised of disabled persons are not included for the most part.

- The strength of the CBR Movement is that its primary focus is on the poorest and most disadvantaged disabled persons, and that it reaches into their villages and homes. Its weakness is that too often disabled persons are passive recipients rather than active leaders in the rehabilitation process.

Greater co-operation between the organisations of disabled persons and community based rehabilitation programmes can help each of these important initiatives become more empowering in approach and more egalitarian in coverage. In a number of countries, CBR programmes have been started by organisations of disabled people. In other countries, CBR initiatives have helped disabled persons to begin to organise and take united action. Either way, disabled persons need to take a more active and leading role in the CBR programmes.

Conclusion

In closing, I would like to re-emphasize how important it is that *disabled children have role models of disabled adults who are* *successful, who are committed to helping others, and who have learnt to stand up for their rights.* When a family with a disabled child sees a team of disabled local persons *doing so much, so well for other people,* it gives both the parents and the child a whole new sense of what is possible. It awakens them to the changes that can happen when marginalised people join together, take charge of their lives, and demand equality.

It is essential that we disabled people help to design, and take the lead in *enablement* programmes that do not try to normalise us into an unjust society, but rather empower us to become leaders in the struggle for transformation. Together we must work toward a social order that provides all people - rich and poor, weak and strong, disabled and non-disabled - with equal opportunities, equal rights and equal respect.

David Werner is the author of *Where There is No Doctor* and *Disabled Village Children*.

Contact Address
HealthWrights
964 Hamilton Drive,
Palo Alto,
California, CA 94301
U.S.A.

3
Fostering Parental Involvement

Pramila Balasundaram

This chapter is based on informal and leisurely conversations with families whose children have a mental handicap. Most of the parents who participated in these conversations have their children attending the Day Care Centre run by SAMADHAN and located in a low income area of Delhi. Although our observations are based on over ten years of service delivery in poor urban areas and with children who have a particular disability, the same issues are likely to arise in any situation where parental involvement is sought in service delivery.

SAMADHAN is a non-governmental organisation (NGO) started by the author in 1981 specifically for children with mental handicap and their families living in areas of poverty and low income in Delhi. The realisation that services were available only for children aged five years and over, and that they were all located in the urban parts of Delhi, prompted our dual focus on low income areas and on infant and preschool children with mental handicap.

Funding is mostly from donor agencies abroad but also from the Ministry of Welfare and through our own efforts at fund raising. Today the organisation provides services to around 500 families and has five centres which offer special education, vocational training and early intervention in addition to the parent programmes.

At first, our services were provided only in the day care centre. But it is always the parents who have the greatest influence in a child's life and hence we have learnt to make mothers and fathers an integral part of our programmes. It was also important to see them as valuable sources of support for us, and as partners with us, in working together for the final benefit of the child.

Parent-Professional Partnership

Traditionally disability services have been oriented only to the child's needs. Usually in such situations, the responsibility of the professionals has been confined to informing parents of the child's progress. The care, education and training of a person with a disability was thought to be so specialised that "mere parents" were seen as unable to handle their own children. Today it has been realised that involving parents in the care and teaching of the child with disability is absolutely crucial. The question is therefore no longer whether parents should be involved but *how* and *when* they should be involved.

Saroj's Story

Saroj is the mother of a seven year old, Down Syndrome child. She recently surprised everyone by speaking out very confidently and with great courage at a National meeting of NGOs. She lives in Dakshinpuri, which is a low income area in Delhi and she is illiterate. However, she was not always so articulate or self confident.

When we first met her and her son, she seemed to have accepted the disability of her son and showed a remarkable degree of composure. She answered all the questions necessary in filling out our family information forms. Since her son was just three, the boy was put on our Home Intervention Programme and one of our workers, also from the same community, was assigned the job of visiting her in her home and beginning the transfer of home management skills to Saroj.

But contrary to our expectations we found that no progress was being made. Saroj would dutifully listen and work as long as the home visitor was present but once she left, no work was done. It was only gradually that we realised that whenever we met Saroj she would put on a brave show for us but that deep down she had yet to accept the fact of having borne a child with mental handicap. She was not yet ready to assume the responsibility of meaningful work with the child because she was still going through the process of grieving and making the many adjustments necessary when a child with disability is born in a family. Her mother-in-law was not supportive and openly scoffed at her attempts to obtain help. The husband was sympathetic but of no help to Saroj. He was a daily wage labourer who worked whenever he obtained a job. He was very conscious of his inability to support Saroj.

In Saroj's case we also discovered that she had been promised a job as a worker in a local factory with good wages. This would have enabled the family to achieve a better standard of living. She had planned to start working after the baby was one year old. But now it seemed as if she would never be able to realise her ambitions. When she was asked why she never told us all this when we were doing the family history, she replied very simply, "You never asked me about my future plans or what I will do now. You were only interested in the baby."

Insert Photo 3.1 here

Acceptance is a Prerequisite to Involvement

Saroj's story taught us a few lessons. When representatives of a service delivery programme first contact parents it is of course necessary that the often time-consuming task of filling out family information data be done as a first step. However, by personally visiting the families at home, first hand observations can provide information which will not come out in a verbal interview carried out at a centre.

Talking to other members in a family will provide different perspectives. Family life styles can give a more realistic picture of whether or not a parent, the mother usually, will have the time to work with the child.

Some of our concerns will be whether the demands made by others in the family on the mother's time and indeed her energy, will leave her with enough time for the child with disability. Is much of her time taken up by routine household chores? Is there someone who can relieve her of some of these chores so that she can spend quality time with the child? These are some of the details which will need a family discussion.

Telling the mother to go home and talk to her family and organise her day in such a way that she will get the time to work with the child is unrealistic. It has been our experience that often mothers do succumb to pressures of critical or non-supportive family members. In such situations, the informal social visit of a community worker or a professional counsellor will provide the mother with the support needed. If the family sees that the skills of the mother are valued and that the development of the child is dependent on her input, there is always a willingness to try. This has held true for all parents whatever the economic group to which they belong.

This is what happened with Saroj. It was only after many visits to her home and discussions with her husband and her mother-in-law that Saroj was "allowed" to come to the centre with her son and the home training programme followed. Today she is an articulate advocate for the benefits of parent involvement. She is a respected member of her community because having undergone a period of training she now helps us in our work in reaching out to the community by acting as a catalyst.

Nurturing Parental Growth

How do we know when a parent is ready to get involved with service delivery? Our experiences tell us that unless there is acceptance, involvement does not happen.

The bonding or relationship between the mother and the infant begins right from the birth of the child. The mother of a child with disability will be often unable to do this bonding because the disability of the child will make this extremely difficult and it may even prove impossible if the child is severely disabled. Mothers of non-disabled will automatically respond to the needs of the child and react positively to the many cues which even a young infant will make. For instance if the child shows interest in an object the parent will use the situation as an opportunity for teaching skills or for play.

A mother who is depressed will be unable to respond to the cues of the child. So the special relationship between mother and child will be extremely slow in developing and sometimes may not develop at all if there is anger or rejection. So, keeping in mind that the reason for involving parents is to maximise the development of the child, it is necessary to first ensure that the parents, and particularly the mother, has achieved a certain amount of emotional maturity.

It is easy to come to conclusions about parents who are not participating by labelling them as uncooperative, overprotective, lazy, or uncaring. Very often the reasons may be that the parents are still grieving, or frustrated at lost ambitions, or resenting the extra work and financial burden. The many emotions parents go through at the birth of a child with disability are well documented; the sorrow, the anger, the shame, the despair and the death wish. Service providers need to be patient, willing to listen at all times and not be critical or judgmental. If parents have not yet accepted the fact of disability in their family, parent involvement may be counterproductive.

All parents can be helped to work towards parental growth in several ways. The first step will be to provide adequate emotional support. If this can be done as soon as the parents know of the baby's disability the better the chances for an early acceptance of the fact of disability. In many societies the myths and superstitions which surround the birth of a child with disability still exist. It is essential to explode such myths, especially when the mother is cited as the cause for the child's disability.

Siba's Story

Siba was a very young mother. Married when she was sixteen years old she had her first baby when she was seventeen years. Sadly for her and her husband, the child - a boy - was born with a handicap. This made it extremely difficult for young Siba to regain any sort of normality in her relationships, either with her own or husband's family as well as with neighbours and society in general. Accusations that she had brought bad blood into the family, that she must have sinned in her past life and was now reaping the bitter harvest, almost unhinged her sanity as did the taunts and much well meaning advice on what she should now do with the "burden" of a child. Being very young and vulnerable, she found solace in complete rejection of the child. Economically well off, it became the responsibility of her own family to baby sit.

Siba was brought to the centre by her husband and we discovered that in him she had a loyal and faithful supporter. Counselling sessions were therefore planned to include Siba, her family, her husband and his family. Sessions began with showing them how unrealistic it was to blame everything on Siba. It was hardest to convince mother-in-law who saw her son as perfect. Introducing Siba to other parents gave her the realisation that she was not alone. Introducing the husband to other fathers made him see that one could continue a normal family life and that indeed other families had done so.

Siba's 'in-laws' finally stopped making an issue of the situation and using Siba as the scapegoat for every misfortune that befell the family. This did take many months but the time and energy invested in the counselling resulted in her beginning to care for the baby herself, instead of leaving him in the care of her own mother. Bonding took place, slowly at first but the day came when Siba began to take delight in every small thing the baby could do. She would report on such occasions with enthusiasm; "he smiled at me today"; "he makes noises when he wants his milk", and so on.

What was happening was that from rejection, Siba had slowly and painfully reached a stage where she accepted the baby as her own. His little needs were met and when the baby in turn responded, it motivated her to start taking complete care of the baby. She still had a long way to go before she could actively start involving herself in the child's development, but the process had begun.

With acceptance came the realisation that the baby was her responsibility. The counselling sessions had been planned to help Siba confront the problem. The process of confrontation is painful. Siba had to admit to herself that the birth of a baby with a handicap had indeed introduced a problem in her life. The question now was to how best to solve the problem.

There were really only two options. Either go through life moping about how unfair it was that she should be the mother of a child with disability or do something about it. This in turn meant admitting to herself that "yes, there is a problem but the problem is mine and I am the one who has to solve it. In solving it I help my baby." It meant being honest with herself and looking at the problem squarely in the face.

It has been said that "those things that hurt, instruct". So it was with Siba. Her capacity to solve the problem was challenged and through the pain of confronting and resolving the fact of having given birth to a baby with a disability, she grew mentally and emotionally. She learnt to put the baby's needs before her own. She took time to observe and think about the baby. She realised that the time she gave the baby and more important the quality of the time she spent with the baby had to change. This took great courage and self determination and most of all a self discipline which was to change her life as well as that of her husband and eventually of his family. This is the best example of parental growth.

There are no short cuts towards achieving such self discipline. Discipline has been described as a system of techniques of dealing constructively with the pain of problem solving. Was Siba able to achieve this transition because she was still young? We do not know the answer. But it shows that when the parents learn to accept and love the person with a disability in their family, then the strength and the energy to cope follows.

Focus on Family Counselling

It may not be possible for all parents to confront their problems so successfully. Some parents may resent the intervention of counsellors or other care givers. Usually attempts at involving such parents in any meaningful activity will fail. There are no rules on how to handle such situations. Each individual parent and family will need an approach best suited to their characteristics as a family and the nature of the problem, and whether or not they have support already available. But it can be safely said that a majority of parents will respond to *warmth and friendliness* and a *non-judgmental attitude*. What will differ is the time taken by different families to reach a stage when they are ready for involvement in service delivery. The healing process must be complete before this can happen.

This is when counselling will prove invaluable. Through the right kind of counselling, the attitudes of the parents towards the child can be improved, particularly if there is a very negative person in the family. A holistic approach to the ***wider family*** has proved to be the best strategy rather than focusing on the parents and the child or as happens most often, focusing on the mother only and expecting her to take on complete responsibility. It is important to recognise that every member of the family will have some kind of skills in coping. A person with a disability in a family will affect different members of the family in varied ways.

Family Strengths

Down through the ages, parents have been caring for their children with a disability in whichever way they thought best and within their capacity to do so. So obviously parents have some measure of coping skills. What are these skills and how do parents use them? Professional workers need to identify and build upon these skills.

To do this effectively we begin by trying to gather as much information as possible of both the strengths and the weaknesses of parents, both as individuals and as part of a family. All of us have our strong and weak points, and the term 'weaknesses' is not used in a negative sense but rather to identify the particular supports which individual families require.

Building on strong points or abilities of parents will obviously obtain better results. This will also help in identifying specific skills a parent may have and in allocating responsibilities to that member of the family who is best suited to it. This may be not only the father or the mother but a sibling or even grandparents. In joint families it may be any one who is part of the extended family. What parents can do will also depend on their financial status and their educational and socio-economic background.

An honest face-to-face discussion about the family members' own abilities and skills will be needed before they can decide on how exactly they can be involved. An exercise in self analysis can identify their skills and their strengths. No one expects parents to be experts or have all the answers. No one is asked to be a SUPER MUM or a SUPER DAD. But the first hand experience they have of living with a child with disability will be invaluable. Making an assessment of family strengths is therefore an extremely useful exercise.

Family strengths will include the total hours which family members can give to the training of a child with disability. It will mean identifying which member of the family has the necessary skills which will most help the person with disability. If the mother takes on the responsibility of working at fixed times with the child with disability, then another member of the family can take on the chores of shopping, for instance. Even younger siblings can help by doing the simple tasks preliminary to cooking, like cutting up the vegetables or washing up. The men in the family can take on the responsibility of providing a recreational outing for the child thus giving the mother a break. Hence family chores and responsibilities can be divided up among the family members.

Lakshmi, a sibling of a speech and hearing impaired boy with mental handicap is adept at using left over pieces of coloured cloth to fashion colourful mobiles for her brother's crib. Broken glass bangle pieces are bent into semicircles over a candle flame to make many interesting play materials. These are used for the cognitive training of the disabled child and the other non-disabled sibling as well. Lakshmi's contribution and the strength she gives to her family is her creativity.

One cannot emphasise enough the need for all family members to pull together. Husband-wife relationships within the family will have obvious repercussions on the development of the person with disability.

Working Together

Parent-professional partnerships form the core of any attempt at parent involvement. When professionals respect the parents' viewpoint, they are listened to more willingly and parents benefit from their expertise. But sometimes parents may not agree with the decisions made by the professional about training programmes. Family needs may dictate more urgent priorities. In our group discussions with parents, the need for the time-consuming jobs of feeding and toilet training were almost always seen as priority but academic skills were not so important.

Ravi, one of the children in our centre was being taught to dress himself. The parents, however, insisted that he should be taught to feed himself first. This was an activity which took more time and since both Ravi's parents were working they did not have enough time to feed him in the mornings before they left. They were not so concerned about Ravi learning other skills. Discussing with the family what skills will be taught first and how much of the training they themselves will be willing to undertake is an essential step in obtaining the cooperation of parents.

What Kind of Support do Parents Need?

Parents who have very minimal educational qualifications respond best to a training programme tailored to suit their specific needs. This may be once a week or a few hours a day depending on how much time is available for attending such sessions. Those with more education may expect more formal training with plenty of opportunities for discussion. Parents who undergo such training do feel a sense of confidence and this helps in coping with their own child at home. They are also better equipped to face confrontations at home or from the community.

Sometimes it is difficult for parents to make time for formal training. With these parents, even coming to the centre and observing a class in progress and the way the teacher handles the child, can provide incentives for a greater participation. Obviously the process of engaging the parents will be longer but the end result will be the same.

It is only when parents have had sufficient experience working with their own children that they are ready to take on responsibilities outside the family. The best advocate for parent involvement is another parent who has trod the same road and found strength and confidence to continue in spite of the odds (see chapter 12).

In a country like India, and perhaps elsewhere, the insufficient facilities for training and services indicate that parents should be involved in service delivery. All parents do teach their children. Is the concern realistic that parents of children with disability may unknowingly take on the roles of therapists and teachers? When the children are normal no one questions the relevance of these parents teaching their own children. Why then is there a reluctance to involve parents of the disabled child?

Benefits of Parental Involvement

The infant and preschool child cannot do without the support of parents as their care givers. It is to the benefit of both parent and child, to equip parents with the skills to provide such support. The vast majority of parents in developing countries are not involved in service delivery because they have not been inducted into programmes where they are an integral part of services. Their experiences are not mobilised and channelled into services they can perform.

Perhaps one reason for this, particularly in India, is the aura round the term "doctor" or "professional". These experts are supposed to know all the answers. Another reason, mostly in families who are poor and uneducated or marginalised in some way, is the lack of education and information on disability. This, coupled with the attitude that "doctor knows best", prevents parents from involving themselves. Parents can in fact play the role of advocate, help in special education centres, organise parent groups, and become active partners in NGOs working for disabled persons. This has been demonstrated in many countries and one of our successful community workers is a parent.

In developing countries, the opportunities for parent involvement is not structured and hence not a vital, pulsating movement which can perform near miracles. Tapping parental resources will provide a wealth of committed and dedicated individuals who can work shoulder-to-shoulder with the 'experts'. For those of us who make do with insufficient equipment, material and professional supports, 'parent power' in service delivery for persons with disability is the obvious answer.

Acknowledgement

Photograph of Saroj and her son supplied by the author.

Pramila Balasundaram has over twenty years experience in organising programmes for children with mental handicaps. She trained in Germany under the sponsorship of Lebenshilfe after completing a postgraduate degree in English Literature. The motivation for her career change was a niece who had Down Syndrome.

Contact Address

SAMADHAN
J-32, South Extension Part-I
New Delhi 110049, India

4
Working with Indigenous Peoples

Laureen Pierre

One of the greatest challenges of introducing any kind of development programme with indigenous peoples the world over, is how to find a balance between cultural tradition and positive change. For the Community Based Rehabilitation Programme which commenced three years ago in the Rupununi of Guyana, this challenge is central to the planning and execution of the programme of work which has a focus on disability.

The Rupununi, also referred to as Region 9 for national administrative purposes, represents the southern area of Guyana. It has a land area of approximately 30,000 square miles of mountains, savannahs, forests and swampy lowlands intersected by numerous creeks and rivers. Its residents are mainly Amerindians - a name which refers to the nine indigenous peoples of Guyana. Three of these peoples - the Wapishana, Macushi and Wai Wai can be found in the Rupununi. There are also other indigenous peoples as well as Guyanese of other ethnic origins who, over the years, have also begun to live there. The total population approximates 16,000, of which 7,000 are Wapishana, 6,000 are Macushi and 200 are Wai Wai.

Like many of their South American counterparts who live under tropical conditions, the indigenous inhabitants of the Rupununi continue to centre their lives around subsistence farming, fishing and hunting. Their living conditions are rudimentary and compared with the rest of the multi-cultural Guyanese society, they are regarded as the most disadvantaged ethnic group.

The Rupununi is considered to be one of Guyana's most remote areas. Until recently, a hazardous trail linked the capital city and other more developed settlement areas with the Rupununi. Access was mainly by an irregularly scheduled and relatively expensive air service. Consequently very little attention was given to planning and executing tangible social and economic development programmes in the Rupununi.

It is not surprising, therefore, that the residents of the Rupununi welcome any indication of developmental support. But more often than not, the relatively harsh living conditions within an environment that is a host for numerous insects, proves to be the first deterring factor to individuals and representatives of government and other agencies who would otherwise wish to make their services available.

Meanwhile, the Amerindians who live in the sparsely and widely settled communities continue to demonstrate a capacity for enduring suffering and survival. Their lives are heavily circumscribed by the physical nature of their environment. For instance they have to adapt their lives to suit a long dry season followed by a rainy season. The latter lasts from May - September each year and is accompanied by flooded rivers and trails which often means days and weeks of isolation for many villages. Communication and transportation links between villages and central administration centres are poor and residents generally have limited access to basic health and education services. The Amerindians have retained a deep affinity to the land and their natural environment and this influences significantly their material culture as well as their world view.

Initiating CBR in the Rupununi

In 1992, having promoted CBR in a number of coastal Guyanese communities, the coordinators of the national CBR programme (see Chapter 7) considered expanding the programme to an interior region. Despite their own awareness of the existing conditions of the Rupununi, they invited more objective opinions from people who were familiar with the Region and they made several visits to the Rupununi to have more first hand view on the matter.

I joined the team which included the Director of CBR, Dr. Brian O'Toole and Ms Pamela O'Toole an experienced educator, on the basis that I was an indigenous person and had worked as a teacher in the Rupununi prior to my current job as a researcher on Amerindian Affairs at the University of Guyana. I felt committed to assisting in what I recognised as a truly exciting programme with untold possibilities.

We held meetings with educators, health personnel, policy makers and administrators of the region. We gained the distinct impression that the CBR focus on disability which prevailed on the coast was not a priority for the residents of the Rupununi region. Similar views were expressed by other residents with whom they spoke. The essence of the recommendations and suggestions from all quarters was that there was an urgent need to improve the quality of life and the developmental needs of *all children* of the region.

Insert Photo 4.1

The decision to engage in field work to observe and document the needs of the children in the Rupununi proved to be an invaluable exercise and is an essential prerequisite for formulating a suitable development programme.

Making A Start

During initial contacts between the CBR programme and the village leaders of the Region (see Chapter 6), disability seemed not to have been a major issue possibly because the social system and conditions of life were generally rudimentary, comparatively speaking. It is not surprising to learn that the mute are good farmers, fishermen and cooks and even blind people can go fishing. With a little assistance from family and friends, people with disabilities seem to play a meaningful role in these simple ways and some even raise their own families.

However those with more acute forms of disabilities find themselves isolated and spurned by their families who do not have the support mechanisms to assist in integrating them into the society.

It is this latter group in particular who have become a focus of interest for the CBR volunteers. Devising relevant strategies for promoting the awareness of disability within native communities was therefore of prime importance. This chapter describes how the CBR workers set about this work and identifies the strategies which have proved most successful.

CBR Village Teams

As noted earlier, the CBR programme began in the Rupununi with the Director - Dr. Brian O'Toole - making a series of one-week long field trips to meet the local community leaders and to listen to their concerns (see Chapter 7).

A representative group of Rupununi residents was responsible for formulating the idea of the promotion of CBR work through the creation of a team of three for each village. In the Rupununi there are thirty-three major villages which, for administrative purposes, fall in five sub-districts. The affairs of each village is run by a Touchau (head chief) and a village council. Apart from this body the scope for demonstrating local leadership is limited. Teachers and Community Health Workers (CHWs) are perhaps among the few who are regarded in this light. It was at an introductory workshop on child development during October 1992, that a number of CHWs and a few teachers from across the region discussed and endorsed the idea of having a CBR team for each village. These representatives were entrusted with the task of assisting their villages to identify the teacher, the CHW and a villager (who in most instances was a member of a village council), to serve on the CBR team.

A series of workshops was planned for each sub-district which allowed the CBR teams of each village to meet once a year in order to acquire and share information, ideas and plans and activities. A regional conference is also planned for each year where the volunteers from across the region meet and review the progress of the programme and share in forward planning. After almost three years, most of the initial members of this team remain unchanged, team spirit is present and because of the relatively high profile of each member of the team in their respective community, the CBR teams receive much needed respect and support as they proceed with their work.

Training Workshops

Training workshops were held for the Community Health Workers, school teachers and village leaders who had volunteered to assist the programme. The focus initially was mainly on early child development and *not* on disability per se.

The most important aspect of this CBR initiation process was determining in what ways the CBR materials developed on the coast in the form of photographs, video material and notes and observation could be used to form an essential part of study and reflection by the Rupununi residents themselves. As it turned out it was the volunteers of the Rupununi programme who had a deciding role to play in this matter. The team began by critically reviewing manuals and video documentaries which has been produced on the Coast. Over the course of a number of months the Rupununi CBR team began to produce teaching materials that were relevant to the culture of the region.

For the CBR volunteers exposure to information through manuals, videos and group discussions during the workshops proved to naturally stimulate their own perspective on attitudes, beliefs and ways in which one could deal with the issue of disability within their communities.

Traditional Beliefs

One of the interesting and valuable exercises which was used to introduce the subject of disability during the training workshops, was to have the participants discuss traditional beliefs and superstitions which surround the disabilities that afflict children from birth. The participants provided anecdotal accounts which answered such questions as why children were born with speech impairments or with problems which did not allow them to use their limbs effectively?

Some explanations hinged on the wrong diet of pregnant women. For example, if a pregnant woman ate mutton this might cause a child to be born with a disability. Some believe that if a pregnant women or the father of the child ate a certain species of deer, the newborn infant might suffer from fits. Others hold the view that some disabilities are due to pregnant mothers eating at night in unlit rooms.

They also spoke of morals. For example if a man engaged in an extra-marital affair, his lover, on becoming envious of the man's spouse, could decide to harm the foetus of the man's wife. This could cause some deformity of the child when it was born.

Similarly, the volunteers shared some traditional methods of preventing and treating disabilities. These included educating women about the kinds of food which they should not eat when they were pregnant and the acts which they or their husbands should not engage in when a woman was pregnant. For example, when his wife is pregnant, a man should not cut the tongues of nestlings or else the child would be dumb. Likewise a man is advised not to kill the snake known as 'camudi' (boa constrictor) as this would cause the unborn child to have underdeveloped muscles in the lower limbs.

The volunteers also described the form of treatment people with disabilities were subjected to when taken to the local shaman or 'medicine man'. These included prayerful chants, drinking traditional herbal brews or applying them externally, and smoking or sweating the patient. Families are often advised to use incense in their homes to guard against 'evil spirits'.

Discussions of this nature were helpful since they allowed participants to reflect on the perceptions of their people. From this, they began to question some of these established beliefs and practices. The resource persons leading the workshops were sensitive to, and respectful of, the local people's culture. They did not seek to impose new views or give trite medical and scientific explanations. Rather, through their own discourses and practical sessions they presented information in a manner which allowed the volunteers to more deeply investigate the knowledge which their people had on the subject as well as the new perceptions which were being shared with them.

While such discussions were usually conducted within the context of early child development, the general effect was that the volunteers recognised how important a role they were already playing, or could play, in guiding their communities through a process of re-examining traditional values and customs. This meant that if any transformation in attitudes towards disabilities was to occur in the several communities throughout the Region, a strong education campaign had to be done on this topic.

This was one of the great challenges which the CBR volunteers realised that they had to meet. Two approaches were adopted. Firstly, through the opportunities provided to the volunteers in a day-to-day basis as they went about their usual work. Secondly by having a series of special events.

Education through Daily Contact

In many ways the Community Health Workers and the teachers were ready to use their own professions as a means of informing communities about new perspectives on disabilities. They incorporated this task into their everyday activities on a small scale. The Health Workers for instance, began to use their ante-natal and post-natal clinics to educate women. Those women who had children with disabilities were encouraged to bring them to clinics to receive immunization. They were told that these children had special needs; that they required greater care and that through the CBR programme, families could learn how to better cope with these children.

Teachers also joined in encouraging parents to understand that in many cases children who had special needs were capable of learning. Parents could assist by making special toys and games to help such children to learn at home and later to have them join in the normal activities of school life.

Special Events

A number of different events were organised by the CBR volunteers in the Region, each one drawing on the local culture and promoting community participation.

Exhibitions: During the first year of the CBR programme, CBR volunteers promoted an Art and Toy Making exhibition for all school children in the Region. The children were asked to prepare posters on the subject of disabilities or to make toys for disabled persons. The competition categories included children from nursery to school leaving levels so that almost every school child had an opportunity to give creative expression to their thoughts.

Hundreds of art pieces were entered for a regional competition as were many craft and toy items. These were made of local material such as seeds and beads, woods and gums.

The top winning entries were sent to a national CBR competition in Georgetown, the capital city. Trophies and prizes were sent to the winners and they have been regarded as prized possessions.

Performances: Dramatic presentations at cultural community events have made another great impact at all levels in the communities. CBR volunteers are generally willing to utilise their skills and talents to generate skits, songs, poems, limericks, dances and short plays which highlight some important message on disability. These are done either in English, Wapishana, Macushi or Wai Wai and sometimes even in Portuguese given the Region's proximity to Brazil. These performances are often simple, almost spontaneous and humorous. More than this, they reflect very much life in the Rupununi; people's attitudes and how transformation can occur. When children, youth and adults attend these cultural presentations they enjoy the drama while learning the message. This mode of communication has added greatly to community events.

Puppet Shows: One novel addition to cultural presentations has been the art of puppetry. Making and using puppets has been part of the training workshops for volunteers. Children and adults are fascinated by simple puppet presentations and a cultural show which includes puppetry is now a major success. Again CBR volunteers take advantage of these opportunities to focus on disability.

Video Productions: Capturing the real life situation of disabled persons on video has also been a major contribution to the education campaign on disability in the Rupununi. Although most of the video programmes have been produced as learning aids for volunteers at the training workshops, these have also been shown to many of the communities at large. Since these videos feature disabled persons of the Rupununi as well as persons from other parts of Guyana, they are viewed with great interest as they project positive images of children and adults with disabilities.

Story Book: A more recent addition to this process of educating the community on disability has been a story book written by a teacher of the Rupununi and one of the regional co-ordinators of the CBR Rupununi Programme. This collection of stories includes many on disabled persons and the stories have been written in English, Macushi and Wapishana. Experiences have shown that the books can be used at all levels in schools. Questions are provided at the end of each story as a test of the reader's comprehension but also to stimulate their thinking about disability and its implications for community living.

Insert Photo 4.2 here

Training Workshops: Apart from these community strategies, the volunteers themselves have gained much support from the series of five day, CBR workshops which have now been held in the five sub-regions of the Rupununi. These exposed participants to information through manuals and videos. The group discussions during the workshops proved to naturally stimulate their own perspective on attitudes and beliefs. Also this was done in ways which the volunteers could use to deal with the issue of disability within their communities.

Survey: During 1993 - 1994 almost every village in the entire Rupununi Region was surveyed to identify persons with disabilities. Practical demonstrations in the training workshops and specially written booklets with guidelines, enabled them to begin to assess persons with simple forms of disabilities. Each team made a map of their village, visited each household and school and carried out simple checks to ascertain the number of people with different disabilities in each village. Altogether the result showed that 1.7% of the Rupununi population had a disability.

The data generated from this survey is currently being used by volunteers and the regional coordinators (VSO volunteers) to assist them in measuring their own progress as they work with disabled persons.

Outcomes

What was especially noteworthy about the work of CBR volunteers during the first year of the programme is that they themselves had gained a much wider understanding about early child development than they had on disability. Yet their reports at the end of that year indicated that they regarded dealing with disability as a priority within their communities. A few communities were outstanding in this respect and were able to mobilise greater community awareness on the subject than others. The main message which they all seemed to have passed on to their communities was that it was time to begin to recognise that people with disabilities could be assisted to have better lives, to be better appreciated as a member of the community and that many had talents and skills which they could contribute to their communities.

In some communities progress is manifesting itself by advancements in integrating children with disabilities into schools. One major success story is that of a young blind child who is musically talented and who has entered into regular school life through the work of the CBR team in his village. The volunteers were able to acquire a banjo for him and he now entertains in school and for community events. Similar efforts are also being made by other village teams and the integration of children into schools is a current major goal for the CBR teams.

New Perspectives on Development

Although these attempts at educating communities about disability were a humble beginning, they have proved to be a sound and practical way to begin to look at the implications of dealing with disability as a development issue within the Rupununi. As the volunteers themselves were quick to point out, Rupununi residents often demonstrated a tendency to request donations from organisations which had contact with their area. These appeals arose because of their largely impoverished situation and the lack of any amenities.

In fact it was not very long after the CBR programme started that the visiting staff received requests to make available such items as wheel chairs and spectacles. Ironically, many of these requests pertained directly to adults and not to children who were the primary focus of the CBR programme.

How was the CBR programme going to deal realistically with requests and expectations and not allow an already deprived population to feel further rejection? This was the question posed to the programme coordinators, the resource persons and the volunteers.

The response was couched in a rather unique dialogue which has started to bring CBR closer to communities at a grassroots level. The dialogue was on social development and what was meant by empowerment of people. Volunteers themselves explored this matter in a simple manner. During the workshops they spent time re-examining the pattern of development within their communities. To begin with they discovered that in their respective languages many words could be used to convey the concept of development. They recognised that development did not necessarily mean infrastructural features but that it also had a deeper significance which could impact on their cultural identity. They also agreed that everyone in the community - including persons with disabilities - should have an opportunity to share and benefit from development.

Over and above all of this, and in relation to the subject of disability, the CBR volunteers were able to appreciate that villages can do simple things to improve the life of persons with disabilities and that this could be an indicator of the level of development within a community. It was not necessary for external organisations to be development donors.

CBR volunteers began to impress these concepts on their communities. While on the one hand CBR has begun to be a channel and support for social development projects within a few communities in the Rupununi, on the other hand the kinds of specific requests from persons with impairments and disabilities have decreased. Simultaneously, there is a wave of genuine and healthier community response to assisting disabled persons.

Future Challenges for the CBR Programme

Now that the CBR programme has started to make a direct impact on the lives of Rupununi residents, including those persons with disabilities, it is likely that the future holds many exciting and perhaps difficult challenges. Individuals, institutions and communities have been gradually awakening to new perspectives on human life and are looking for more explanations and solutions.

For the CBR programme this certainly means keeping up the momentum which has been started; the strengthening of existing partnerships which have been forged and assisting volunteers to seek more opportunities for educating themselves on this subject.

Already every year a small number of CBR volunteers from the Region join other CBR volunteers from across the country in intensive workshops which are geared to enhance their capacity to serve as trainers. At the moment many of the Rupununi volunteers have been selected to pursue another training exercise which would empower them to serve as resource persons or trainers in other Amerindian communities outside of the Rupununi. In this way the values and ethos of the CBR programme can be spread more widely throughout the country at relatively low cost and with little reliance on personnel from outside the country.

Working with indigenous peoples is generally a rewarding experience but the approach adopted to the issue of disability in the Rupununi Region with indigenous peoples stands out as an excellent paradigm for others to follow. Some of the points highlighted in this chapter illustrate the tremendous response of volunteers and communities to relatively minor and 'low-key' initiatives; yet these attempts were ones which focused on disability as a real human concern.

This emerging model has attracted much interest outside of Guyana, especially through the many videos which illustrate the work of CBR in the Rupununi. Nevertheless, the basic lesson remains. Each society has to restructure for itself, its beliefs, perceptions and responses to disability. In so doing, it will rediscover the power to channel its own further development.

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Laureen Pierre herself an Amerindian, works as a researcher in the Amerindian Affairs Unit in the University of Guyana. She holds a Masters degree in history. Laureen has worked as a consultant for a number of international organisations and specialises in development issues. She is a founding member of VARQA, one of the major development foundations working in Guyana in the areas of primary health care, basic education and literacy.

Contact Address

Amerindian Research Unit,
University of Guyana,
Turkeyen,
Greater Georgetown
Guyana

5

Attitudes and Beliefs about Disability in Tanzania

Joseph Kisanji

People are constantly evaluating and making judgements about other people and events. We react to people and situations on the basis of how we evaluate and judge them. This chapter focuses on reactions towards disability and disabled people in historical and contemporary terms. The generally held view that attitudes in non-western cultures are very negative is closely examined through an analysis of attitudes in Africa as epitomised in the folklore from Tanzania.

The author declares his bias towards people-centred, or autonomous development in which local communities and nations reflect on their own situation and take action to solve their problems (Freire, 1973). The phrase *"non-western cultures"* is used in this chapter to refer to nation states and local communities popularly known as "developing countries" or "the developing world". This is to avoid the economics-centred, material accumulation, stage theory of development which these phrases suggest. Likewise, industrialised or "developed countries" are referred to as *"western cultures".*

The use of the concept of culture places disability in its proper context, especially in relation to attitudes and attitude change in the community. It is also an attempt to encourage positive intercultural relations without which stereotyping, domination, oppression and imposition of foreign values in education and social work often occurs. Gadamer stresses the need for cultures "entering into an open-ended dialogue, where neither party is in control (and) there are no privileged...cultural positions" (quoted in Welch, 1993).

Historical Perspectives on Attitudes towards Disability

History is replete with examples of disabled people worldwide being ridiculed, killed, abandoned to die or condemned to permanent exclusion in asylums and ridiculed (Pritchard, 1963). Anang (1992) claims that the Greeks abandoned their disabled babies on hillsides to die while early Chinese left their disabled people to drown in rivers. In Europe, Nero Commodus is said to have targeted bow and arrows on physically disabled individuals and the Church in the 15th century sanctioned the extermination of disabled persons (Durant, 1944; Onwuegbu, 1988).

Coleridge (1993) traces through history the killing of people with disabilities, beginning with the Spartans who killed disabled persons as a matter of law; the endorsement by Martin Luther to kill disabled babies because they were 'incarnations of the devil'; the English eugenicists who eliminated disabled people under the Darwinian evolution theory of the 'survival of the fittest' and the Nazi Euthanasia Programme under Hitler to exterminate disabled people as they could not make any contribution to society. These persecutions recorded in western cultures are still evident today.

In a world guided by economics, with its concern for investment and maximum rate of return, inequalities of opportunities are created for people with disabilities. There are people today who are strongly in favour of non-treatment of newborns with severe disabilities, much as were the nineteenth century eugenicists (McDaniel, 1989). Termination of life is now affecting foetuses. For instance, Gudalefsky and Madduma (1992:7) give an account of the "shocking and unacceptable" statement by a European delegate at a recent world conference who reported "that his country has solved the problem of defectives by the introduction of widespread amniocentesis and other prenatal testing procedures".

However, amid the raging persecutions, history also presents rays of positive societal perception and action. For example, Anang (1992) reports on the interest in the problems of blind people which became manifest in Egypt in 2650 BC. Subsequently Egypt began to provide opportunity for blind people "to engage in gainful employment" and to be known as the "country of the blind". As a result of this fame, Anang (1992:17) writes:

> *Pythagoras travelled to Egypt and observed the work being done with the blind in Egypt and carried the story of their work to Greece.*

Pythagoras' visit to Egypt created interest in the study of eye diseases and influenced public attitudes towards people with blindness and other disabilities.

Favourable practices in rehabilitation and community care were found all over the world. For example, Miles (1983), in his review of literature, reports of the use of prosthetic and artificial eyes in India around the 6th century BC. and "a remarkable tradition of community care for the mentally disordered" which began in Belgium in the 5th century AD.

On the educational scene, the contributions made by such educational thinkers as Froebel, Russeau, Locke and Montessori, to name but a few, have had an indirect influence on the understanding of disabled learners (Ishumi, 1976). The history of special education is in fact a story of changing attitudes towards people with disabilities; from private tuition, institutions, special schools to integration and now gradually to inclusive education. It is worth noting that the idea and practice of integrated education is not a 20th century innovation. Johann Wilhelm Klein advocated it vigorously in

Austria in 1810, prepared a guide to assist regular class teachers who had blind children in their classes in 1819, and this led to the issuing of a policy statement on integration in 1842 (Gearhart and Weishahn, 1976).

Historically, therefore, attitudes towards disabled people have been a mixture of persecution as well as tolerance. However, the tolerance shown has been paternalistic. Disabled people were perceived as incapable of making their own decisions and of taking control of their lives; they were viewed as people who always need to be helped or as objects of pity and charity (Coleridge, 1993). This paternalistic conception of disability is clearly evident in the work of voluntary organisations, especially in their fund-raising activities (Ralph, 1989). Unfortunately, paternalistic attitudes tend to create dependency and an incapacitating learned helplessness in people with disabilities. It erodes the self-esteem of the recipient of charity (Oliver, 1990).

Modern practices recognise and respect the disabled person as a person first and as disabled second. Disabled people are not perceived as inferior or second-class citizens, but capable of communicating and participating, entering into dialogue with other people (Freire, 1973). These are the empowering practices, the very basis of people-centred development, which recognise that disabled people, or any other group of human beings in society, need to be responsible for their own affairs.

Attitudes to Disabled People in Non-Western Cultures

There is ample evidence that all cultures - western and non-western - exhibit reactions to disability and disabled people which form a continuum (Ingstad, 1990). Yet much literature on non-western cultures is dominated by descriptions of negative attitudes. O'Toole (1988) has summarised these descriptions thus:

> *In the West the disabled have been stereotyped as being dependent, isolated, depressed and emotionally unstable...Such negative feelings are amplified in LDCs [Least Developed Countries] where the overwhelming impression, from published literature, is of attitudes towards the disabled which are very negative.*

Ingstad (1990) argues against this stereotyping of non-western cultures and describes it as a recently created "north-south myth".

> *In order to raise money, create awareness..., a picture of the situation for disabled people has often been painted as negatively as possible, emphasising shame, hiding, killing, etc.*

Particular caution must be exercised when reviewing western literature on attitudes or literature that has been written by, or on behalf of, a charitable organisation.

However, regional, country and community-specific initiatives which are aimed at developing relevant strategies for changing negative public attitudes in favour of disabled persons are indeed laudable. The study carried out in Pakistan following the International Year of Disabled Persons (IYDP) in 1981 provides an excellent example of a country-specific action-oriented attitude consideration, whatever the researchers' initial assumptions (Miles, 1983). Kisanji (1993) and Walker (1986) have similarly provided an overview of the situation in Africa.

There are also a number of studies on attitudes at community level (Bickford and Wickham, 1986; Muya and Owino, 1986; O'Toole, 1988). Most of these published and unpublished works reveal a mixed pattern of attitudes which are a mirror image of the worldwide situation. Hence it is misleading to argue that attitudes in non-western cultures are very negative.

An examination of the published materials on non-western cultures shows that most of them are impressionistic, anecdotal (Miles, 1983) and written for a western audience often by westerners. Although the studies which are reported in literature are sometimes carried out with or in consultation with local professionals, the interpretation of data cannot escape the inevitable influence of western culture.

Each culture has its own unique characteristics which usually are best understood by indigenous people. However some of the local professionals, products of non-indigenised western education, may not understand their own culture (Thairu, 1985; Thiong'o, 1986). Misinterpretations of practices, therefore, may be made by both local and foreign researchers and caution needs to be exercised when reviewing findings on attitudes in non-western cultures.

Further problems in attitudinal research include difficulties with sampling procedures, attitudinal measurement and attitudinal biases (Gajar, 1983). A recent computer search on attitudes towards disability and disabled people, with *DISABILITY, ATTITUDES, DISABLED PEOPLE* as the keywords, gave 133 entries which included both rigorous studies and non-empirical descriptions of attitudes. The studies focused on perceived causes of disability, parental reaction immediately following the identification and confirmation of the impairment in the child or family member, educability and employability of disabled persons. Child rearing practices, despite their importance in showing action oriented attitudes, were not covered.

Data were collected from disabled persons, parents, students, teachers, co-workers and other specific professional groups who have gone through western schooling. The findings of these studies may not be generalisable to oral (orate) cultures.

Studies of attitudes in orate cultures are bound to face even more problems. Ethnographic research takes a long time to complete. Mastery of the local language to a native speaker level would take many years. It is no wonder, therefore, that there have been so few studies on attitudes in non-western cultures. Local professionals have largely been content with impressionistic descriptions which may express mainly personal perceptions rather than genuine community attitudes.

However, community attitudes are an expression of a people's culture. A study of some aspects of culture ought to reveal generally held views about disability and disabled people. These aspects may include customs, paintings, drawings, carvings, and the folklore and language used in relation to disability and disabled persons and folklore. Ingstad (1990) provides a hint in this direction when she writes:

> *In the old days in Europe a disabled family member was considered a shame, a sign of God's punishment and thus someone to be hidden, killed, etc. This may have been true to some extent, but if we go to what is probably our best source, folktales and literature, we get a different picture (p.188).*

The study described in this chapter was based on the realisation, that folklore may shed more information on attitudes. The main purpose was to identify community rather than individual attitudes and to represent both orate and non-orate cultures. It sought to find out whether communities in Tanzania understood the characteristics of disabilities and to survey the general attitudes towards disabled people. Although Africa is such a vast continent with diverse cultures, an examination of proverbs in various regions may yield patterns of attitudes similar to those reported in this study. A cursory search points to such Jabo proverbs from Liberia (Herzog, 1936) as "the arm is beautiful, yet it has a knot" and "one trusts his wrist before he speaks contemptuously".

Serpell (1993) uses proverbs from Zambia to point to three themes related to child rearing or education in Chewa society as it is "afforded by non-specialised adults to their young charges and apprentices" (p.70). The themes are (1) elders have a responsibility for the upbringing of children, (2) early experience has profound influence on later behaviour; hence the effectiveness of educational intervention early in life, and (3) instruction is essential for success in life and it requires an awareness of how learning takes place. Although the proverbs listed in each case do not refer directly to childhood, parenthood or disability, their deeper meanings are immensely relevant to disabled persons, as the analysis of proverbs from Tanzania will show. These and other similar proverbs suggest that community attitudes in Africa can, with minor variations, be generalised. To this end, community attitudes in Tanzania are presented as a case study.

Disability in Tanzanian Proverbs

Proverbs, sayings, riddles, folksongs and tales which carry notions related to disability and disabled people were collected by the author using documentation and interviews. A literature search for the period 1935-1990 was carried out. Interviews were also conducted with tribal elders (N=44), primary school heads (N=10) and teachers (N=45). The data obtained was then analysed thematically by disability.

The thematically arranged proverbs, folksongs and tales were circulated during 1994 to 11 Tanzanian students at the Universities of Bradford, Cardiff and Manchester in the UK to verify their meanings and usage as well as to elicit their contributions to the disability-related folklore. A few additions were made, especially with regard to folksongs and folktales. The content and editorial comments received were incorporated into the analysis.

As the proverbs have been in existence for many years, as noted by the community elders (60 years of age and above) and from published material (Omari, Kezilahabi and Kamera, 1978; 1979), the dominant attitudes in the proverbs have existed for at least 50 years. In order to present a trend and pattern analysis, the data were arranged according to themes. These are (1) disability characteristics, (2) disability in various aspects of community life, (3) attitudes which show persecution (cruelty), and (4) attitudes which show accommodation, equality and human rights.

Disability Characteristics

An examination of 78 proverbial sayings collected through interviews and from published books indicated that personal characteristics of persons with sensory and physical impairments as well as those with severe intellectual impairments were well known.

A. Visual Impairment

1. *Kipofu hamwelekezi kipofu mwingine kwa mwenge*
   A blind person does not lead another blind person using a torch. This proverb is similar to the English one, "If the blind lead the blind, both shall fall into the ditch".
2. *Kummulikia kipofu ni kumaliza mzigo wa nyasi na wala hawezi kuona* To light a fire for a blind person to see, you will burn all the grass from the bush; the person will not see.

The two proverbs define blindness as lack of vision; it would be absurd for a non-sighted person to use a torch.

B. Hearing Impairment

1. *Nduguyo akifa sikio utapata shida kuita* When your relative's ear dies, you will have great problems to call him/her.
2. *Kumwimbia kiziwi ni kumaliza nyimbo bure* To sing to a deaf person is a mere waste of songs.

Here the proverbs refer to inability to hear and difficulty of engaging in communication as well as enjoying audition-dependent activities such as music.

C. Intellectual Disability

1. *Ngongo ni zuzu na Ngomisho ni zuzu* or its short form *Ngongo na Ngomisho* Both Ngongo and Ngomisho are fools! They cannot lead or help each other.
2. *Kichaa huponywa, ujinga hauponywi* Mental illness can be cured; stupidity or foolishness cannot.

An intellectual impairment affects understanding and the community considers this fact to be more serious than mental illness.

D. Physical Disability

1. *Agana na nyonga kabla ya kuruka* Make sure you are physically fit before you take a leap; literal meaning: Your hips should agree before you jump.
2. *Mzee (mgonjwa au mlemavu) anajifahamu mwenyewe* or *Aliye dhaifu yapasa ajifahamu mwenyewe* An elderly, sick or disabled person is the best judge of his/her needs and difficulties; s/he should make these known to those near him/her otherwise it will be difficult for them to offer appropriate help when it is most needed.

One can only use affected parts of the body within limits.

E. Emotional and Behavioural Difficulties

1. *Asiyekomesha tabia mbaya hupatikana na makuu* One who does not stop bad habits lands into big problems.
2. *Asiyesikia la mkuu huvunjika guu* He who does not listen to one's elders breaks his/her legs.

Behaviour difficulties can lead to tragedy.

These proverbs provide evidence of the culture's understanding of both the distinguishing features of given disabilities as well as the limitations associated with them. They also present disability as permanent and make a clear distinction between an intellectual disability and mental illness.

Relative Importance of Specific Parts of the Body.

There is evidence from the proverbs collected that the Tanzanian culture places more value on some parts of the body, or a combination of them, than others. Damage or loss of those parts held dear by the community determines the definition and severity of disability. The following proverbs provide examples of this notion.

1. *Heri kufa macho kuliko kufa moyo* It is better to go blind than to lose heart.
2. *Jicho ni moja, nalo laingia mchanga* Sand has entered the only eye!.
3. *Nduguyo akifa sikio utapata shida kuita* When your relative's ear dies, you will have great problems to call him/her.
4. *Afadhali kuchakaa nguo kuliko kuchakaa akili* It is better to have worn out clothes than to have no brains.
5. *Asiyekiuno naye huvua* A person without a waist, which represents a woman's beauty, undresses when taking a bath in a river, sea or at a well like anyone else.

In addition to the commonly understood disabilities such as blindness, deafness, physical disability and intellectual impairment, Tanzanian culture also includes body shape, lack of attractiveness or ugliness as disabling conditions.

Classification of Proverbs According to Life Concepts

Proverbs permeate all aspects of everyday life. Disability and disabled people feature in all areas. Specifically, the proverbs present disability as a life and social leveller. However, disabled persons feature mainly metaphorically to highlight the community's moral and social duties and responsibilities as well as people's wellbeing. In all, 12 themes were identified.

A. Disability as a Social Leveller

1. *Kabla hujafa usikashifu kilema* Before you come to your deathbed, do not laugh at someone's deformity or disability.
2. *Usimcheke kilema* Do not laugh at a disabled person.

B. Respect for Individual Differences

1. *Kucheka chongo ya mwenzio na hali yako umeificha* Do not laugh at someone else's one-eyedness when you have hidden yours.
2. *Ukienda na mwenye chongo nawe jidai chongo* In the company of a one-eyed person, pretend to be also one-eyed.
3. *Mtu asiyekamilika viungo au akili, ukimtania hudhani unamtukana* When you tease a person with a disability, s/he may think you are insulting him/her.

C. Human Rights

1. *Ukila na kipofu, usimshike mkono* When you eat with a blind person, do not hold his/her hand. The same proverb is sometimes stated as: *Wala na kipofu, jichunge mkono wako* When you eat with a blind person, mind your hand.
2. *Usimdharau kilema hata kama si ndugu yako* Do not look down upon a disabled person even if s/he is not your relative.

D. Parental Responsibility in Bringing Up a Disabled Child

1. *Hata kama ni mjinga ni wako* or *Wako ni wako tu, ajapokuwa mjinga* Although s/he is a fool, s/he remains your child or relative.
2. *Ni bora uwe nacho cha thamani ndogo kuliko kukosa kabisa* It is better to have something of less value than nothing, i.e., a disabled child is better than no child at all.

E. Training for Survival and Independence

1. *Hata kama ni jinga litengenezee upinde* Even if stupid, give him a bow and a quiver of arrows.

F. Ability

1. *Usimwonyeshe kipofu njia* Do not show a blind person the way, i.e., when you teach something to a blind person s/he may develop greater expertise than yourself in that subject.
2. *Katika nchi ya vipofu, chongo ni mfalme* In the country of the blind, the one-eyed man is king.

G. Education, Guidance and Counselling

1. *Sikio la kufa halisikii dawa* A dying ear does not respond to medicine; it cannot be cured, i.e., it refers to someone who does not stop a socially unacceptable behaviour despite repeated advice against it.
2. *Kichaa huponywa, ujinga hauponywi* Mental illness can be cured; stupidity or foolishness cannot, i.e., people should exert their efforts in learning, otherwise those helping them will be discouraged.
3. *Asiyesikia husafiri mbali sana, maana hata akiambiwa anakokwenda hatasikia* A stubborn person travels very far before s/he realises s/he is off-track, i.e., young people should take heed of advice given to them lest they regret.

H. Collaboration and Participation in Economic and Social Activities

1. *Kipofu hamwelekezi kipofu mwingine kwa mwenge* A blind

person does not lead another blind person using a fire or torch; i.e., people are urged to contribute according to their abilities.

2. *Kula na kipofu ni sawa na kula peke yako* To eat with a blind person is like eating alone if a sighted partner takes advantage of his/her disability, but in a collaborative effort partners ought to respect each other.
3. *Asiyekiuno naye huvua* A person without a waistline undresses when taking a bath like anyone else, i.e., even a poor person can contribute something in the community however small.

I. Marriage and Family Responsibilities

1. *Apendaye, chongo huita kengeza* To someone in love, the one-eyed is a squint, i.e., someone in love does not see the shortcomings of the beloved.
2. *Mcheka kilema si mkwe wangu* He who laughs at a disabled person cannot be my in-law.

J. Political and Social Leadership

1. *Katika nchi ya vipofu, chongo ni mfalme* In the country of the blind, the one-eyed man is king.

K. Medium for Teaching Moral Values: Honesty, Integrity, Happiness and Freedom

1. *Kipofu hadanganywi jicho* A blind person cannot be promised a functioning eye, which s/he desperately needs, i.e, we should not make false promises.
2. *Mbona wanidanganya kana kwamba nina chongo?* Why do you deceive me as if I am one-eyed?.
3. *Upendo humfanya bubu acheke/afurahi* Love makes a deaf or dumb person happy, i.e., kindness pays.
4. *Afadhali kuchakaa nguo kuliko kuchakaa akili* It is better to have worn out clothes than to have no brains, i.e., individuals should behave responsibly, should have integrity.

L. Medium for Teaching Aesthetic Values: Beauty, Harmony and Elegance

1. *Asiyekiuno naye huvua* A person without a waistline undresses when taking a bath like anyone else.

   In many societies in Africa, one criterion of a woman's beauty is her waistline. However, when taking a bath or a swim in a public place - a river, well or beach - even the woman who is not so well endowed with a waistline takes off her clothes. This proverb is used when a person is able to contribute only something small at such functions and occasions as parties, weddings and funerals.

Attitudes to Disability

The same proverbs identified in these aspects of culture may be interpreted as representing negative (dislike or cruelty) or positive (like, supportive or empowering). Examples were found for each of these aspects.

Persecuting Attitudes (Dread, Dislike and Cruelty):

1. *Sijali hata akiwa na usaha masikioni, si mwanangu* It does not matter to me whether s/he has a running ear or not; s/he is my child.
2. *Afadhali kuchakaa nguo kuliko kuchakaa akili* It is better to have worn out clothes than to have no brains.
3. *Ukioga pamoja na mjinga hutakati* When you take your bath with a fool, you do not get clean or *Ukicheka na jinga, angalia jicho lako* When you play with a fool or stupid person, watch your eye. Take care in selecting your friends.

Accommodating Attitudes:

1. *Usimcheke kilema* Do not laugh at a disabled person. No-one wants to be disabled, but disability can befall someone at any time.
2. *Kucheka chongo ya mwenzio na hali yako umeificha* Do not laugh at someone else's one-eyedness when you have hidden yours. Do not celebrate other people's problems while you have your own shortcomings.
3. *Hata kama ni mjinga ni wako* or *Wako ni wako tu, ajapokuwa mjinga* Although s/he is a fool, s/he remains your child or relative; it is your responsibility to take care of him/her.
4. *Ni bora uwe nacho cha thamani ndogo kuliko kukosa kabisa* It is better to have something of less value than nothing at all; a disabled child is better than no child at all. A parent should not lose hope or slacken in one's effort to bring up a disabled child.
5. *Usimwonyeshe kipofu njia* Do not show a blind person the way; when you teach something to a blind person s/he may develop greater expertise than yourself in that subject.

Reflections on Proverbs and Disability

Proverbs as Raw Material for Understanding Attitudes: Proverbs are common in all cultures; those that use predominantly using the written word and those that are mainly orate (using the spoken word). The main function of a proverb is to generalise a community's experience or "to cope with a situation as it arises, by regarding it in the light of something which has occurred before" (Herzog, 1936). As such, a proverb does not refer to the details of the original situation. Traditionally, in Africa for instance, each proverb was accompanied by a parable which provided a sketch of the original situation. The proverb was, therefore, a summary of the gist of the story, given by one of the actors or spectators (Herzog, 1936). The stories for the proverbs in this chapter, are now in the process of being collected.

Traditionally, proverbs have served three functions: legal, social relations and as an avenue for generalisations (Herzog, 1936). Proverbs were used to classify the facts of a case on the basis of an existing law or some precedents. Thus proverbs provided legal formulae. They were also used to smooth social friction and dissatisfaction among relatives, friends and other community members. The same proverbs could be used to help the individual to adjust oneself to a given adverse situation or "quoted for advice, instruction or as a warning - always to prevent and lessen friction". This social function was, and still is, more effective in Africa than perhaps anywhere else because seniority by age or status is still being highly valued. Advice, instruction and or warning given to others by seniors is evident from the fact that of the 12 life areas covered by the proverbs in this study, the theme "education and counselling" has 15 proverbs, whereas the average number is five for the other themes.

The third function of proverbs is that they act as vehicles of concept generalisation through the use of metaphors. Lakoff and Johnson (1980) conclude that metaphors are:

> *One of our most important tools for trying to comprehend partially what cannot be comprehended totally: our feelings, aesthetic experiences, moral practices and spiritual awareness. These endeavours of imagination are not devoid of rationality; since they use metaphor, they employ an imaginative rationality.*

There is justification, therefore, to study the metaphors in proverbs if we are to understand attitudes towards disability and disabled persons in society.

Attitudes Reflected in Proverbs: The proverbs collected in this study were those that made direct mention of disability or disabled persons. They were analysed to understand various cultural beliefs, customs and values about disabled persons. Attitudes represented in the proverbs include respect for individual differences, support for active participation in appropriate activities (as training for survival and independence), demand for parents to take full responsibility in the care and upbringing of a disabled child, the value attached to having children (whatever the condition of those children), and disability as source of inspiration for honesty and "good Samaritanism" (helping people in need). These attitudes are clearly positive, providing the basis for mutual understanding between disabled and non-disabled community members and promoting the quality of life within the "consciousness" of the community.

Proverbs also acknowledge community awareness of the difficulty of teaching and counselling persons with disabilities. There are also instances of both disabled and non-disabled persons succumbing to helplessness and, therefore, resignation to supernatural powers. As expected, elements of negative, unfavourable reactions have also been identified, but the overall picture is one of tolerance, respect, care, assistance and integration. A closer look at the proverbs will help in understanding the implications of this study to grassroot workers, and especially to those in community based rehabilitation (CBR) and inclusive education.

Reference to Causes of Disability:. Although many references to attitudes towards disability in literature are concerned with causes of disability and their influence on people's behaviour (cf. Walker, 1986; Anang, 1988), only one out of 78 proverbs referred to causes. The proverb, *Kwa matendo haya uliyonitendea, kama hukufa utalemaa* (For what you have done to me, if you do not die you will become disabled), represents the belief in seniority by age and/or status and the consequences for violating it.

Most literature refers to curses from God, gods and ancestors. The religious nature of Africans makes the latter source of curses plausible (Mbiti, 1970; Diop, 1989). However, the fact that proverbs constitute a coping strategy for new situations in the light of past experiences, reference to living elders of the family or clan seems to evoke relevance, immediacy and, therefore, effectiveness.

Characteristics of Disability: The proverbs indicate that most tribal communities in Tanzania have a good knowledge base about the personal characteristics of disabled persons. This is expected in view of the fact that disability exists in the community and that disabled and non-disabled people come in contact with one another in the home and the community. Disabled persons are both parents and children, members of families. In other words, disability is a characteristic part of any human society (Groce, 1990).

Behavioural difficulties have been the concern of communities in Tanzania as revealed by proverbs. It is possible that this category is not perceived by the society as a disability, but rather as a non-conformist behaviour in a culture where the community transcends the individual (Mbiti, 1970).

Reference to Parts of the Body: The proverbs collected in this study point to the importance attached in traditional and contemporary communities to the rounded development of the human person; physically, emotionally, socially and intellectually. Greater importance is attached to some parts of the body than to others. The parts given prominence are limbs, eyes, ears, the brain and the heart (the heart representing emotions), in that decreasing order of occurrence in proverbs. These may be related to the main activities in the communities and the nature of the environment, which combine to produce a culture which demands agility, alertness and mutual understanding and cooperation. Impairment in any of these parts creates limitations in the ability to cope with environmental and social demands, hence evoking fear, overprotection, pity, compassion and charity (Miles, 1983).

Community Tolerance and Acceptance of Disabled Persons: In many communities in Tanzania disabled people are, as among the Maasai in Kenya and Tanzania, "as far as possible integrated in the normal routine of the homestead and the community" (Talle, 1990). Disability is, therefore, taken as a fact of life. Parents and the community are expected to take care of their disabled children and adults. This explains the reluctance of some parents to send their children to schools and programmes located away from their localities (Kisanji, 1993).

Conclusion

The characteristics of major disabilities are clearly represented in the collection of proverbs from Tanzania. These include visual, hearing, physical, intellectual and behavioural impairments and difficulties. Worth noting is the clear distinction made in the proverbs between mental handicap (commonly referred to as *ujinga*) and mental illness (*wehu or kichaa*). Closely linked to the characteristics are the limitations imposed by each disability.

There are very few instances in which negative or rejective attitudes were identified. Proverbs in Tanzania show that disabilities are feared and are, therefore, used metaphorically to exhort community members to behave in socially acceptable ways. Public attitudes reflect fairness and equal opportunities for all community members including those with disabilities. Through disability related proverbs people are urged to contribute to the community welfare according to their ability while at the same time urging parents to promote the acquisition of necessary skills in their children.

This is indeed the empowerment process which remains a rhetoric at national and international level. Disabled people need to live in a more just society which recognises their needs and acts to reduce or eliminate the societal harsh environments, social and physical barriers which prevent them from participating in the welfare of the state and community. Indeed, one cannot meaningfully speak of development in the community from the autonomous standpoint when disabled people are left out or ignored. This is what Coleridge (1993) refers to as a dehumanising experience. Frontline workers in rehabilitation and integrated education ought to take into account the cultural basis of disability as an entry point in the communities they work.

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Joseph Kisanji is a lecturer in the Centre for Special Educational Needs at the University of Manchester, England and co-ordinator of the M.Ed. course in Special Education (International). He was formerly a lecturer in Tanzania and managed the UNESCO Subregional Special Education Project in eastern and southern Africa for six years.

Contact Address

Centre for Special Educational Needs,
School of Education,
University of Manchester,
Manchester, M13 9PL
England

6
Developing Livelihoods

Mavis Campos

Throughout the world, there is a jobs crisis. Times are hard for millions of people in both industrialised nations as well as in developing countries. Consider these facts.

- 30 per cent of the world's labour force is either out of work or under-employed. That means that more than 820 million people world-wide are either unemployed or working at a job that does not pay a subsistence wage. Youth unemployment is worsening.

- Unemployment is highest among unskilled workers and immigrants in most countries. Poor countries are hardest hit. The situation in Africa is particularly troublesome with most countries experiencing a major decline in living standards. In many countries, the gap has been growing between people earning high and low wages.

- A farm labourer in a sugar cane plantation in the Philippines is paid seven pesos (28 cents) per hour but has to pay 22 pesos (88 cents) for one kilo of sugar. A woman in Thailand has to sew 80 pairs of blue jeans to earn enough money to buy one pair of jeans.

In these situations, how can people with disabilities find and keep employment? Even without accurate figures on the size of the problem in developing countries, it is obvious that people with disabilities are more exposed to unemployment than the rest of the population. In many urban areas the chances of their being without work are five times more than for others. Even where people with disabilities have access to good vocational rehabilitation services geared to finding the right sort of job, they can still expect to meet physical, cultural and social barriers which place them at a disadvantage. With reduced income opportunities, their family and social lives are also severely limited.

The outlook is worse for disabled women, who are among the most disadvantaged groups in Asian society. They have fewer opportunities for vocational training and are discouraged by their family members to leave the home and often denied education.

In this chapter we review how best to create livelihoods for people with disabilities. From our experiences in the Philippines, promoting self-employment seems to offer the most hope (see also Chapter 11).

Vocational Training

There has long been a perception in Western countries that vocational training and employment of people with disabilities is the purview of specialized centres. Such thinking has migrated to the developing world.

Vocational training gives people with disabilities a sense of equality when competing for employment particularly in urban areas. Traditionally, the training takes place in separate special centres in an urban setting. People with disabilities from rural areas are either recruited, or are attracted to these training centres. This migration brings with it problems of adjustment to urban life, high cost of living and difficulties in finding affordable accommodation. Often the vocational skills they acquire are likely to be of limited value in their rural home life and members of the family may not perceive an improved work potential in them.

Trainees often have to rely on passive income support whilst attending the centres. But such 'dole-outs' tend to discourage work force participation and reduces self-esteem. The main justification for the payment is that the persons are “unemployable”.

In rehabilitation services people are often seen and classified by the single dimension of their disability and certain procedures are automatically prescribed, rather than considering people as individuals with a varying range of characteristics and skills. For example, is it really our experience that someone who goes blind in late age suddenly develops a burning desire to make a basket or a mat? I knew an electrician who went blind at 50 from a vehicular accident. He was the despair of the rehabilitation worker who tried to teach him basket-weaving. Yet he could still repair radios and do the rewiring for his neighbours.

Likewise it used to be the practice - and it may still be in some areas - to teach Braille at any age. Some older people have shown a remarkable aptitude for learning it and there is much to be said for teaching the Braille alphabet to an older person who needs to use it for playing cards, or to read the labels on containers or cassettes. Yet, if someone who goes blind at 50 and wants to continue to read fluently, (although many people do not), would it not be better to help him or her learn how to use a tape-recorder so they can listen to talking books?

I am not discrediting vocational centres or skills training classes. Many local organisations run them excellently and many people with disabilities enjoy them. But are they in a sense a soft option? Someone who loses sight late in life does not lose the skills and interests of a lifetime. The role of the rehabilitation worker might well be to act less as a provider of specialised, exclusive services, and more as a *facilitator,* to help people with disabilities within their family and their community, so that they can continue to use their previous skills, interests and associations.

A characteristic feature of almost every village is its wealth of skills, interests and social contacts, already familiar and wider than anything which can be provided in a setting designed exclusively for people with disabilities. Such community integration, far from diminishing the role of the rehabilitation worker or the local community, requires from them exceptional organisational talent and skills in networking and establishing contacts. Community-based rehabilitation (CBR) has become the main emphasis in most developing countries and in countries like the Philippines, it has changed the lives of people with disabilities and transformed public attitudes.

An essential component of any comprehensive CBR project should be to provide people with disabilities with the opportunities to generate their own income.

Self-employment in the rural setting

In many countries rural people account for 70-80 per cent of the total population. As with the general population the majority of the people with disabilities therefore live in rural areas.

Most people are engaged in the same occupations as members of their extended family and local community. These include farming, fishing, livestock rearing, managing stores, food processing, vending, handicrafts or some village trade.

Our experiences have shown that the community can help to improve the job marketability of its disabled members, develop their skills through the provision of on-the-job training and promote income-generating activities suitable to their special circumstances. The role of services is to make available facilities, equipment and loans as necessary. The employment opportunities open to people with disabilities can then be broadened, and the tendency of "job-typing" - for example, associating blind people with basket-weaving - can be repressed.

A person with disabilities who is taught skills compatible with their disability and, as a result, is able to engage in some aspects of the family farming, fishing, handicraft or other business enterprise, is just as integrated into the mainstream as a person working in a factory in the city, doing simple repetitive, boring and not too remunerative jobs.

There is a growing acknowledgment that the needs of people with disabilities are best met in their own setting. From a social point of view, this approach preserves and takes advantage of the traditional role of the family and the community in caring for the material and emotional needs of the people with disabilities. Furthermore, it reduces the economic costs of transportation and accommodation.

Every disabled individual who is assisted from a state of enforced dependency to achieve productivity and self-sufficiency is clearly an asset. The family well-being and individual dignity are enhanced even when the person with disabilities is unable to achieve total self-sufficiency, but becomes somewhat less dependent upon others by contributing even in a small measure. In our experience the disabled person engaged in family work, or self-employment is a role model and has motivated non-disabled members of the family and community into becoming wage earners.

In sum, self-employment offers tremendous and varied possibilities for encouraging people with disabilities to take to business enterprises. The advantage is that they can undertake the tasks for which they have the aptitude and competence, at a pace compatible with their disability. As they work in or near their home, problems of travel and mobility are reduced.

Experiences in the Philippines

In the Philippines a number of non-government organisations working with people with disabilities in CBR programs have gained valuable experiences in creating training and employment opportunities. I would like to share some of these experiences. The case-studies of entrepreneurs will give a better insight into our efforts of ensuring a better quality of life for people with disabilities.

The development of these livelihood programmes is based on the concept that the person with disabilities is central to, and an active participant in the programme. The person with disabilities and the family make the decision and create the jobs. The project, and its feasibility, is discussed with the person with disabilities, the family, the field worker assigned in the area, and the project co-ordinator. A project proposal is submitted to the administration. On the recommendation of the project co-ordinator a loan is extended at an interest rate of six per cent per annum.

The field worker monitors the project, assisting the disabled person with organisational skills and simple accounts, facilitates the repayment of the loan, or recommends a second loan for expansion or diversification. This is how Rennel is making a difference in the life of her family.

Insert Slide 1 (Rennel) Photo

Rennel, a blind woman of 35, lives with her family in a village surrounded by rice fields. Her family encouraged her to help with simple household chores but always under their supervision. She prepared the feed and tended to the ducks and chickens they kept, and worked alongside her sister in preparing the family meals. After the field worker trained her in mobility and daily living skills, her family were encouraged by her capability to do many things on her own. Rennel was now confident and motivated to have an income to help the family.

The loan was for pig raising. Her family put up the pen, and Rennel was responsible for preparing the pig feed from the root crops she grows in her garden and the bran and rice stalks she gets from the rice mills. It was her job to feed the animals and clean the pen. The pig raising did not keep her busy enough and she ventured into making rice and cassava cakes which were sold as afternoon snacks. With the profit from the sale of the cakes and one of the pigs, she renovated their house and had the thatched roof replaced with the more durable galvanized iron sheets. For the first time too, they had electricity installed in their home.

Her older sister was encouraged by Rennel to open a store in front of their house which sold all the basic needs of the village community. With a second loan, a refrigerator was bought for the store and Rennel makes ice candies and sells soft drinks which are very popular with the village children and farmers, especially during the hot summer months.

It is very obvious that the family's quality of life has improved substantially in the two years that Rennel has had this small scale business. She is also much admired and respected by her family and neighbours. Her loan payments are regular and she has some savings. With help from her sister she maintains the accounts and manages the finances. “I am saving to have enough capital to buy the store from my sister who is moving to another village. All this should keep me quite busy”, she adds with a chuckle.

Agriculture: Numerous job opportunities in agriculture and rural occupations exist. Field workers who have close rapport with their clients can facilitate and assist the disabled person into these existing income generating activities by identifying the specific aptitudes and providing on-the-job training. Often a family member becomes the trainer.

In many Asian countries, most of the agricultural operations such as weeding, tilling, manuring, sowing and harvesting are labour intensive as they are done manually. A number of persons with disabilities working alongside family members are engaged in these activities.

The objective is not to make the disabled person an expert agriculturist but rather to train him or her as a useful and contributing member of the family unit so that the disabled person can assist the family in various farm and non-farm jobs. A trained hand truly becomes useful to the family in several ways. This happened with Joseph.

Insert Photo 6.1 Joseph

Joseph, now 19 years old has been suffering from epileptic fits since he was four years of age. Medication was irregular as the family could not afford it and Joseph suffered frequent seizures. Due to his condition he did not go to school and was always in the home with his grandmother while the other members of the family worked in the sugar cane fields near his home. When the field worker identified him, she first referred him for medical treatment. Now with regular medication his seizures are under control.

Although Joseph has learning disabilities secondary to epilepsy, he has shown an interest in farming. On given preliminary training by his mother, he was encouraged to develop his own vegetable plot, in which he takes great personal interest and pride. He now works with his mother in the sugar cane fields and is paid a daily wage.

Crafts: Home based or cottage industries which specialise in handicraft products and in Christmas decorations have recruited some disabled workers. In the Philippines, gift items, household and handicraft products made from wood, shells or ceramics are currently among the leading export items.

For such an enterprise to be successful, it is essential that raw materials are easily available. With capital through the CBR livelihood loan assistance, and the marketing of the products arranged by non-government organisations, some disabled people manage small business enterprises in handicrafts. Pogi started small but now is known internationally for his craft-work.

Insert Slide 2 (Pogi)

Stricken with polio when he was three years old, Pogi, now 45, developed severe contractures and scoliosis. Because of the lack of professional management, Pogi crawls when moving about, without kneepads and with only a pair of rubber slippers slipped through both hands.

Even in the early years, disability did not prevent him from striving to be independent and contributing towards the family. He lives with his mother in a coastal village and learned fishing from his neighbours. His meagre income supported both him and his mother.

Five years ago he attended a four week training course on "pandan" weaving, at a community centre near his home. This was sponsored by a group of individuals with market outlets in the USA.

"Pandan" trees belong to the palm family. The leaves are separated from the midrib, cleaned smooth with a knife and left to dry. The dried leaves are then woven into beautiful trays, bread baskets, place-mats, etc.

Pogi became very skilled and soon made a name for himself for his quality "pandan" crafts. A local exporter, recognising his skill and the quality of his work, hired him. She provided the tools and the designs. Pogi works at home and his employer collects and pays for the work on completion. A family member also earns an income from harvesting and preparing the "pandan" for weaving. Pogi has trained a number of non-disabled women in his neighbourhood whom he employs when he has bulk orders and during rush production periods.

In 1991 Pogi went to Hong Kong to participate in the 3rd International Abilympics and won an award in the category on "Waste Re-Use".

The CBR program has linked Pogi up with exporters and overseas agencies, and the supervisory staff provide the support services, and facilitate the orders, insurance and shipment of products abroad.

Vending: As soon as your car comes to a standstill in the traffic jams in Manila or you stop at the traffic lights, a little face appears at your window holding a garland of flowers. "Won't you buy my pretty flowers, Sir?" She is a street vendor.

It is a common sight to see vendors, many of who are children, weave their way through the traffic, selling a variety of goods such as cigarettes, newspapers, dusters, towels and food. Many people earn an honest living vending. Without any systematic training, blind people in particular seem to do well as vendors. In rural areas the vendor goes from house-to-house. Rodolfo is such a vendor.

Insert Slide 3 (Rodolfo)

Forty year old Rodolfo, blinded by measles as a child, learnt simple carpentry from his uncle and occasionally earned some pesos from making tables and chairs from bamboo slats. More popular however were the bamboo clothes pegs he made. His customers were only from the immediate neighbourhood. Rodolfo did not go around the village as he had no sighted guide to take him..

The field worker who identified him just two years ago, found him to be highly motivated and eager to learn independent travel techniques as he wanted to be a vendor.

On completion of basic rehabilitation skills and after discussion with his aunt, who offered to help him with the wholesale purchasing and keeping of accounts, Rodolfo was given a loan to start his business. He travels from village-to-village selling a variety of goods. What has made him a successful salesman is the personal interest he takes to satisfy his customers by selling those commodities that they need and which they can order through him.

The family support, Rodolfo's own initiative and skills, and periodic follow-up by the field worker have ensured success. To add to his income he has started a small duck raising project. He has a bank account and plans to expand and diversify his business when he has enough funds.

In today's world it is not sufficient to provide only knowledge and skills related to rehabilitation. We should address the issue of empowerment versus delivery of services. Empowerment means helping people take charge of their lives. Rennel, Pogi, Joseph and Rodolfo were restrained by social, financial and attitudinal forces from asserting such control. Through their income-generating activities they have overcome these barriers.

Social Marketing

The ever growing unemployment and under-employment in developing countries pose a major challenge in the employment of people with disabilities. More than six million able-bodied Filipinos, many of who are trained professionals, work as domestic helpers overseas due to the staggering unemployment problem in the Philippines.

Global inflation, increasing population, computerisation and tremendous advances in science and technology, all result in minimising labour intensive employment. Moreover the lack of public awareness regarding the potentialities of people with disabilities further decreases opportunities for these people in open employment. A number of solutions have been proposed.

The passing of the quota scheme law, where a certain percentage of jobs were reserved for people with disabilities has been very popular with governments of developing countries. I find this discriminatory. What about unemployed women, ethnic minorities and the urban poor?

Quota schemes and various legislative acts are often merely documents wherein are enshrined noble and lofty ideas. They are often ineffective because the infrastructure for the implementation is not there.

Rather than the negative strategy of compulsion and punitive measures against employers, I would try the persuasion and demonstration approach. What do I mean by this? For us in developing countries, it is a good strategy to demonstrate to the employers and employees the potential of the person with disabilities, by offering him or her as an apprentice. If our aim is integration and equalisation of opportunities for people with disabilities, this individualised and cost beneficial strategy of mainstreaming people with disabilities in the open labour market in urban and semi-urban settings is more acceptable.

This handing over of a person with disabilities to the artisan, craftsman, or employer for on-the-job training may eventually ensure his future employment. A vital consideration is to select a well motivated, well adjusted client with a pleasing personality. The greatest pride of a teacher or instructor is the achievement of his pupil. Therefore the instructor will do everything in his power to ensure employment of his pupil. He knows him, knows his capabilities and he is challenged to teach him the skills because this person with disabilities will do him proud and boost his own morale. Once an employable level of skill has been reached, the industry or enterprise may offer the disabled person permanent employment on the recommendation of the artisan trainer. Can we ask for more?

This is how two of our hearing impaired clients have found regular employment with the city government. For two months they were apprentices on a landscaping and beautification project of the city. They learnt by watching the trainer and by practising and improving their skills. They so impressed the trainer by their attitude and willingness to work, that they were offered permanent employment on his recommendation to the city officials.

It is really a social marketing strategy whereby we "market" the skills of people with disabilities, and convince the employers by gentle persuasion and sales talk. However we should be careful to match the person with the job demands. People with disabilities should get into jobs that they are capable of performing and which are satisfying to both themselves and their employers. The successful placement of a person with disabilities is the best publicity to win over the confidence of employers. We cannot illuminate the world but we can build many "lighthouses"!

Hope and Encouragement

Although I started this chapter with a somewhat bleak picture of the global employment situation, the employment potential of people with disabilities in our experience has been most exciting. I hope the case studies will provide encouragement to readers of how people with disabilities and their families are capable of creating viable livelihood projects if given access to support and opportunities.

It is also my hope that the case studies, though focusing on a developing country like the Philippines, will interest people with disabilities in industrialised countries, as they demonstrate people like themselves managing their own businesses successfully in far less favourable conditions. With jobs in the open market becoming more and more scarce, they too may consider the possibility of self-employment as a practicable option to social service assistance or pensions.

To our colleagues, rehabilitation workers, and staff of institutions, there is a poignant message. Successful enterprises of many people with disabilities have been developed with the help of the family and the community and without much assistance from rehabilitation institutions or intensive vocational training. Is there not then a need to look at new approaches in rehabilitation?

Why self-employment?

If a vast majority of people with disabilities live in rural areas, we must evolve strategies to take our rehabilitation services and livelihood programmes to the rural areas. Self-employment, properly tackled is a viable income generating option for many people with disabilities. The person with disabilities makes the decision and assumes a responsible and creative role in the enterprise. It usually involves the whole family, who provide the support, security, and often times the skills needed by the person with disabilities. In most developing countries the extended family still plays a major role.

These enterprises are located in or near the house so that mobility problems and transport costs are substantially reduced. Village based enterprises use readily available materials that have a local demand. They are therefore appropriate in that they produce goods which poor people need at prices they can afford.

In producing handicrafts as Pogi does, optimum use is made of local labour, local equipment, local materials and the skills of the entrepreneur.

In economic terms, self-employment represents possibly the most cost effective way of creating jobs. Capital requirements are usually very small. For example the maximum loan that is given out by our project for livestock raising or to run a store is P3,000 to P5,000 pesos (US $120-200).

Loans, rather than grants, have proved helpful in instilling values of responsibility and commitment. The borrower tends to take the enterprise seriously and makes the effort to succeed. With steady repayments, additional loans are made available for those who need the money for expansion or to enter a new business in addition to an already established one as many of the people in our case studies wished to do. What the person with disabilities needs is an economic investment, NOT a dole out, NOT social welfare, NOT charity.

Afterthoughts

I have focused on self-employment as an individual activity. I would like to make mention of group enterprises located in urban areas. For example, in Manila a group of blind masseurs have pooled their resources and skills to start a business together and they are doing very well. If the group has the right leadership this form of self-employment has some obvious advantages. The people involved can share the numerous responsibilities of business, they have company as they work together and they can benefit from the support and encouragement of each other when problems are encountered.

I realise too that I have failed to mention some other avenues for creating employment such as co-operatives of the disabled both industrial and rural, sub-contract jobs like packaging or simple assembly line jobs that can be done at home or in production workshops. They are being considered within various programmes in the Philippines.

It is clear that a lot of work has still to be done. Our programmes should be flexible, open to new ideas, ready for growth, to make room for the rapidly changing situations in rural environments especially.

Our commitment remains, to enable the person with disabilities to acquire the necessary skills to live the life of his family and community.

- Where his or her ability NOT disability is the core issue.
- Where he or she becomes so completely woven into the fabric of community life that they "disappear" into the mainstream.
- Where he or she is ONE OF THEM.

Ways and means to achieve this end will change and MUST CHANGE if we remain true to our mission.

This is the vision I share with you.
This is the challenge I leave with you.
Let us all work towards making it a reality.

Mavis Campos is a specialist in the education of children with visual impairment and for 12 years worked with the Ministry of Education in Malaysia as a teacher and supervisor of integrated education programmes of blind and low vision students. She was also Principal of St. Nicholas School for the Blind, in Malaysia for eight years.

Mavis has conducted teacher training courses for special education teachers of the visually impaired in Thailand, Papua New Guinea, China and the Philippines.

From 1989 to the present, she has been based in the Philippines as the Education and Rehabilitation Adviser of Christoffel Blinden Mission and is involved with community based rehabilitation training. She also co-ordinates the prevention of blindness program of Christoffel Blinden Mission partners in the Philippines.

Contact Address

Cataract Foundation Philippines
R-132 Riverside Medical Center
Ninoy Aquino Drive
Bacolod City
Philippines 6100

7

Mobilising Communities in Guyana

Brian O'Toole

The gap between the need and provision for rehabilitation cannot be closed by developing, or even expanding, conventional services. Instead a new pattern of services, characterised by fewer experts, less advanced forms of training and simplified methods of intervention, needs to be developed. The challenge is to find ways of providing the most essential assistance to high numbers of persons utilising the readily available resources.

The goal of Community Based Rehabilitation (CBR) is to demystify the rehabilitation process and give responsibility back to the individual, family and community. Rehabilitation then becomes one feature of community development whereby the community seeks to improve itself. Once the community takes on the responsibility for the rehabilitation of their disabled persons, then the process could truly be called 'community-based'. In such a process, rehabilitation becomes one element of a broader community integration effort.

The philosophy of CBR is immediately persuasive, but can it be translated into practice? Is community involvement in the area of rehabilitation realistic? Is it possible to develop rehabilitation as a 'process', in which a number of persons are involved, rather than as a 'product' which is dispensed by others? This chapter examines the way in which the 'Hopeful Steps' CBR programme in Guyana, South America attempts to mobilise the community to assume a sense of ownership for the rehabilitation process.

Guyana: the Country

Guyana is located on the Atlantic shoulder of the South American sub continent. It is bordered by Suriname on the West, Venezuela to the East and Brazil to the South. Guyana is a land of 83,000 sq. miles with an estimated population of 0.8 million. Ninety percent of the population live on the narrow coastal region. 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 reveal both positive and negative trends. Infant mortality is declining, from 69 per thousand in 1960 to 33 per thousand in 1985, and so is the crude death rate, from ten per thousand in 1960 to six 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 $590 in 1994. The percentage of the national budget allocated to health has been one of the lowest in the Caribbean.

Guyana has only one special school which is based in the capital Georgetown, and serves the needs of hearing-impaired and intellectually impaired children. There is a waiting list for entry to the school. In Georgetown there is also a centre for physically handicapped children and a Unit for visually impaired children is attached to a regular 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 . There is a significant gap between needs and available services.

The Beginnings of 'Hopeful Steps'

A two year, pilot CBR project was conducted in Guyana from 1986-1988. Before the project began a series of meetings was held with personnel from the Ministry of Education and Ministry of Health, as well as with parent groups, community leaders and rehabilitation professionals.

Arrangements were also made for the training of prospective field-workers to be offered as a course by the Institute of Adult and Continuing Education (IACE) of the University of Guyana. The CBR programme complements 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. Sixty persons 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. In all, 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. All but two of the volunteers were women. About one fifth of the volunteers had a relative with a disability.

Many of the volunteers were already playing key roles in the community as teachers and nurses. A number of the volunteers were therefore well placed to make a wider contribution to their community. It was not therefore a matter of us taking whoever we could get from the area as volunteers. The pilot project 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 persons with disabilities.

The pilot project lasted for 2 years with the volunteers meeting twice per week to learn about ways in which they could help disabled children. The majority of the volunteers soon became deeply involved in the project and were eager to meet together to discuss their anxieties, doubts and to share their successes. A sense of belonging soon emerged and the volunteers came to regard the project as their own.

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 which would help the child to learn new skills.

One of the key features of the pilot programme was the involvement of the wider community. A rehabilitation committee was formed which took responsibility for the programme. They approached a local Hindu organisation and created a Resource Unit in their village for disabled children who were unable to attend regular schools. The Hindus provided the building and the local committee equipped the unit with material donated by the wider community. The Ministry of Education seconded the headteacher and two other teachers to work in the unit. All three teachers were 'graduates' of the CBR programme.

The local rehabilitation committee continues to meet on a regular basis to review progress and still oversees the development of the Resource Unit eight years later. Hence the project continues to be a community-based model of rehabilitation.

The Expansion of the 'Hopeful Steps' Programme

On the basis of the results from the pilot project an expansion of the Guyana CBR programme began in 1989, funded by Amici di Raoul Follereau and the European Commission. The goal of this phase was to expand and consolidate the CBR programme in Guyana. The hope was to expand the programme into two new coastal areas of Guyana working through volunteers. In a third area the goal was to work through school teachers.

A further aspect of this new phase was to explore the relevance of the concept of CBR in one of the indigenous regions of the country.

In the expansion phase, efforts were to be made to work more closely with the existing government infrastructure and to explore ways to raise up a new cadre of workers who would be able to introduce the CBR philosophy into new regions of the country.

Once again the major focus of the 'Hopeful Steps' programme was based around the use of volunteers from the community. In the two new areas of coastal Guyana in which the programme has expanded, three times as many people have applied to be accepted as volunteers on the new training programme as could be accommodated. The drop-out rate over the course of two years was no more than five per cent. The volunteers have proved to be a committed cadre of individuals who have given generously of their time. Over 70% of the volunteers have remained deeply involved in the programme three years later. The volunteers are generally accepted by the families and have generated a high degree of wider community involvement.

It should be emphasised that the 'volunteers' came from a wide cross-section of backgrounds. Nurses, midwives, and school teachers were well represented amongst the volunteers. In other cases it was the family members of persons with disabilities who volunteered their services.

CBR Teams in the Interior

The Rupununi region of Guyana is the home to almost half of the Amerindian population of the country who live in a number of very isolated and sparsely populated communities (see Chapter 4). Introducing the CBR programme in the Rupununi has created collaboration between a number of agencies who share the common goal of empowering communities to help themselves.

Over the course of eight months a series of five, one week field trips were made by the author to the region. Discussions were held with the local community leaders in ten villages.

The main activity of these early exploratory visits was to listen keenly to the people and to try and understand their needs. In each village a public meeting was held to introduce us to the community and to provide a forum for the people to express what they felt were their major needs.

The following needs were expressed (the number of villages mentioning each concern is given in brackets)

- improved water and sanitation (10)
- training in health and education (8)
  (areas mentioned included: upgrading the skills of Primary Health Care workers and teachers, as well as training more microscopists for malaria detection and dental nurses)
- education of the community (5)
  (on issues such as alcohol abuse)
- improved methods of agriculture (4)
- improved Health Centres (4)
- development of kitchen gardens (3)

After three years of the 'Hopeful Steps' programme in the Rupununi region it has been very instructive for us to reflect back on this original list of priority needs to see how many were addressed by this particular programme. As you read on, you will be able to form your own judgement.

Training Workshops

It was felt that the greatest contribution our programme could make in the interior was in the raising up of human resources. The major focus of the 'Hopeful Steps' programme in the first three years therefore was on providing training for identified leaders within the community. Over the course of the past three years a total of 24, one week workshops have now been held in this isolated region. As in other parts of the country, the training is sponsored by the Institute of Adult and Continuing Education (IACE) of the University of Guyana although this is the first time that the University has had a presence in the Rupununi region of the country.

The region, comprising 33 villages, was divided into five sub-regions and over the three year period, a four day workshop was held in each one. The topics covered in the workshops were as follows:

Year One: early stimulation, child development, introduction to disabilities, ways to influence awareness within the community concerning disability issues, puppet making.

Year Two: ways to carry out a survey, toy making workshop, assessment and teaching ideas to promote development in the first 6 years of life, examination of child development from the perspective of Amerindian culture.

Year Three: leadership training skills, consultation, integration of children with disabilities into regular schools, ways to conduct workshops in local villages

Insert Photo 7.1 here

In addition to the above, a literacy training workshop has also been held in each sub region for all the teachers which focused on the promotion of literacy and numeracy skills in the children. The themes of the various workshops emerged out of the dynamic of the intervention and were not predetermined from the outset.

Attendance at the workshops has often entailed the participants travelling long distances on foot, by bicycle and by canoe. On three occasions, people have walked for over 13 days to participate in the workshops.

CBR Teams

In each of 33 villages there is now a team of three persons who constitute the CBR team, namely the Community Health Worker, a school teacher and a village leader.

In all the literature on CBR we read of the need to develop a multi-sectorial approach. However the number of effective examples demonstrating this are few. Our hope was to bring educators and health workers together for a common training to develop a unified vision of the needs of their communities. This was the first time that such a joint model of training has been undertaken in the region.

In addition however the Amerindian communities have a lifestyle and tradition that has evolved over many hundreds of years. Any intervention that is insensitive to the traditional patterns of leadership would not succeed. The team were therefore joined in each case by one of the village leaders. It is always easy to present a coherent rationale for a programme as one reflects on its evolution. In practice however, there was limited awareness of the goals and objectives of the project at the beginning of the programme. As such, in some cases better choices could no doubt have been made to form stronger teams.

However, three years later with considerably more awareness and involvement in the programme, a new model of management has been added. The expanded model has emerged in collaboration with the Baha'i Health Partnership which has been operating an extensive Primary Health Care programme throughout the Rupununi region over the same period of time. Now the plan is to develop a Village Health Assembly (VHA) in each of the 33 villages in the Rupununi. To date 24 VHAs have been elected by all the adults in the village. In the elections, there is no canvassing and no nominations and in each village a very high percentage of the community has turned out to take part.

The VHAs are now challenged to address the needs of their community. 'CBR issues' therefore become one area of their focus. Already two day workshops in 14 villages have been held for the newly elected VHAs to deepen their understanding of the challenges facing their community and the need to develop a new style of moral leadership based on service to the community.

Community Development

The work in the Rupununi is emerging into an integrated community development project. One example of this is the collaboration on the 'Facts for Life ' project with the Baha'i Health Partnership that is operating in the region. All 33 villages participated in the 'Facts for Life Festival' in which villagers of all ages wrote poems, songs, skits, short stories and produced posters to communicate the essential health messages featured in the joint UNICEF, UNESCO and WHO publication *'Facts for Life'* book. The Festival captured the imagination of the villagers. It proved to be a way of giving expression to their rich culture in order to communicate health messages.

Another aspect of the programme in the Rupununi is the promotion of training in literacy. Following one of the early workshops on CBR a request was received from the teachers 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 one Rupununi region. All the practical arrangements were undertaken by the teachers themselves. An outcome of this initial workshop was collaboration with the Ministry of Education 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 has been developed by the CBR team to meet this request. The Guyanese Ministry of Education subsequently invested US$50,000 in the production of these literacy materials for use in other parts of the country. As a result of the literacy project, libraries have been established in 24 of the villages.

Partnerships have also been formed with other groups. The Social Impact Amelioration Project (SIMAP) is a body 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 officials invited the CBR project to be the catalysts and intermediaries for their programme in this region. As a result visits were made to six villages to meet with the community to learn of their needs and to formulate proposals to fund these needs. Projects have now been completed in three of the villages to improve the water supply and upgrade the local health centres. The CBR team's role has been in helping in the formulation of the proposals, networking with the funders and monitoring the implementation of the project.

The 'Hopeful Steps ' programme in the Rupununi began three years ago with very modest goals. The vision has however widened over this period. The seeds are planted for an integrated model of development in this region. This direction has emerged out of on-going consultations with the local communities. The various innovations were not designed from the capital city but arose out of an attempt to respond to the expressed needs of the community.

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. This has included the production of a video and audio cassette of the indigenous music of the region; a story book - written in the local languages - promoting awareness of the needs of disabled children within the folk lore of the people of the region; as well as a video and educational training materials on the rainforest to help the children living on the coast of Guyana appreciate the majesty and potential of this region of their country. Another input has been a series of story books on appreciating water as a resource.

When the programme began three years ago we were informed that there were no disabled persons 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 contribute to the development of all of the children in the Rupununi. However having gained the trust of the people, the focus has now widened to encompass the needs of the disabled persons. A comprehensive survey of disabled persons of the entire region has been completed recently and a Plan of Action to respond to the needs of those identified by the survey is now emerging. Had we adopted a narrow disability focus from the inception the CBR programme would have been dismissed as an irrelevance within the region.

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

Creation of Regional CBR Committees

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 Regional Committees are assuming more and more of the management functions of the programme and are helping 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. The Committee structure has evolved out of the project and was not preconceived from the beginning as the way to manage the innovation.

Regional Resource Units

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.

Development of Training Materials

As the programme evolved we felt the need for locally produced video- training materials that would reflect our own particular needs and culture. Dr. Roy McConkey played a key role in the development of the training materials, produced and developed in Guyana. 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 materials which have been translated into Arabic, Spanish and Portuguese. 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. The materials have been created by a team of persons to produce a collaborative effort.

One example of the training materials is the production of a video-training package on puppet making. 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 persons as one contribution towards improving attitudes within the community to persons with disabilities. A video of their efforts was featured on national television as a result of sponsorship from a variety of local community businesses.

The word 'empowerment' is common in the literature on development, 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.

Promotion of Community Awareness

From the beginning, 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 programme. This process of keeping the community informed of the developments within the project was nurtured through the publication of a quarterly CBR Newsletter which is distributed to over 500 persons throughout the country.

Wider role for CBR Co-ordinators

The term 'community involvement' is repeatedly extolled 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.

Adequate and appropriate training is a crucial first step to be provided for the CBR workers. However, 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 CBR worker and develop the respect of the family for them. The role of the Regional Co-ordinator is to help the volunteers, the disabled persons and the families to identify their own needs and then to assist them in formulating creative responses to the challenges. In response to this nurturing model the self-confidence and self-worth of the participants grew as they realised they could 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.

At present the 'Hopeful Steps' programme operates in five of the 10 regions of Guyana. Plans are now prepared to expand into two more regions over the next two years. In each of the five regions the CBR programme employs two or three part time 'Regional CBR Co-ordinators' who live within that region. In addition we are fortunate to have three full time Voluntary Service Overseas (VSO) volunteers from the United Kingdom. In all cases, the Regional Co-ordinators are part-time, paid staff.

The Regional Co-ordinators have been drawn from a very diverse range of backgrounds. In most of the rural areas in Guyana there is no one available with a rehabilitation/disability training. Of the 13 co-ordinators listed below, 10 have received their training as part of the CBR programme.

- Parents of disabled children (2)
- Head of Nursery School (2)
- Nurse (2)
- Education administrator (2)
- Physiotherapist (1)
- Teacher of the hearing impaired (1)
- Health Visitor (1)
- Occupational Therapist (1)

- University lecturer (1)

Working within an Existing Infrastructure

The early years of the programme relied solely on volunteer manpower from the rural communities. Their original 120 hour training programme grew to over 150 hours as they requested additional elements to enhance their repertoire of skills. A major challenge however emerged in terms of how to incorporate CBR into the existing government infrastructure in order to expand coverage in an economically viable manner.

Of the original 96 volunteers who were trained in three Regions - 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 have invested considerable time and resources in this process and that they were quite capable of presenting the 10 hour modules on their own. Over 160 teachers have now completed the 10 hour course developed by the CBR volunteers.

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 newly formed teams began by using the guides as a virtual script for the sessions but as their confidence grew they introduced other material into the training.

The time which has been invested in the development of training materials and human resources is now beginning to pay dividends. Two new, University accredited, CBR training courses are now taking place in ECD and Berbice Regions. Each course is for 120 hours. The courses are managed and presented by resource persons who have been raised up through the early years of the CBR programme. The National CBR co-ordinators play no more than a monitoring role in these courses. The various training materials that have been produced on the programme form the nucleus of the course.

These 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 loyal to the programme far beyond their initial commitment as volunteers for 2 years.

The CBR programme in the Rupununi is now being expanded by each of the 33 CBR teams presenting workshops for community leaders and parents in their own village on early stimulation and the making of toys.

In collaboration with the Ministry of Education another element of the CBR programme was developed to train Nursery School teachers within the Essequibo Coast region. A series of discussions was held with ministry officials and with the teachers of the region. 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. The Resource Units operate out of the Nursery schools on a weekly basis and provide a meeting ground for parents of disabled children.

Insert Photo 7.2 here

A programme that therefore began on a modest scale with volunteers is now expanding and beginning to forge links with the wider community.

Involvement of Disabled People

The CBR programme in Guyana has focused on the needs of children over the past nine years. In accordance with the written constitution, more than half the members of each of the four Regional Committees are parents, family members of disabled children or people with disabilities.

A number of the children who entered the programme some years ago are now young adults and recently the focus of the programme has widened to embrace the needs of adults. Whilst the programme has had considerable involvement on the part of parents and family members of disabled children, the involvement of adult persons with disabilities has been far more limited. This highly significant imbalance is now a major focus of the next phase of development of the 'Hopeful Steps' programme. Already each of the Regional CBR Committees has this challenge as a major focus on their agenda.

Our funders, AIFO, are sending Mr Tambo Cammara, from Mauritania, one of the international leaders of the disability movement, to Guyana to help to stimulate that process. The lack of involvement of disabled persons in the 'Hopeful Steps' programme is a reflection of the very low profile played to date, by the disability movement in Guyana.

Lessons Learnt

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 the attempts that have been made to work within existing infrastructures have often become little more than a minor facet of an existing service provision to which no particular priority is given.

CBR offers to policy makers, professionals, planners and community leaders and to persons with disabilities themselves, a new approach to rehabilitation. Our programme has travelled a far way from its uncertain beginnings almost a decade ago. Aspects of the programme are presently being evaluated by independent evaluators. Two student researchers are presently in Guyana for six months from the University of Amsterdam and a Masters student from the University of California at Berkeley is carrying out her dissertation on the CBR work in the Rupununi. Within the year, two documents will be available that are the products of extensive, independent evaluations by researchers from prominent research institutions.

For our own part, we believe five main lessons have been learnt as we reflect on the past ten years work in the area of mobilising communities. They can be summarised as follows.

1. A profound faith and respect for the rural people

The goal of the project has always been to help the rural people to bring about change in their own condition and, in the process to take more responsibility for their own affairs.

A significant element of the 'Hopeful Steps' programme has been focused on raising up human resources from one region to introduce the CBR programme into other areas. Those involved in this process have never been used in this role before. The term 'empowerment' is now replete in every article on development. The CBR workers in the Guyana programme may not know the term 'empowerment', but they feel a sense of pride that they are now pioneering the CBR programmes to others in new regions.

The goal throughout the project has been to reinforce and nurture, rather than supplant, the authority of the teachers, health workers and community leaders in the regions. Education and training of local personnel are at the core of the project rather than the provision of services by external agents.

Efforts have been invested in helping each person realise the role they can play in the development of their community. For many persons the prevailing attitude at the beginning of the project was that the rural people of Guyana were poor, passive recipients of what others would donate to them. The change in attitude is reflected in the comments made by one of the health workers to an independent evaluator (Saha, 1995):

> *We have been encouraged to do something...to help ourselves....this is a self-help programme....we have learnt that we can do something...it is very encouraging.*

The philosophy which has permeated this project calls each individual to play a more active role in their own development and to inspire people to realise that they can indeed play a key part. Integral in this process has been an appreciation of the profound spirituality of the people of Guyana. For many of the people involved in the project the activities were a tangible way in which they could put into action their desire to be of service to others.

2. Promoting sustainability by avoiding dependency

In facilitating the sustainability of the intervention the local communities have been encouraged to take as much responsibility for the project as possible. The work of the Village Health Assemblies (VHAs) throughout the Rupununi and the Regional CBR Committees on the coast have provided the medium through which to involve the community at all phases of the project. The VHAs and Regional Committees have a clearly understood decision-making role and members feel a sense of real responsibility for the programme which they are increasingly regarding as their own. Both groupings are providing a definite channel to facilitate the consultative process within the rural communities.

The goal of sustainability is the touchstone of all development interventions. Only time will tell whether this project will be sustainable beyond the inputs of external interventions. The emergence and growing maturity of the VHAs and the Regional Committees, along with the high emphasis given to the training of these bodies in the skills of consultation, leadership skills, problem solving and decision-making, has established a very promising basis for long term development.

Some other features of the project which have promoted sustainability include:

- the clear match between regional needs and programme objectives;
- the use of the existing health and education infrastructure rather than creating new cadres of workers;
- the management of the programme is based within the rural regions;

- the focus is on involving and empowering communities.

A strong base has therefore been established on which to build for longer term sustainability.

3. Development needs to be in harmony with the local culture

The 'Hopeful Steps' programme is guided by respect for the culture of the regions and tries to proceed in harmony with it. Considerable time was expended at the outset of the project to meet people throughout the regions to learn about the needs of the areas. For example in the Rupununi, one of the major activities of the first year of the project was to produce, in consultation with the teachers and health workers, a set of training materials on child development and early stimulation which reflected the practices of the native peoples of the region. These ideas were then produced in the form of a series of video programmes and an illustrated teaching manual called 'A New Tomorrow' which has now been used throughout the region and with native peoples in a number of other countries in Central and South America.

Insert Photo 7.3 here

Project staff have also helped local people to record the music and oral traditions in their region and to write story books in local languages. Festivals of local poetry and song have been held and a children's newspaper started, all of which have illustrated the rich cultural heritage of the people of Guyana.

Examples of 'harmonious development' are not always easy to document. However the desire of many persons in the region to see the programme expand suggests that it is evolving in a way which is respectful to the people and their administration. A further illustration of this principle was gaining the consent of local officials at each stage of the programme intervention.

4. The promotion of unity

A guiding principle for the project was to promote the unity of the community. The programme has been effective in establishing partnerships, both within the Rupununi region and on the coast, with services and departments which normally work separately. The bringing together of these pre-existing resources also promotes the sustainability of the intervention. The support of the government's efforts in the area of health and education is a reflection of the desire to promote sustainability rather than attempting to develop alternative structures. It is not unusual for NGOs to supplant and disempower the existing government system. By contrast this programme endeavoured to support the government workers who work at the base of the health and education systems within the various regions.

5. The key of consultation

A guiding principle of the project was that it should be founded upon open and equitable consultation. The programme facilitated the coming together of people from diverse backgrounds and perspectives to a common forum to discuss their needs and concerns. They were given access to the decision-making process at every level of the intervention.

A key element in this process was for us to be able to listen carefully and then act on what was heard. There was no script in hand at the outset of the project. The actions of the project emerged out of the dynamic consultative process. For example, during the exploratory visits in the Rupununi and at the needs assessment exercise at the first series of workshops in each sub-region, the goal was to try and appreciate the needs of the area. In adopting this approach we were fortunate that our funders, AIFO and the EC, realised that such a process takes time and cannot be hurried.

The programme that was subsequently developed was therefore characterised by flexibility and responsiveness to suggestions from within the region. This process was further facilitated by a deep sense of respect on the part of the programme initiators for the people of the region. The process of consultation proved to be the major key at each of the subsequent workshops where the facilitators constantly adopted a reflective process in analysing progress to date.

Will the Model Work Elsewhere?

Can the model of mobilising communities outlined here be duplicated elsewhere under similar conditions? It is our belief that the model is replicable given certain conditions:

- the promoters of the innovation have a belief in the potential of the people they are serving.
- the innovators have the ability to guide individuals, who for so long have been traditionally led by others to take charge of their own affairs.
- the active participation of the recipients of development is achieved at all phases of the development process.
- the community has a desire for change.
- the developers and implementers of the programme are willing and capable to listen to people who may not be articulate.
- the innovators are experienced in the art of consultation.

- the funders allow the implementers sufficient time throughout the programme to facilitate the consultative process.
- partnerships are effectively established between all the key players and the major government agencies.

The 'Hopeful Steps' programme has attempted to develop a management style which would allow the lofty concepts of 'community participation' and 'empowerment' to be nurtured. 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. From a modest beginning in one region of the country, the Hopeful Steps CBR programme has now emerged into a wider integrated development project involving several thousand people.

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Brian O'Toole is a British educational psychologist who has worked in Guyana for 17 years. Initially he spent six years introducing and developing the Special Education programme at the University of Guyana and for the past nine years he has directed the Guyana Community Based Rehabilitation Programme. He has worked as a consultant in rehabilitation for PAHO-WHO, UNESCO, UNICEF and Save the Children UK and Norway.

Contact Address

Guyana CBR Programme,
c/o European Commission
PO Box 10847,
Georgetown, Guyana

8

Mobilising Parents of Children with Disabilities in Jamaica and the English Speaking Caribbean

Gerlin Bean and Marigold J. Thorburn

In many countries around the world, services for children and adults with developmental disabilities have come about because of the efforts of parents. In Europe much of this began in the 1930s.

In this, as in many other respects, developing countries have lagged behind. This may be partly because a larger segment of their population has been disadvantaged in other ways which put disability as a low priority. There is more poverty, services of all kinds are fewer and they are less accessible. The dependency of Third World countries at the national level reflects their dependency at the individual level. Consequently advocacy efforts are stifled.

There is probably more ignorance and shame about disability because the population at large have not been exposed to relevant and accurate information. Nor are they aware of the newer trends particularly those relating to rights of persons with disabilities.

Since 1980 however, the parent movement in the Caribbean has gathered strength, especially in relation to families whose children have a developmental disability. To a great extent, much of this change has come about because of the sharing of experiences and training facilitated by the Caribbean Association on Mental Retardation and Other Developmental Disabilities (CAMRODD) from 1970 onwards.

As professionals working with developmentally disabled children in Jamaica, the first and most obvious gap seemed to be the lack of services to families at crucial times, such as at diagnosis, at school entry, adolescence and later adulthood.

Much progress has taken place since 1970 in special education (CAMRODD, 1990, PAHO, 1993), but there are still a large percentage of children with disabilities who have not derived any benefit from the educational system. The rights that are automatically accorded to the non-disabled child are not extended to the disabled child, even at the individual level, in their own homes by their own parents.

Further, rights to basic services such as health care and transportation, are frequently denied to mentally retarded persons who are regarded as low priority and not worth the effort or expense. The list of situations that discriminate against persons with disabilities is long and includes many aspects of everyday life, such as access to buildings, schools, transportation, houses, religion, voting, insurance, driving, even the home itself.

Parent Participation

Prior to the economic, oil-related crisis in the seventies, it seemed that Caribbean governments might get involved more actively in services. Unfortunately, by the end of that decade and in the early 1980s when structural adjustment policies began to bite, it became apparent that if anyone was to do anything for children with developmental disabilities, the parents would have to be in the forefront, not only as caregivers but as organisers. In spite of this, little emphasis has been given to parents and their needs even in the voluntary organisations.

Numerous barriers to parent participation exist in Third World countries. But during the past 10 years we began to realise that mobilisation and training of parents was not only desirable for sustaining services to children, but it was *essential* if these children are to have a secure foundation for becoming contributing citizens to their society. As Bronfenbrenner (1974) notes,

> *The involvement of the child's family as an active participant is critical to the success of any home-based, intervention programme. Without such involvement, any effect of intervention appears to erode fairly rapidly once the programme ends. In contrast, the involvement of parents as partners in the enterprise provides an on-going system which can reinforce the effect of the program while it is in operation and helps to sustain them after the program ends. (p. 4)*

As in many aspects of Third World developments, there has been very little written about the involvement of parents, though many people have experience and can cite anecdotal observations. Generally speaking however, many professionals in developing countries still regard parents as part of the problem rather than part of the solution and often act in a paternalistic manner to them. The medical model frequently prevails with its focus on 'the doctor knows best'.

This chapter traces the evolution of the voluntary and parent movement in Jamaica. Drawing on examples from the Caribbean, we will show how parent training and the intimate involvement of families in community based services has resulted in more participation by relatives, the benefits it has brought to families and the leadership roles now undertaken by parents. The process, and the progress however, is slow.

The Challenges of Working with Families

At present, many people who are exposed to children and their families, are witnessing a crisis in parenting. The family has become split apart and shredded, leaving many children to find their own way, or even to take on a role in economic support. A response to this situation is getting under way, but do we have enough people to take a leadership role in such a dismal situation? And where is the child with a disability in all of this?

Child Rearing Styles

A long-standing feature of child rearing in Jamaica (Grantham-McGregor, Langman and Desai, 1983) as well as in other parts of the English-speaking Caribbean, is the use of punishment as a tool in discipline and learning. These researchers concluded that:

> *A picture emerged of a rich social life and authoritarian discipline, with little conscious encouragement of play or verbal interaction. However, at the same time, emphasis was placed on formal schooling. The children's level of development was related to levels of stimulation in the home. (p.69).*

Similarly in our experience of conducting workshops on managing behaviour problems, two popular beliefs were 'spare the rod and spoil the child' and 'children should be seen and not heard'. Such beliefs extend across all social groups. Middle class children are often reared by domestic helpers while their parents are out working long hours. The situation described above may well apply in this group, although they will certainly have more toys and appear on the surface to be better off.

How does this affect the child with a disability, especially those who have problems in learning? It seems very likely that they will be subjected to punishment even more frequently and because of their slow learning, they will be written off as a future investment; being denied their fair share of the pie.

Another feature, specifically relating to childhood disability, is over-protection. This may occur because the parent feels guilty or sorry for the child and tries to 'make it up to her'. Such over-protection and over-indulgence in turn, stultifies the child's desire to become independent. Such parents may be very loving towards the child and give excellent care, but they tend not to participate in training in the home (Terwindt, 1992).

An opposite response is for the child to be neglected and discriminated against. If money is short in the family, what is available will go to the able-bodied children. Those with disabilities, may have poor attendance at school; being left at home alone.

Finally, the child's problems may reach a crisis stage, where the family can no longer tolerate the child's behaviour or when he or she becomes too big to be moved around. This usually happens when there have been no services available during the preschool period and the problems have got worse instead of being prevented or resolved at an appropriate time. In some cases, the parent seeks an institutional placement as the solution to their problem.

Traditional Beliefs

Aside from poverty and lack of education, many parents who had the capability of leadership do not come forward as one might have expected. Since parents of disabled children come from the same cultural background as the society in general, one has to examine the attitudes and beliefs of the people of the region to understand this phenomenon.

Most societies have traditional beliefs on many subjects. In the case of childhood disability there are two main areas that affect families; first, beliefs about the causes of the disability and secondly, misconceptions about the effects of the disability and the child's needs. Some of these beliefs are detrimental to the child in that they are not only hurtful and unpleasant for the parents - affecting not only their attitudes and child rearing practices - but they are also counter-productive. For instance parents may not want to take part in a home based programme as they do not think it is relevant or because they are waiting for a miracle to happen.

Community Perceptions of Disability

In 1993, 3D Projects carried out a study of knowledge, attitudes and practice in three areas in Jamaica (Thorburn, 1993). The findings are of interest, especially in relation to two previous qualitative studies carried out in 1987 and 1992. These had indicated that some of the main parental experiences which militated against parent involvement included lack of a supportive family, poor experiences with services at the time of discovery of their child's disability, misunderstanding of the nature of disability and the scope and possibilities of rehabilitation (Terwindt, 1992).

A stratified survey was conducted in June, 1993 in the parishes (i.e. districts) of St. Catherine (Spanish Town and Linstead) and St. Mary, with 300 persons in each area, made up from five age groups (15 to 59) and twelve occupational groups with a minimum of 30 in each group.

The questions in the questionnaire were divided up into five main categories:

- Supernatural beliefs

- Misconceptions about behaviour and expectations for people with disabilities
- Denial of human rights
- Feelings of competency and willingness to help people with disabilities.
- Knowledge about disability services

Supernatural beliefs were held by a significant minority, with negative beliefs less prevalent (18%) than the idea that disabled children are "sent by God" (40%). These beliefs are significant if held by parents, because they may interfere with intervention efforts or may encourage isolation and "putting away the child".

Perhaps these are also the reasons for some of the most pervasive misconceptions, i.e. the preference for special schools and special homes. The supernatural beliefs were associated significantly with age (the youngest and the oldest age groups) and with low-income occupations.

Fortunately, the positive assertion by 96% of respondents that programmes should be shared by the government and the community - only 25% thought that the government should have full responsibility - was borne out by the expression of personal willingness to help a neighbour or a person having a fit or to volunteer if training was provided. These have an important bearing on the development of community based services and the involvement of parents.

In conclusion, the main barriers to community integration were seen to be:

- some persistent supernatural beliefs;
- the lack of awareness of the possibility that community and home based services can be effective;
- the persistent belief that special institutions are best;
- the lack of recognition of some human rights, particularly to full participation, integration and equality of opportunity.

The big plus however is the generous willingness of the community to help.

Evolution of the Voluntary Movement

There have been two main phases in the evolution of the voluntary movement in both Jamaica and other Caribbean countries; the period before 1970 and the decades afterwards. The watershed of 1970 saw the shift from very small, charitable efforts in a few of the countries to more wide scale programmes, some of which were supported by the governments of the region.

The events that occurred at various stages in the region and Jamaica were mutually reinforcing. The turning point in 1970 began when the countries of the region met together for the first time to discuss 'Mental Retardation: Needs, Resources and Approaches'.

In four countries of the region who already had a few schools for deaf, blind and mentally retarded children, more voluntary associations were formed and short term training began under the auspices of the Caribbean Association on Mental Retardation, later to become Caribbean Association on Mental Retardation and Other Development Disabilities (CAMRODD). CAMRODD'S bi-annual conferences have enabled people working in the field to keep up-to-date with new developments.

In 1975 the Caribbean Institute on Mental Retardation (CIMR) was initiated by CAMRODD as its technical and resource development arm. From there on, there has been augmentation of existing services and the development of new ones, especially in the areas of early intervention and vocational rehabilitation (CAMRODD, 1990; Thorburn and Houston, 1990). Leaflets and booklets for parents and community workers were developed for use by the various organisations in the Caribbean.

Another important development was initiation of training courses in special education in teacher training colleges made possible through technical assistance to the Government of Jamaica by the Netherlands Government. In fact this was a three pronged approach; as well as teacher training, special education units were built in primary schools and the Centre for Assessment and Research in Education (CARE) was established in 1980 as a specialised programme of Mico Teacher Training College.

Until 1990, most of the emphasis was on service development and professional workers and quite rightly so in our view. Our experiences in trying to establish parent groups and community based services in Jamaica where services were absent or minimal were unsuccessful at first. We found that parents would not come to meetings, training or join in supportive efforts until their own basic needs for themselves and acceptance of their children were being met.

Since 1988, CAMRODD began to shift away from service development to a stronger focus on parents, and particularly on their leadership.

The Jamaican Experience

Family involvement had been taking place in Jamaica since 1975, when a home-based, early intervention programme was started in Kingston (Thorburn, Brown and Bell, 1979). This focused on the mother or care-giver training the child. The curriculum used was an adaptation of the Portage Programme (Bluma et al., 1976) and families were supported and guided at home by a specially trained and recruited community worker.

During this project it became apparent that first, parents themselves needed more education and training and second, that being a parent of a child with a disability was an asset to the work of those acting as community workers.

In 1980, for the first time, we deliberately selected parents as our Community Workers and at the end of 1982 when funds for the St. Catherine Early Stimulation Project ran out, the St. Catherine Parent Association for Disabled Persons kept the project alive. From 1983 to 1984 the Association took part in a parent training project held in four different main towns of the parish. In each area between 20 and 30 parents and other interested persons took part.

The objectives of the training were:

- how to get services for their children;
- how to work together as a group;
- how to stimulate maximum development in their children;
- how to learn skills for greater economic independence.

All of these objectives were met and a more vibrant parish association developed, though attaining the first objective has taken a longer time than we anticipated.

At their annual general meeting in 1984, the parents voted to re-kindle the home visiting programme but this time it was decided that it should address the needs of all types and ages of people with disabilities. The outcome was a new community based rehabilitation (CBR) programme.

Another outcome of the parent training was an excellent selection and recruitment process for the CBR project workers. All were identified during the training courses.

This experience in 1983 to 1984 led us to realise and articulate some basic issues that needed to be addressed if we were to be able to get parents involved.

1. We must adjust our approach from a centre-orientated, inward view to an outgoing, community orientation.
2. We must be responsive to the perceived needs of people and not impose our own view.
3. Disability is often associated with poverty and poor people are usually poorly informed and lack influence.
4. The stigma of disability isolates them from family and community and discourages them from seeking their rights.
5. Disability may create an additional burden on an already handicapped family and they quickly become apathetic and "burnt

out", especially as services are lacking or inaccessible in "user-unfriendly" systems.

The above insights may seem pretty obvious now but they were written eleven years ago (Thorburn, 1984).

TABLE 1: PARENT ORIENTATION COURSE OUTLINE

This is the outline of a 10 day parent training course in orientation to disabilities designed by 3D projects Ltd. It has been used successfully in Jamaica and in other countries over a number of years. The main topics covered are:

Day 1: Parent-child relationship; situation of disabled children in Jamaica and the world; barriers to development of services; attitudes, misconceptions and beliefs; early signs of disability.
Day 2: Normal development and what can go wrong; need for screening and use of screening tests; disability and handicap - definitions.
Day 3: Prioritising handicaps; recap on screening; actual use of tests on children; nature and behaviour of mentally retarded children; seizures (a doctor should participate here).
Day 4: Learning problems; more on signs and effects of mentally retarded children; play as an aid to development; simplified methods of teaching these children.
Day 5: Group work - designing play programmes for participants' children; orientation to employment possibilities for mentally retarded persons.
Day 6: Motor problems (a physiotherapist should lead this day's session); types and effects of physical disabilities; group work - examination of children to determine their problems; cerebral palsy; independent living for disabled adults.
Day 7: Behaviour problems; reasons for children's behaviour; parental attitudes; use of drama by parents.
Day 8: Speech and hearing problems (a speech therapist should participate if possible), what parents can do to help each other.
Day 9: Familiarisation of parents with programmes in their areas.
Day 10: Review of course and plan for further action; discussion on the main needs of disabled people in the community; resources available in parent group and their community; skills bank - set up registry of what each person can contribute.

Regional Developments

The Jamaican developments began to influence other countries in the region through conferences and seminars which in turn stimulated the development of similar programmes in Belize, Trinidad and Tobago, Grenada (Thorburn, 1986; 1990), and more recently, in Antigua and Dominica.

This growth in turn influenced CAMRODD which began a new thrust, with the help of the Canadian Association for Community Living and the Roeher Institute in Toronto. The focus was on leadership development as outlined in the mission statement "New Trends for the 21st Century" (see Table 2). This "Blueprint" and the accompanying statement on rights and goals in five different aspects (education, the home, parent and public education, services and employment) has been a fundamental feature of all our training programmes since 1991. We have found that the Blueprint serves as common ground for training parents and professionals and for research.

Parent Participation in Voluntary Organisations

Prior to the advent of some of the efforts described above, parent involvement in the work of many of the voluntary associations in the Caribbean region was not very evident. The process of empowerment had only just begun. The Blueprint was introduced and incorporated into a regional leadership training programme conducted by CAMRODD, which was begun in late 1991. By the end of 1992 we had a corps of parents who were prepared to act as change agents in their countries. 1993 saw the parent leadership training taking place in Jamaica and a new cadre of empowered parents and workers in the field evolved. To complement this, CAMRODD has begun a new phase of training in partnership with the Norwegian Association for the Mentally Retarded, which has provided three day courses for groups of parents in 12 different islands in the region. The topics covered are chosen by the parents' groups themselves, but the purpose is to encourage the formation or development of parent groups (see Chapter 9).

Voluntary Associations and Provision of Services

As remarked earlier, although there has been an active voluntary movement in the Caribbean from the early 1930s, these organisations, with one or two exceptions, have been or became charitable organisations. In spite of the sterling pioneering work, their main missions inevitably were paternalism, segregation, pity and dis-empowerment.

Parents, and even more so the persons with disability themselves who started to speak out for their rights, were regarded as trouble makers. In one country, during the International Year of Disabled Persons, the national committee almost had to resign in order to get the government to agree to have a person with a disability as the paid co-ordinator for the year.

Normalisation

In the early 1970s, normalisation and integration was the gospel according to Wolfensberger (1972) who described three stages in the evolution of voluntary associations for the 'mentally retarded'. These were:

1. Providing services
2. Obtaining services
3. Advocating for social change

One of his dictates, which has haunted countries of the region, was that voluntary associations should reject the temptation to provide services. The dilemma is, if we don't, who will? Nearly all the original voluntary associations submitted to the overriding need as they saw it. But it led to what Wolfensberger had predicted; getting bogged down in fund-raising and administration and omitting to satisfy the many other needs of parents, particularly for support and information. As a result, during the late 1970s, new organisations of parents erupted and challenged the status quo. Even so, it has only been in the last seven years that CAMRODD has really responded to the need to fully empower parents.

At the same time, it is also necessary to inform professionals - gently but firmly - of a more preferred role, that of support rather than service. This means shifting from what has been called the 'medical' model to a compensatory one where the person being helped is fully informed of the options, is encouraged to make their own decisions and fully participates (or not) in their chosen intervention (see Chapter 2).

Parent Empowerment: How does it happen?

The process of deliberately developing parent empowerment in the disability field probably began in 1990 at the 10th Conference and 20th anniversary of CAMRODD, although the planning started earlier in 1988 when the CAMRODD Executive Committee decided to begin the leadership development programme.

Through a "grassroots" approach of having a series of sub regional meetings, in three different countries in two rounds, the

"Blueprint" was conceived and delivered (see Table 2). The workshops were basically a lot of parents and other interested persons coming together to brainstorm about their vision for the 21st century. Their dreams, their hopes, their problems were all taken down verbatim, and from that first account, they were analysed, pulled into shape and re-drafted for the second round of workshops.

The process of empowerment might not have happened so quickly in this way if it had not been for the fact that many parents who took part in the "bottom-up" planning of the Blueprint, had already been exposed to training from 3D Projects and were very well equipped with knowledge and skills.

Also, during this process, a number of these people stood out as being particularly articulate and some of these were invited by CAMRODD to participate in a leadership development programme. This began in November 1991 with three separate, one week training courses, finishing in April, 1992. By the time of the first course, the distillation of the fledgling "Blueprint" was completed and by the second course, it was printed and available for the leaders to use.

Since then, it has been used as a basic text for all courses in the region and it is also given to many influential persons throughout the region. Sometimes a whole day is devoted to it, sometimes a couple of hours; the longest was three days. The most impressive occasion was during a CAMRODD parent training course, where three government ministers attended the opening and stayed on for two more hours to discuss the Blueprint!

Of all the topics that are included in training workshops, we regard the Blueprint as the most powerful in enlightening and empowering participants. However, it cannot stand on its own. Other issues need discussing; the dispelling of myths and misconceptions, and the sharing of bitter experiences which leads to solidarity. Knowledge is power and parents, once attuned to the process, have insatiable appetites.

TABLE 2: OUTLINE OF CAMRODD'S BLUEPRINT

The Purpose:

The Blueprint outlines an agenda for action.

1. To define together goals, objectives and strategies for the Caribbean Region;
2. To develop a sense of Mission - A new organisational approach now and for the 21st century;
3. To identify and train accountable leaders in the CAMRODD community.

Our Dream:

Is that every individual with a disability takes his/her rightful place in the society of his/her respective countries; that every individual with a disability be treated with dignity and equality and be given the opportunity to develop self-respect.

Our Goals:

In order to realise our philosophy and our dreams, we will work towards specific goals in the areas of:

- Education
- Home
- Parent and Public Education
- Services
- Employment

NB. Specific goals are then outlined for each of the five areas.

The acquisition of competence in skilful handling of their own and others' children is also very empowering. As a result of this newly gained knowledge, skills and changed attitudes, we have found that parents speak out for themselves against discrimination, paternalism, talking down, or being dismissed without an explanation by professionals who think that they cannot understand. Many of our parents now realise that they know more about childhood disability than many professionals.

Future Developments

In spite of all the above developments, parent advocacy is only just beginning and it has a long way to go. We perceive a problem area which relates to the bipolar social structure of Jamaican society, with its diverse ethnic make-up and racial stratifications, where light and white skinned people are mainly in the upper income brackets and those of darker hue in the lower. It is the latter who have become empowered in spite of their limited educational opportunities. The other group, potentially more influential in seeking and making changes, have not been involved in the advocacy process and their concerns mainly focus on their own children's needs. They lack vision in the larger picture. This group now badly need to be educated and become more active in a movement which has a unified view of what is needed at the macro-level. Then all their children can be accepted and take their rightful place in society.

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Gerlin Bean was born in Hanover Jamaica. She studied nursing in England and then went on to take a degree in Social Science and Administration at the London School of Economics. She worked in England and Zimbabwe before returning to Jamaica to work with

3D Projects. She has been active in Black, Community and Women's Politics since the late 1980s and is presently studying for a Masters Degree in Public Health and the University of the West Indies.

Marigold Thorburn is Director of 3D Projects, a community based rehabilitation programme in Jamaica. She is also an associate lecturer in the Faculty of Medical Sciences at the University of the West Indies. A graduate in medicine of the University of Birmingham, England, she has lived and worked in Jamaica since 1960 and has been a pioneer in the Region of early intervention and CBR since 1975.

Contact Address

3D Projects,
14, Monk Street,
Spanish Town,
St., Catherine,
Jamaica

9

Fostering the Formation of Parents' Associations

Pål Skogmo

In this chapter, I will draw on the experiences of my organisation - the Norwegian Association for the Mentally Handicapped (NFPU) which was formed in 1967, and on other experiences of working with our partners in developing countries which began in 1981.

The reader should bear in mind that the content of the chapter is based on a limited scope of experiences and that the approach for mobilising parents of disabled children cannot be uniform. It will differ from country to country, from district to district. It will vary according to religion, tribe and social class.

The most important message I want to get across, is that some form of organised grouping of parents, is a very important element in any work to improve the human rights situation for disabled children as well as adults. Too often mental disabilities bars them from effective self-advocacy. I will try to show some of the pitfalls in parent empowerment work; how it must be an integral part of the difficult field of organisational development, and I will share some visions for the future. As our experience is from associations of parents with children with mental handicap, I will mainly discuss this type of parents' association.

The Norwegian Experience of Parental Empowerment

I am looking forward to the day when it is no longer necessary to ask the question: *'why is parent empowerment important?'* Advocacy organisations of the physically handicapped, the blind and the deaf are making their voices heard in more and more corners of the world. The voice is dwindling of charitable organisations and other organisations for the disabled, who in a way insist that, *'we know your problem better than you do'*.

But the voice of parents' associations for persons with mental handicap is still very weak. Associations are there, but not so many with parents in the front seat. The professionals are very often in full control, helped by the myths and mystery surrounding mental handicap. Even if the long term goal is to ensure the highest possible degree of self-advocacy for people with mental handicap, a parents' association is still the closest you can get to an *"of"* organisation for this disability group.

We know that strong forces have been, and will continue to be opposed to the growth of active parent movements. You will find opposition among politicians, who wish they could be left alone to set their budget priorities, without having to cope with another pressure group. You will also find opposition among professionals, who wish they could be left alone to handle persons with mental handicap the way they feel is the right way to handle them.

In the 1950s, the Norwegian Government developed a policy towards persons with mental handicap which would result in a handful of large institutions providing life-long institutional care for everybody in Norway with a mental handicap. Big units would be more efficient, and efficiency was the main concern of the government at the time.

The Norwegian professionals were also in favour of this ideology, as it would give them better opportunities for specialisation and research, and they would have a bigger professional environment; in general, better working conditions.

So why has Norway shifted from an ideology of locking up thousands of people with mental handicap in massive institutions, to a totally opposite ideology where individual freedom is the top priority, and where such persons are secured private flats in their home community? The answer is simply: *parent empowerment.*

Individual parents with children in these huge institutions started asking questions: 'Is this really the best life for my child?'. They came together in parents groups, and learned that other parents had the same doubts about what they were often told by professionals: *'leave this child in an institution, forget it and have another baby'.*

In groups, the parents started questioning the professionals and the politicians, and they realised the role they themselves had to play to secure a better life for their children. The parents posed a real challenge to the professionals and the politicians when different parents groups came together to form a national organisation (NFPU) in 1967.

Since its foundation, NFPU has had one prime aim: *the normalisation of the lives of children and adults with mental handicap.* A major step was taken in the early 1990's, when the National Reform for Persons with Mental Handicap was introduced. The reform plan states that normalisation is based on the belief that all individuals should have the right to be included in their home communities and that each individual should be supported to have, as much as possible, a life cycle of activities and rhythms appropriate to one's age and culture.

In the Norwegian context, this means that children should get the necessary support to allow them to live at home with their families and to attend kindergarten and public schools in the local neighbourhood. As adults, the support should enable them to have their own home and some kind of paid employment. Normalisation also includes the possibility of taking part in cultural and leisure time activities.

Numerous studies show that the life situation of persons with mental handicap has been improved considerably over the last couple of years. There is also no question that without the persistent struggle of the national parents association, the National Reform would not have taken place, at least not for many years.

Twenty-five years ago the situation for persons with mental handicap in Norway was pathetic in comparison with other disability groups. Today, persons with mental handicap are setting the standard to which other disability groups are striving.

Our International Experiences

But Norway is Norway and Tanzania is Tanzania. Why do we think that what is right in Norway, is also right in Tanzania? Is it not one of the unfortunate experiences of several decades of international development work, the simple fact that experiences which are relevant in the North, can be totally irrelevant in the South?

We have had a variety of experiences during 13 years of partnership work in developing countries. We count more setbacks than achievements; more frustrations than shining examples. But we have never had any reason to doubt what is the most important issue in our work; it is, and will always be, parent empowerment.

When the overall objective is to safeguard the human rights of persons with mental handicap, the best foundation to build on is the parents and other family members. Hence the key goal is to empower them and help them to understand that they have a role to play, as individuals, as a group, as a parents' association.

The economic, cultural and social conditions will differ, and so will the type of achievements that a parents' association can reach. But it is a tool that must never be overlooked in serious development work for disabled children.

Empowerment is a Process

'Outside forces' cannot empower parents of disabled children. Empowerment is a process which the individual parent has to go through, starting with how to gain more knowledge in meeting the needs of their own child in the home situation. Equally at the other end of the line is a parent who fights for the rights of all persons with mental handicap through a strong national parents organisation.

What an outsider can do, is to try and help to create a situation where parent empowerment can take place, both the basic empowerment on individual and local group basis, as well as empowerment through a national organisation.

The situation for people with mental handicap and their families will differ a lot from country to country, as well as within the same country. The picture is not just black and white; it has many different shades and colours. But there are some features that seem to be overwhelmingly present:

- The parents have limited knowledge about mental handicap and the situation of their child.

- The mother is normally blamed for having given birth to a baby with mental handicap.

- The reaction from the surrounding community is so negative that parents will prefer to hide their child.

These are issues you have to address in the process of parent empowerment. That is why this work is so important and so difficult.

Challenging Community Attitudes When we say that the parents have limited knowledge about mental handicap, we are not totally biased towards Western concepts of knowledge. We recognise that communities in all parts of the world have been coping with mentally handicapped citizens in their midst from time immemorial. They have gained experience which has resulted in traditional knowledge, relevant to that particular community. The problem is however, that this traditional knowledge can lead to actions from the family and the surrounding community which do not safeguard the human rights of the person with mental handicap. On the contrary, traditional knowledge will quite often result in very serious violations of their human rights, in some cases to the extent that they are denied the right to life (see Chapter 4).

I think it is fair to say that most Northerners, involved in this kind of work in the South, have in a way tried to jump directly to Western knowledge about mental handicap, without taking fully into account the knowledge people actually have. Local professionals, trained in the same school of thought, have also been quick to dismiss the traditional knowledge. For the educated elite in towns, it is perhaps possible to jump like that, but for the vast majority of the poorer and less educated parents, you will never counter their misconceptions by lectures alone.

How to bridge this gap, between traditional and "modern" knowledge, is one of the challenges I will pose to you the reader. Maybe you could be in a position to try to create a forum where the traditional knowledge can be brought out in the open, and where parents themselves can search for ways of conveying appropriate knowledge about mental handicap to parents in ways that make sense to local people.

The Mother is Blamed If we move on to the question of *'who's to blame for the disability'*, the universal answers is the mother! As far as I know, it is very rare that the traditional knowledge on mental handicap imputes the husband with any responsibility. It is the mother who has done something wrong, or it is something that "runs in her family".

The implications, when we talk about parent empowerment, are serious. The worst result is quite often that the family becomes a one-parent family; the husband simply takes off. And even if husbands remain, many take lightly their responsibilities for maintaining the family. Obviously life becomes much more difficult when the mother has to carry the responsibility for their children alone. For the child with mental handicap, the result will normally be that the mother has less time and less money to meet their needs.

Consequently, the overall objective of our work - to safeguard the human rights of persons with mental handicap - becomes so much more difficult when husbands are allowed to continue to blame the wife, and to run away from their responsibilities. Again, there is no uniform solution to the problem, the challenge is to find the best way to deal with it in your particular cultural and social setting.

Negative Reactions from the Community The third issue, which is closely linked to the previous two, is the negative reaction from the surrounding community that can lead to the unfortunate situation where many children with severe disabilities are kept hidden.

This occurs in all countries around the world and is in fact a very natural reaction from the parents faced as they often are with a lack of correct knowledge about the causes of mental handicap and the potential for neighbours to make mainly negative references to the parents, in particular the mother. Little wonder parents try to avoid their neighbours knowing about their disabled son or daughter.

Breaking Barriers is Possible

Is it not naive to think it is possible to break these massive barriers against empowerment of parents with a child who has a mental handicap? We believe that barriers CAN be broken because we have seen it happen. We know of mothers, in very difficult situations, who have gained the courage to come out in the open with their child and face the negative attitudes of the surrounding community with their head high. We have seen groups build up more strength in the collaboration with other parents in a similar situation and becoming active members of our partner associations. And we have seen fathers, who have realised that it was totally wrong to blame the wife and dismiss the mentally handicapped child; fathers who are now actively campaigning to make other fathers realise their wrongdoing.

But these empowered parents are still very few in number. How do we reach the other millions and millions of parents out there? The way we see it, it has to be a *parent-to-parent* process. Professionals and well-wishers can bring important contributions to this work. But when it comes to communication, the most efficient communicator is often one who is more or less in the same situation as yourself, but has gained a little more knowledge than you have.

We therefore have a vision about a ***network of parents***, in which parents can learn a little more, move a small step forward and carry their knowledge on to other parents in the network. A network where one father can convince another father that he should stand by his responsibility as a father and not run away.

It is so important to remember that what can seem to be a small achievement in terms of parent empowerment, can mean a world of difference for the main person on the agenda, the boy or girl, man or women with mental handicap. If a parent manages to give one other parent the support he/she needs to bring the child out of hiding, this could mean giving that child a totally new life.

From Parent Groups to Advocacy Organisations

Parental empowerment must not end with the mobilisation of individual parents or the setting up of local parents' groups. It has to go beyond localities into a national advocacy organisation, which can make the voice of the people with mental handicap and of their parents heard in 'the halls of power'.

We Norwegians come from a country where membership of all kinds of organisations have played, and still are playing, a crucial role in shaping our society. We are therefore surprised and frustrated when our message about the importance of organisations does not get across. To us it is so obvious that you have to come together in an organisation to fight for your rights. But in societies and cultures where the western system of advocacy organisations is totally alien, this is not so obvious.

The challenges faced in this work can be divided into two major groups:

- *How do we help the group to function as an organisation?* This involves recruiting and maintaining a membership basis, having committees and an organisational structure that can work and the setting up of appropriate administrative procedures.

- *How do we help the organisation to fulfil its objective?* This includes working to safeguard the human rights of people with mental handicap; doing efficient advocacy work with the government and providing support and encouragement for parents who have children with mental handicap.

The experience of NFPU, and I think the experience of many organisations in this field, is that too much time, money and energy are spent on the first challenge, leaving limited resources to help the organisation fulfil its objective. Unfortunately, we cannot say that good organisations are in place. In our partnership programmes we still have to focus strongly on the very practical side of organisational development.

I will only deal with a few issues in the vast field of organisational development. From our experience, there are some areas of particular concern, irrespective of whether you are an 'insider' or an 'outsider' in the struggle to make a parents' association work.

Motives are Important

I will start with a sensitive, but important point: 'what are the motives of those who are actively involved in the organisation?'.

In Norway we have a saying that you have to examine someone's 'heart and kidney' to find out the motives of a person. In most cases we do not have to go into such delicate examinations to see the motive behind the involvement. It is not too difficult to notice when money and status are more important than a genuine interest in the work for persons with mental handicap.

In a world of international donor agencies, you must also have recipients. The establishment of Non-Governmental Organisations (NGOs) has become the fastest growing 'business' in some developing countries. Enterprising people will sit and consider: 'should I start a business, or should I set up an NGO?' They will look at which areas of development are 'in fashion' with the donors and design an NGO to fit with the fashion.

I am not saying that it is wrong to be enterprising, but if the prime objective of an organisation becomes the provision of income for a number of people, then the 'real' objectives automatically takes a back-seat position.

In some societies, a position on the Board of a humanitarian organisation can add to your status in the society. Hence an organisation working for persons with mental handicap is likely to attract such status seekers. Many such people may end up doing a good job once they are inside the organisation and they become committed to its cause, but there is always a risk of ending up with a chairman who spends more time on announcing the fact that he is the head of this organisation, than the time he spends on actually working for the organisation.

Money is a difficult issue in any organisation, whatever the true motives of the organisation. In most countries of Africa, the economic situation is going from bad to worse and for more and more people the struggle for survival overshadows most other aspects of life. It is understandable that people in an increasingly difficult economic situation, start looking at the organisation as an additional source of income.

It may be understandable but it certainly not acceptable. The result of their action inevitably will be that the ability of the organisation to work for the interests of people with mental handicap is reduced. And for all of us who believe it worthwhile to fight for a better life for people with mental handicap, we are undermining all our efforts if we close our eyes to corruption.

Financial Control through Democracy

Many attempts have been made to establish systems for sound financial management in organisations. Leaving accounting technicalities aside, we see proper democracy in the organisation as the best guarantee against serious misuse of funds. You have a greater risk of misuse of funds if you have a totalitarian leader, who treats the organisation as his own property, or if you have a very powerful administrative headquarters which controls all affairs and keeps information away from the members.

If the members of the organisation are mobilised, and there is a proper organisational structure which gives the members a chance to have influence and control over the activities of the organisation, they will not allow their leaders to use funds in a way that does not benefit the organisation. If an organisation has strong local branches, the members will demand transparency in money matters and they will not keep quiet if the leaders divert money away from the branches.

Struggles for Power

So who are the people who are more likely to have the right motives for setting up and running an association for persons with mental handicap? It is probably not very surprising that we see the answer in parents who are mobilised and empowered from the grass-roots.

A fundamental idea of organisational development is violated when outside forces start interfering in the affairs of an independent organisation. But when you take a closer look at what is going on in the organisation, you will find ever so often a power struggle taking place. A struggle between on one side the professionals, politicians, money and status seekers holding a firm grip of the affairs of the organisation, and on the other side the mobilised parents who think this should be their organisation and willing to fight for the interests of their children and themselves.

In this power struggle we in NFPU have to say to the leaders of the organisation: 'sorry, but we are on the side of the parents'. We cannot sit back and watch powerful figures using their position to keep the parents in the back seat forever.

We have to make sure that the funds which the organisation receives is used to promote mobilisation and empowerment of parents and not for the opposite purpose. In doing so, we are clearly infringing on the right of the organisation to run its own affairs but in our view, a worse alternative in the long run, is not to take sides in an unequal power struggle.

National Parents' Associations

Another difficult area is to move the organisation from a centralised structure, towards one that is more decentralised. Organisations start in the capital city, they declare themselves to be a national association, but even after many years, you will find that nearly all the powers and activities are still located in and around the capital city.

It is important for an advocacy organisation to have a strong central body. After all the major task for an advocacy organisation is to lobby the central government on all the different issues of the rights for people with mental handicap. This is an issue which requires strength.

But the real strength of an organisation lies in its membership. Nor is it just in the numbers - although it can matter a lot if you have 50 or 5000 members behind you - but also in how the members participate actively in the organisation. Strong local branches, covering at least the more populated areas of a country, is a must for an organisation which calls itself 'national'.

Of course there are many good reasons why an organisation remains centralised; long distances, poor communication and lack of transport. But behind the words, there are often signs of a power struggle. Those who are in control of the organisation - whether they are parents or professionals - are very reluctant to help develop strong branches, which in turn can threaten their own powerbase. The important task is to help to establish the conditions which can give the parents outside the capital city, a chance to develop local branches and play an active role in the organisation.

Advocacy or Delivery of Services?

What should be the concerns of a parents' association ? Should it be delivering services, operating CBR-programmes, running day care centres, classes and workshops, or should it concentrate purely on advocacy work? A proper discussion of this issue would fill this book so I will just bring in one example from our experience.

The main argument put forward as to why a parents' organisation should deliver services, is that the members are asking for services for their children. What is the point of joining the organisation, if the organisation is not helping you with what you need more than anything else? It is an argument with great relevance but with a serious dilemma. If the organisation uses most of its resources on meeting the immediate needs of the parents and their children, who will then carry on the fight for the long term objective, namely the creation of a society for all; a society where a disabled person has equal opportunities?

NFPU have over the years provided considerable support to our partner organisations to enable them to run different services, particularly for children with mental handicap. But a critical look at the effects of this support, shows a more or less static situation. The progress and the development of new services elsewhere is missing. We are happy for the children who have got some basic services and for whom life is better. But we are very unhappy for the overwhelming majority of children in need, whose lives never were affected by the activities of our partner organisation.

Services to disabled children and adults should be provided through the same structure that delivers services to the non-disabled population. When the government has taken on the responsibility to provide primary education for the children of the nation, the job for the parents association is to fight with all available means to make sure that children with mental handicap are not excluded from the school system. If you give up and say: 'since the government is not giving our children education, we have to set up our own classes'; then you are giving the government an excellent opportunity to continue to neglect the rights of children with a mental handicap.

Parent Mobilisation and CBR Programmes

Are you attached to a Community Based Rehabilitation (CBR) programme where persons with mental handicap are directly or indirectly excluded? There are many CBR programmes of that nature; I have worked in one myself. Children with mental handicap were defined as a disability group which was 'too difficult for us to handle'. We totally overlooked the importance of early stimulation and we never recognised the potential of the parents.

A CBR programme is actually an ideal starting point for developing a parents' association. You will have a network through which you can identify the parents and you have a system of delivering services to the disabled children, which should strongly involve the parents and other family members. In order to allow the users to have a real influence on how the CBR programme develops, there must be some kind of organised group of the adult disabled, as well as for groups of parents with disabled children.

Depending on the scope of the programme and the density of the population in the area, it could either be an association for parents with children in all disability groups, or an association for parents with mental handicap. In many cases it will be best to start by including all disability groups, as many parents are likely not to differentiate sharply between mental handicap and other disabilities. As they gain more knowledge about the child's impairment, they will find that they have more in common with parents who have a child with a similar disability. If the number of parents is large enough, they could choose to split in groups, and eventually attach themselves to the relevant national disability organisation - if there is one.

Basic Principles

Of the different tools we in NFPU have for running our organisation, there is one that we have come to see as particularly important - our 11 point list of basic principles (see table). These principles have provided individual members, committees and staff with a common understanding of what we are struggling for. They have given us a clear direction for our work, and have served as important reference points whenever we have faced new developments.

An advocacy organisation is a political organisation, but sometimes we need to have a near religious approach to our task. Many times, the fulfilment of our main objective - a society where people with mental handicap have equal opportunities - can seem just as impossible to reach as a society where the ten commandments in the Bible are fulfilled. A list of basic principles is the commandments for an advocacy organisation. Important as it is to list one's principles, it is even more important to live by them!

BASIC PRINCIPLES
Norwegian Association for Mentally Handicapped

1. Persons with mental handicap have an equal right to life.
2. Persons with mental handicap have the right to grow up within their own families, or in a comparable environment with stable adult contact.
3. Persons with mental handicap have the right to education at preschool age, to properly adapted and equal education in ordinary schools at all levels of the educational system, and the right to adult education.
4. Persons with mental handicap have a right to a home of their own in accordance with normal standards and the minimum lifelong suitability.
5. Persons with mental handicap have the right to employment and/or meaningful activity.
6. Persons with mental handicap have the right to participate in cultural, leisure and holiday activities according to their own individual interests.
7. Persons with mental handicap have the right to a normal way of life, and to adequate and properly adapted assistance.
8. Persons with mental handicap have the right to the company of others, and to a family and sexual life.
9. Persons with mental handicap have the right to participate in making decisions which affect their own life situation.
10. Families with persons with mental handicap living at home

have the right to practical and financial support in order to provide necessary care.

11. Persons with mental handicap have the right to an organisation which can protect their interests.

New Organisational Models?

We in NFPU believe strongly in the partnership work we are doing. We believe in parent empowerment and in the development of advocacy organisations. But we do not want to hide the fact that difficulties are sometimes near overwhelming. And we should never stop asking the basic question: 'how do we find the right kind of tools for this work'? 'Are there other ways of doing it which can work better?' 'Is there another way to link together parents within a country, so that jointly they can make an impact on their children's future?' 'Should we just forget all the Western or Northern organisational models and search for completely new models which are more appropriate to the culture and traditions in the different countries?'

Which ever way we work, the real solutions to the problems, the right answers to all the difficult questions, will only be found right there where the person with mental handicap lives with his or her family. And families are where the challenge lies, for all of us.

Pål Skogmo spent 12 years working as journalist and editor of various Norwegian newspapers. He joined the Norwegian Volunteer Service in 1984 and started working in Mombasa, Kenya as administrator of the Bombolulu Coast Workshop for the Handicapped, a sheltered workshop and a farmers' training centre for 80 physically handicapped persons. In 1987 he took up a position as coordinator for a Community Based Rehabilitation Programme (CBR) in Kilifi, Kenya, where he worked until 1990. From 1990 to 1991 he was the Secretary General of the Norwegian Anti-Apartheid Movement before moving to his present post with the Norwegian Association for Mentally Handicapped (NFPU) as a Programme officer in the section for Development Cooperation.

Contact Address:
Norwegian Association for Mentally Handicapped - NFPU,
Rosenkrantz Gate 16,
0160 Oslo,
Norway

10

Schools for All: National Planning in Lesotho

Pholoho Khatleli, Lilian Mariga,

Lineo Phachaka and Sue Stubbs

Policy makers and planners in developing countries do not have an easy task in creating educational opportunities for disabled children which are appropriate, affordable, effective and sustainable. One of the major difficulties they face is to gain access to reliable, relevant, useful and critical literature about policy development and practice that is relevant to developing countries. Not only is such literature extremely sparse (particularly in relation to Africa), but it is also characterised by an unreliable and misleading use of hard data, a confusing and uncritical presentation of key concepts and unacknowledged cultural bias (Stubbs 1994). These will be discussed in turn.

Fact or Fiction?

First, a glance at situation analyses at a country or regional level reveals a plethora of 'facts and figures' that aim to set the scene in relation to the education of disabled children. Statistics relating to numbers of disabled children are not only extremely inconsistent, but are presented as fact, whereas in reality disability is defined and perceived very differently according to culture and context. Hence data about numbers of children with disabilities can be very unreliable.

Reliance on statistics is disturbing for other reasons too. It encourages a belief in the necessity of surveys as a precursor to services; yet there is little evidence to show that such surveys are followed by the provision of services. Indeed there is evidence to suggest that more reliable data can be obtained once services are established (Saunders and Miles 1990).

Another concern is that the 'problem' is located in the disabled child rather than in the country's attitudes, policies and institutions which are often negative or discriminatory towards disabled children. Proposed solutions to the problem of disability therefore focus on its prevention and cure rather than on changing societies.

Statistics referring to 'formal educational provision' usually refer to special schools and units and are often taken as an indication of the status of special education in a country. Yet again, the assumptions frequently go unchallenged. Disabled children or children with special needs are by no means a clearly defined group. There is certainly no clear consensus on what is special about them and even less as to the best way of meeting their needs. Ironically, countries with the most special schools (therefore appearing to have the best formal provision) often demonstrate great resistance to the principles and practice of integrating disabled children into mainstream schools (Barnartt and Kabzems 1992). On the other hand, mainstream schools which respond flexibly to the different needs and abilities of children without labelling them are ignored in such data.

Key Concepts

Another key characteristic of the literature is the uncritical presentation of key concepts such as 'special needs', 'special education', 'disability' and 'handicap'. In their countries of origin, these concepts have always been fluid and highly debatable (see Ainscow 1991, Slee 1993). Yet in the literature on developing countries they are presented as fixed and self-evident, and the debates surrounding them are either missing or only partially presented.

Although efforts are made to export 'state-of-the-art' thinking about education (UNESCO 1993), the key issue is that the research underpinning this thinking has its origins entirely in the West. There is often a substantial time-lag, resulting in policies being created in developing countries on the basis of beliefs which have been discredited in their country of origin.

In addition, inaccurate transmission can lead to some interesting interpretation; for example, in one workshop, 'integration' was understood to mean that children with all types of impairment would be educated together in one big special school (Save the Children, 1993).

The concepts of 'special needs' and 'disability' are often used interchangeably yet they are in many ways distinct. Children using wheelchairs or callipers may be disabled by attitudes and inaccessible schools but their educational needs are in no way 'special'. Their disability is not an educational problem, but rather it is a social issue. The literature on 'special needs education' increasingly focuses on changing the classroom environment and teaching methodology to embrace a wide range of learning ability (Ainscow 1991). But this ignores the issue of 'disabled' identity (Swain et al. 1993) and the need for disabled children to have positive role models.

Cultural Bias

The third predominant characteristic relates to the lack of a cross-cultural perspective not only on concepts of special needs and disability, but also in terms of key concepts such as 'child' and 'education' (Miles and Miles 1993). Peters (1993) argues that both education and disability are social constructs and as such need to be defined within the context of individual countries. The concepts of 'emotional/behavioural' problems or 'learning disability' are increasingly seen to be dependent on the socio-economic and educational environment rather than being located in the child.

These changed perspectives are even more pertinent in non-Western cultures. The whole existence of the learning disability paradigm is being challenged by South African writers (Kriegler 1989, Guma 1992, Kriegler and Farman 1994). The small literature which does examine disability and education cross-culturally reveals some major differences between cultures (Hawkins 1989, Connors and Donnellan 1993) and according to Serpell, Mariga and Harvey (1993), research on child development has been conducted 'through Western filters'.

In summary, the literature relating to the education of disabled children in developing countries is on the whole sparse, dubious in terms of its hard data; it is uncritical of key concepts and culturally blind.

Gaps in the Literature

In addition, the literature ignores several key issues which are crucial in the development of sound policy and practice.

The first of these relates to participation in the process of the development of educational policy and practice by consumers - namely disabled people, parents and children from developing countries (Oliver, 1992). Despite a growing recognition by development professionals and educationalists that participation is essential for sustainable, effective and relevant change, the voices of consumers are rarely heard or acknowledged as important. Community-based Rehabilitation (CBR) programmes (O'Toole 1993) have tried to address some of these issues and the more 'grass-roots' programmes do try to involve disabled people and parents. Although they often promote the integration of disabled children into mainstream schools, their approach to education tends to be on a 'one-off, bottom-up' basis with a weak conceptual understanding of special education issues. As a result, these initiatives make little impact on the system as a whole.

Secondly, there is hardly any acknowledgment of indigenous belief and practice in relation to the education of disabled children. It has already been pointed out that cross-cultural studies do reveal great conceptual differences, yet such studies are rare. The occurrence of 'casual integration' - where children with a range of impairments are already attending mainstream schools - has been highlighted by Miles (1985), Kisanji (1981) Tungaraza (1993) and Mariga and Phachaka (1993a). Yet formal integration programmes rarely acknowledge or build on this. Equally communities have cared for and educated their disabled members for thousands of years, yet this too is ignored in the literature. Extended family networks, systems of apprenticeship (Anson-Yevu 1988) and a broad tolerance of difference have all been important features of informal community care and education down through the years and from which formal programmes could learn much.

A third major gap is sources of influence. UNESCO has been a major influence on special education for many decades, yet the role, function and limitations of UN agencies in a changing world is never discussed. Policy and practice is often determined entirely by the funding criteria of major, bilateral donor agencies such as DANIDA. The impact on education of the World Bank structural adjustment policies and the 'New World Order' cannot be ignored, and yet it is rarely examined and discussed.

The role of the West in keeping developing countries poor is not mentioned. Instead a deficit model of the developing country is presented, where such countries are characterised by death, sickness, poverty, disease, lack of services and lack of political will (Wiesinger 1986, Mittler et al. 1993). Hence descriptive country or regional situation analyses abound; albeit with all the weaknesses discussed above. Descriptive accounts of programme implementation are also plentiful as are Western experts' recommendations for solving the problems of developing countries.

What is too often missing is critical evaluations of past and current practice, together with discussions of criteria for judging the 'success' or otherwise of development programmes. A thorough understanding of the potentially conflicting aims of such programmes is a crucial factor in determining policy and practice. For example, is the aim to fit all children into the existing school system or is it to adapt systems to children; is it to empower disabled children or to improve teaching methodology?

The following account of the Lesotho programme has tried to avoid the weaknesses discussed above and to address some of the gaps. It is hoped that this will pave the way for a more reliable, relevant, useful and critical literature which can provide a more substantial basis for development of policy and practice in the future.

Insert Photo 10.1 here

Introduction to the Lesotho Programme

The integrated education programme in Lesotho is a national programme which aims to include all primary schools. It is being implemented by the Ministry of Education with support from international Non-Government Organisations, such as Save the Children (U.K.) and the United Nations agencies.

The programme is innovative in a number of ways. One central aspect is the focus on changing teachers' attitudes, knowledge and teaching methodology in order to enable a broader range of children to benefit within a mainstream environment. There will be no separate cadre of teachers, no separate training courses, certificates or salaries, and no special units. Existing special schools (only four) will be used to support integration in the mainstream primary schools. Parental education and involvement is seen as crucial, together with a range of other sectors of society such as organisations of disabled people, different professionals and different government ministries. Children with all types of disability, over a wide age range are being supported in the programme; many are already in schools, and others have been integrated as a result of the programme.

Lesotho: the country

Lesotho is a small mountainous kingdom surrounded by the Republic of South Africa. Harsh winters and high altitudes make much of the country inaccessible in winter. The population is estimated at 2 million, mostly consisting of Basotho peoples whose language is Sesotho. For over a hundred years, until independence in 1966, Lesotho was a British Protectorate. Throughout its history, Lesotho's economy and stability has been inextricably linked to that of South Africa where a quarter of the workforce has sought employment (Mariga and Phachaka 1993a). Lesotho is divided into 10 districts, with Maseru as its capital (Figure 1).

Insert Figure 10.1 here

The provision of education in Lesotho is a joint venture between the Government, churches and the community. In 1992, there were over 370,000 children in primary schools, which is about 75% enrolment (Lesotho Ministry of Education, 1992). The pupil-teacher ratio is estimated at 54:1, and about 85% of teachers are qualified. However, a study conducted in 1990 shows a high drop-out rate; nearly 80,000 children are enrolled in grade 1, with less than 30,000 remaining in grade 7, and two thirds of these are girls.

Traditional Beliefs and Practices

The Birth of a Disabled Child: The traditional beliefs and practices surrounding disability are a complex mixture stemming from practical experience, the need for survival, spiritual beliefs and traditional attitudes to health. When a disabled child is born, this is usually perceived as negative. The mother in particular feels responsible, and is desperate to discover the cause. Some beliefs about causes include contact with other disabled people when pregnant, eating protein, transgression in a previous life, unfaithfulness during pregnancy, witchcraft, incest, evil spirits, lack of proper attention to ancestral spirits and heredity. Health professionals often contribute to this negative response by breaking news in an insensitive manner or concealing information.

Coping Strategies: Once the child is born, there are several possible consequences. The marriage may be threatened, although strictly speaking there can be no divorce because a Basotho woman does not marry her husband; she marries into the family or lineage and so is the wife of that lineage. The woman will feel responsible for the child and will believe it her duty to keep the child at home in order to please the spirits. Greater misfortune could befall the family if the child was sent away and came to any harm. Boy children are more desired than girls, and for disabled boys, greater effort will be made to seek a 'cure'.

A variety of coping strategies exist within traditional Basotho culture. The extended family system of care depends on a complex system of responsibilities and reciprocations, which ensure that the needs of family members are met despite the destabilising influences of migrant labour and cash economy. These are supported and perpetuated by Basotho customary law and indigenous education (Simms, undated). An indigenous system of parent education is still practised and helps parents better understand their disabled child, the causes of the disability and coping strategies needed. This occurs informally for members of extended families and formally for adolescents at initiation schools. The extended family also contributes towards the non-formal education of the disabled child, focusing on self-care and activities of daily living. Social integration within the community is regarded as very commendable amongst the Basotho, and children are encouraged to play with, and to help disabled children.

Education and Employment: Although education is usually8 not prioritised for the disabled child because there are no perceivable benefits, many disabled children do attend school. The feasibility study revealed that 17% of primary school children experience a learning difficulty related to visual and hearing impairment, mental handicap and other disabilities (Mariga and Phachaka 1993a).

Most begin school at a much older age than their peers. There could be a range of reasons for this including parents waiting until they have gained basic social and functional skills, a lack of knowledge about the benefits of schooling, and delayed access to mobility aids. However, primary schools in Lesotho already accommodate a very wide age range, particularly for boys who often spend many years herding animals and then begin or re-join primary school in their late teens. Although these disabled children are physically and socially integrated and teachers often try to help them, the relevant knowledge and skills to meet their specific educational needs is missing (Snell 1987).

Employment is also assumed not to be an option because children with disabilities are discriminated against or the workplace is not accessible. Not surprisingly, disabled children and adults often lack self-esteem and face many other difficulties in developing their full human potential.

Origins of the Programme

Prior to the 1980s, specialist provision for disabled children had been the responsibility of NGOs, churches and individuals. During the Decade of Disabled People (1983 - 1992), disabled people, parents and their organisations began to demand national educational provision for disabled children. At the same time the concepts and language of universal human rights, social justice, solidarity and individual dignity were spreading and gaining support and influence. Lesotho, in the heart of South Africa, was inevitably strongly affected by this. It was increasingly recognised that marginalised and vulnerable groups need to participate in change and to become empowered to promote their own development. Education is one key to this empowerment.

In 1987, the Lesotho Ministry of Education funded by USAID, commissioned a consultant, Marg Csapo from Canada, to undertake a study and devise guidelines on special education. This work initiated the process of policy development and programme planning which led to the current programme. The report by Csapo (1987) highlighted that the small number of institutions offering specialist care and education not only violated the traditional care-taking practices of the Basotho extended family, but they were costly, were unable to meet more than a minority of needs, and were even detrimental to the child's emotional and psychological wellbeing. She made several recommendations including;

- build on traditional care-taking practises,
- promote integration into mainstream schools,
- use specialist services in a more targeted way and ensure they support mainstream education,
- promote sustainability by making programmes self-supporting,
- up-grade teacher training,
- provide itinerant special education teams to support mainstream teachers,
- encourage families to send their children to school,
- promote public information on disability,
- include special education in both in-service and pre-service curricula.

From 1988 to 1990, discussions developed between the Ministry of Education, the Lesotho National Federation of Disabled People and Save the Children Fund (UK). SCF is an international non-governmental organisation. SCF was developing its disability work within the Southern African region, and became instrumental in finalising the Special Education policy and developing an operations plan for its implementation.

The Ministry of Education sent the Head of the Early Childhood Education Department, Lineo Phachaka to the United States to study special education in order to be able to implement the programme on her return. The 1990 conference on Education for All (Jomtien) also gave added impetus to promoting the integration of disabled children.

In 1991, the Special Education Unit was founded within the Ministry of Education. SCF seconded Lilian Mariga, a special educationalist with extensive practical experience from Zimbabwe, to work in collaboration with Lineo Phachaka to develop and implement the programme.

Feasibility Study

In line with the principles of participation and the importance of respecting and building on traditional beliefs and practices, an extensive feasibility study was carried out. The aim of this study was:

> *to provide baseline information which will enable the Ministry of Education to implement its stated policy of promoting the integration of children with special educational needs into the regular school system at all levels.* (Mariga and Phachaka 1993a).

The specific objectives were: to create awareness about the policy among primary school teachers; to assess the numbers and types of children with special needs already in primary schools; to investigate the attitudes of teachers, pupils and parents towards integration, and to identify pilot schools. A sample of 314 randomly selected primary schools (26% of all schools) in 8 of the ten districts formed the basis of the study in which 2,649 teachers, a sample of pupils in grades 5, 6 and 7 and nearly 1,000 parents were interviewed.

The study took over six months and was very thorough; providing not only a wealth of information on which to build an appropriate programme but also involving the community right from the initial stages of implementation. Some of the key results included;

- Over 17% of all primary children had some sort of impairment which affected their education; including visual, hearing, physical and learning impairments; mental retardation and epilepsy among others.
- Children with learning disabilities formed the largest group (over 12% of children in school).
- Over 85% of teachers were in favour of the policy of integration.
- All of the pupils interviewed were in favour of integration as were 99% of parents. A small number of parents feared their children would be ridiculed, or that disabilities may be contagious.
- Physical conditions of schools were very poor for all children and were mostly inaccessible to wheelchair users.
- Although teachers do their best to help slow learners, they lack the knowledge, skills and support to benefit them significantly. The teachers welcomed the idea of further training.

Whilst the feasibility study indicated that integration was feasible, it also highlighted some constraints to implementation. The existing policy did not have guidelines on implementation and there was no documentation on the existing specialist services. The largely NGO-funded specialist centres (twelve schools with 400 children) had negative attitudes towards integration and many of their policies and practises contradicted the government policy. There was a lack of both human and material resources; only one trained education officer, and no books or equipment.

These constraints were overcome in a variety of ways. There was no intention to close down the special schools. A long process of awareness-raising and discussion helped staff realise that they had a role to play in support of the process of integration.

The Special Education Unit formulated its own objectives for implementation. These included: the development of curriculum materials and training in their use; piloting the material and integrating children in ten pilot schools; the development of a parent-training manual, on-going awareness-raising at all levels, and finally, the integration of the curriculum into the National Teacher Training Pre- and In-service training curricula. Substantial time was taken after these objectives were formulated to discuss them with key people in the Ministries of Education, Social Welfare and Health, and with Disabled People's Organisations and special school staff.

Key Principles

The principles at the heart of the programme are a blend of the best of traditional Basotho approaches to education and disabled children, and of the thinking on disability and education in relation to human rights which has been developing globally, particularly over the last decade (Helander 1993). These three principles can be summarized as follows.

1. Human Rights and Social Justice

- Equality: disabled children are children first and should have equal rights, opportunities and dignity.
- Social Integration: disabled children belong with their families and communities.
- Social justice: services and opportunities should be available to the community as a whole and not limited to small privileged groups.
- Solidarity: responsibility for fostering human life is shared by all. Society has a duty to offer support to those who need it.

2. Involving communities

- Participation is a basic human need and essential for ensuring sustainable and appropriate change.
- Indigenous beliefs and practices should be respected and built on in innovatory programmes.
- Commitment and involvement at all levels is necessary for successful integration (i.e. policy-making, administrative, training, school, community and family levels) .

3. Schools and society must change to include all children

- Impairment is a feature of the individual, but disability is caused by the barriers - attitudinal, organisational, environmental - which society builds to exclude children and adults with impairments.
- All children can learn and have a right to education within their communities.
- Difficulty in learning is a normal part of schooling; children are all individuals.

- All children benefit from flexible and child-centred approaches to teaching.
- Mainstream schools have a responsibility to cater for pupil diversity.
- Learning should be meaningful and relevant to the context and culture.
- Promoting inclusive education requires that attitudes and power structures change; barriers to inclusive education need to be removed and negative stereotypes and discrimination should be challenged.
- Education is the responsibility of the whole community, and collaboration between parents/carers and teachers is central.

Integrated or Inclusive Education?

The term 'integration' is used to refer to a wide range of practices which have very different impacts on children. If the child is seen as 'the problem', then integration will focus on trying to make the disabled child fit into the existing system. Children will be described as 'not being able' to be integrated into existing mainstream classrooms, and therefore exclusion or separate provision (including special units) are justified. With this individual model, there will be an emphasis on professional diagnosis of the child and on identifying their 'problems' but very little emphasis on changing professional attitudes and the environment. In this approach, the impression is that disabled children are a separate or special group, yet in reality there is no clear dividing line between children.

Another approach, which also comes under the heading of integration, is based on very different principles;

- all children have a range of different abilities.
- all children can learn.
- all children can experience difficulty in learning.

In this model, if certain individuals are excluded then the focus will be on identifying those barriers which exclude them. In education, these include policies (or lack of policies), teacher methodology, curriculum, attitudes, lack of knowledge and skills, school buildings and general development issues such as poverty and lack of transport.

This approach does not deny the fact that a disabled child is 'different' but says that being different is not a negative thing. In fact it can be positive. The disabled child is encouraged to be proud of who she is and positive disabled adult role models are seen to be an inspiration to all children. This approach which focuses on the responsibility of the teacher and adaptation of the environment also means that other marginalized groups benefit, such as linguistic or ethnic minorities or traumatized children. The aim is to include *all* children, not just to integrate a chosen few. For this reason *'inclusive education'* is increasingly being used as a more accurate term for this fundamentally different approach.

This latter approach forms the basis of what is meant by integration in the Lesotho programme. Change is a process however, and the environment and attitudes cannot be changed overnight. Schools aim to reach large numbers and to achieve certain basic goals. This has to be balanced with individual needs. Furthermore, education is not only the responsibility of schools, and sometimes the home/community environment supported by a CBR programme is a more effective way of providing appropriate education for the small minority of severely disabled children. Although the term 'inclusive education' has been developed from policy and practice in the West, in many ways this is a much more accurate way of describing the traditional approach to education in Basotho society. Schools do not exclude children provided they can get there and their parents are able to send them. Also the traditional non-formal education systems ensure that all children benefit from some sort of education.

Implementation Strategies

The implementation of the inclusive education policy was based on the twin themes of awareness raising and on the development of indigenously produced curriculum materials.

Awareness-raising: Awareness-raising activities were considered to be integral to the whole process of implementation. During the feasibility study itself, awareness of the policy on integration was raised amongst the community and most professionals. Later, specific workshops were run for the Special Education Curriculum Committee, District Education Officers, school managers, local chiefs, district administrators and parents of children with and without disabilities.

Training workshops on special education were held for the ten pilot schools (see later) together with the seven district resource teachers.

A 45 minute recording was produced on special education to be broadcast to the public on radio Lesotho.

Finally, a meeting was held with the National Teacher Training College director and staff, to prepare them for the inclusion of the curriculum component into the mainstream syllabus. A key issue here is that the policy of including disabled children in schools was not presented as an option or a luxury, but as government policy which needed to be implemented.

In addition to written reports, the whole programme has been recorded in a series of informal video programmes. These are not only an excellent means of documenting the programmes' progress but also provide an accessible and effective resource for awareness-raising.

Curriculum Materials: The feasibility study had revealed that there was hardly any literature on special education existing within Lesotho. Teachers needed access to basic information about impairment and teaching methodology, which they would be able to refer to during, and after, training. Therefore the development of curriculum materials was one of the first tasks.

In line with the principles of participation and consumer representation, a *Special Education Curriculum Committee* was formed in order to develop and review the materials. The committee had the following representatives from the following institutions: Ministries of Education, Health and Social Welfare, the University of Lesotho, National Teacher Training College, Lesotho National Federation of the Disabled (LNFOD), Early Childhood Development Department, International Labour Organisation (ILO), parents of children with and without disability, two physiotherapists, and teachers from mainstream and special schools.

The first draft of the materials consisted of curricula for in-service teacher training, syllabi in different areas of disability, an assessment booklet, along with in-service and pre-service training course content. The committee met regularly to review these materials paragraph by paragraph.

In addition to the primary aim of producing appropriate and relevant materials, this painstaking process meant that the committee not only gained considerable knowledge about impairment and teaching methodology, but professional barriers were broken down as the subject of special education was 'de-mystified' and made accessible and understandable to the wider community.

These materials were produced in order to be incorporated into the mainstream curriculum. Whenever and wherever possible, the child would follow the existing curriculum but given the limitations and relative inflexibility of this curriculum, it was recognised that some children needed individual programmes.

Pilot Schools

The ten pilot schools identified during the feasibility study were chosen in order to reflect a range of situations. A balance of schools which had positive, negative and neutral attitudes to integration were chosen. Schools in close proximity to special schools and those in remote areas were included. The ten schools are from eight of the ten districts in Lesotho (see Figure 1). The pilot schools each had about twenty children identified as disabled in some way. They had a range of different impairments and covered a wide age range.

Training of Personnel: Once the draft materials were produced, they were presented to the heads of programmes at the Ministry of Education. A one-day workshop was organised for twenty-four District Education Officers to introduce them to the materials. A similar workshop was run for managers of schools. The participants were very positive about the materials and pledged their support to teachers.

Insert Photo 10.2 here

From the pilot schools, one teacher from each grade, plus the headteacher, attended a three week, in-service training workshop on the materials. They received 120 hours of training in this initial workshop. The resource persons were all from within Lesotho and included both professionals and disabled people from LNFOD. At the end of the workshop some of the headteachers and class teachers who had felt negative about integration were some of the most enthusiastic and committed advocates.

Although teachers had initially attended with some reluctance - giving up some of their holiday - the main feedback from teachers at the end was that the training had made teaching in general more interesting and had improved their overall teaching skills and understanding of how children learn.

Follow-up workshops were then held at six monthly intervals in which teachers' recommendations and requests from the previous workshops were incorporated. For example, there had been a strong request for many of the key lectures to be repeated at the first follow-up. All the schools wrote and submitted their own reports on their piloting of integration. These hand-written reports are included in the official workshop report and provide colourful insights into the very practical experience of integration;

> *Integration does wonderful things; 'Mathabo came to school without speech, but she now speaks! She came from home with her mouth open, but now she can close her mouth, even when she is not reminded.' (Mount Royal School).*

Insert Photo 10.3 here

> *'We have come across some problems, but our feeling is that the*

> *programme will succeed since there are teachers who support the programme, and luckily they are hard workers. Above all the community we are serving is very pleased and would like to see the programme live.' (St. Bernadette's Primary School)*
> (Mariga and Phachala, 1993b).

Each of the pilot schools is involved in raising awareness with their neighbouring primary schools as well as running their own workshops and training courses for parents and the other teachers.

Parents: All disabled children are different, and so are their families and their response to their disabled child. Recognition of the distinctive and unique characteristics of each family is central to the programme, and the approach to partnership with parents is flexible.

The involvement of parents at all stages is a key principle of the programme. However it was also realised that in order to promote the sustainability of the programme, parents should take responsibility and not expect everything to be provided by professionals and government ministries.

Therefore in response to the needs of a parent of a child with severe learning difficulties, the Special Education Unit encouraged the formation of a Parents' Association, which has been twinned with a Norwegian Association of Parents of Children with Mental Handicap (NFPU), who provided the funding for this endeavour (see also Chapter 9).

The Parents' Association then invited Mrs Mariga and Mrs Phachaka to run workshops for them on mental retardation and behaviour modification. It was a real eye-opener to parents that they had a role to play in modifying the behaviour of their children if they were to succeed in an integrated programme. A parent training manual has been developed and workshops given to parents involved in pilot schools. Parent workshops include parents of non-disabled children who often have concerns about how the programme will affect the education of their children. There are plans to establish a resource centre which will be controlled and run by parents.

Assessment and Programming: There is a plethora of Western-developed tests which are inappropriate and invalid in the context of Lesotho. The Unit decided that assessment tools needed to be developed and standardized in the social and cultural context in which they would be used. Other considerations were that materials should be local and easily accessible, and that the tests should be simple and usable by local teachers and parents. Examples include covering one eye with a mug when using the 'E' chart, and using a mug and spoon as a rattle to test hearing.

Following the feasibility study, the Special Education Unit identified an Educational Assessment Team (EAT) whose task is to support the teachers in developing their own assessment skills. The EAT consists of an orthopaedic technician, teachers of children with intellectual impairments, teachers of hearing and visually impaired children as well as the members of the Special Education Unit. The team visits the pilot schools and assesses children, giving advice to parents and teachers, makes referrals (e.g. for eye and hearing tests) and works with parents, teachers and other professionals to draw up Individualised Education Programmes (IEPs). They run workshops for teachers on the use of the assessment booklet and to support the training they have already received.

The focus is very much on responding appropriately to the child's learning needs rather than on labelling.

Networking: From the start, it was recognised that the disabled child and their family are part of a community and have a range of different needs and priorities, not just educational. It was also realised that meeting the educational needs of disabled children would involve all levels of society, from government to community, and would require collaboration and involvement of different sectors such as health and social welfare.

The networking started with policy makers and other key people in different departments in Ministries of Health, Education, Social Welfare, Teacher Associations, Disabled Peoples' Organisations, and key institutions such as the University, Teacher Training College, National Curriculum Centre, teachers from the Resource Centre, Community-Based Rehabilitation (CBR) personnel and Parents' Associations.

Regular consultation meetings are held with policy makers and teacher trainers, and they are represented on the Curriculum Committee. The Lesotho Federation of Disabled People (LNFOD) has been committed to this programme since its initiation, and is represented on committees as well as being involved in the planning, training and placement of students. Staff from the Special Education Unit have also participated in the LNFOD Disabled Activist Training workshops. There are currently three CBR programmes operating in Lesotho. Liaison includes awareness-raising, assessment, parent training, referrals and school placements.

Special school staff have been involved throughout and are encouraged to offer a supportive role but there have been problems in this area. Almost all the existing Special Education Centres are non-governmental and provide long term care facilities which are expensive and disruptive to family life. They lack clear objectives and insufficient staff to give a sound education. Attempts to involve staff at the planning stage met with a lot of resistance. This was partly because they feared their schools would be closed down. However, the recommendation from Csapo's report stated clearly that they should have a role as resource centres (Csapo 1987) so there has been a continuing effort to assure the special school personnel that they do have an important role, albeit a different one. Disabled children in special schools are now encouraged to spend some time in local mainstream schools.

Sustainability

Finally we consider some of the issues which affect the sustainability of this integration programme.

Structures: Throughout the piloting stage, meetings have been held with the National Teacher Training College and it is envisaged that the Special Education Component will be included in the professional studies programme by 1996. The ten pilot schools will be used for teacher placements. Knowledge about different impairments and about teaching methodology which responds to pupil diversity will then be institutionalised and fully integrated within the Lesotho teacher training systems. There will be no special courses, certificates or special salaries; the content and methods will be an aspect of good teaching practise for all children. The specialist teachers will be part of the normal district resource team which is an itinerant team which supports schools on a range of issues.

Resources: Resources have been limited throughout. A lot of care was taken to ensure that the programme was not over-resourced at an unsustainable level. Over-resourcing also can create competition and power struggles and make true participation very difficult. The Special Education Unit consisted of only two officers (Mrs Mariga and Mrs Phachaka) for the first two and a half years of the programme. All materials had to be created by the Unit; this ensured that they were kept simple and were locally available. Financial and technical support has been provided by donors such as SCF and UNICEF but in such a way as to promote the development of internal financial and technical support.

Government Commitment: The Ministry of Education has now budgeted for the training and curriculum development aspects of the programme. They have also provided additional staff. Throughout the programme, efforts have been made to establish a wide funding base. UNICEF funded the initial feasibility study, Save the Children Fund channelled the funds from Comic Relief to pay the salary of the Special Education Advisor along with various other contributions, and the Norwegian Parents' Association funds the Lesotho Parents' Association.

Participation: The most important contribution towards appropriate sustainability has been the careful attention paid to the participatory process. This has often meant that different aspects of the programme have taken much longer than if the Special Unit had just 'got on with it'. The Special Education Unit officers Mrs Mariga and Mrs Phachaka, prioritised this process by going out to many different groups of people, spending a lot of time with them, listening to them and learning from them. The aim was to ensure that the whole programme was firmly rooted in the positive aspects of existing belief and practice. As in a traditional Basotho partnership, the knowledge and skills developed in other countries has been married into the Lesotho lineage of traditional family care and now that the whole community has been involved, there can be no divorce!

Impact

The programme has gained national recognition from policy makers, parents and many professionals. Attitudes have begun to change; in some cases in quite radical ways. Teachers have developed confidence, knowledge and skills which help them become better teachers of all children. A major strength is the establishment of formal and informal networks and support systems involving different sectors and levels of the community.

There have of course been constraints. Progress may have been faster with more resources but then again, the steady development has meant that the roots are firmly established. The programme has had to respond to external influences such as political instability within Lesotho, and also the major upheavals in the region due to the dramatic changes in South Africa.

Internal constraints such as changes of staff and the pressures for other aspects of educational reform have also had to be worked with. The changes that teachers are being asked to make are fundamentally different from traditional ways of working and teachers are not used to being agents of change. The approach used involves all levels in order to offer maximum opportunity for support and success; the government policy and national plan provides a very important basis for change, the involvement of several teachers plus the headteacher from the pilot schools ensures a whole school approach and mutual support, and the networking and community involvement ensures that the changes are relevant, appropriate and integrated into indigenous belief and practice.

The Future

The long term goal is that the programme will become an integral component of mainstream education. It may also be a model for other countries in the region to learn from, as it offers an alternative approach to other integration programmes operating in Africa. The issues of early childhood education and vocational training and employment are very closely related to the programme. It is hoped that increased collaboration with CBR and LNFOD, together with continued inter-ministerial collaboration will ensure that the goals of 'equalisation of opportunities and full participation' are getting closer. A full evaluation of the programme is planned for May 1995, eighteen months after the piloting of training materials.

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The photographs are by Sue Stubbs.

Pholoho Khatleli worked as teacher for six years in a regular primary school before studying at the Birmingham University, England where she obtained her B.Phil. in visual handicap. She is currently an Assistant Inspector for Special Education in the Lesotho Ministry of Education.

Lilian Mariga is Special Education Advisor, Ministry of Education, Lesotho. She is sponsored by Save the Children (UK) and had previously worked in Zimbabwe as a headteacher and national co-ordinator of a home-based learning programme. She is currently a vice-President of the International League of Societies for Persons with Mental Handicap.

Lineo Phachaka trained as a primary school teacher and taught for 12 years before going to the National University of Lesotho and the University of Washington, USA, where she obtained a postgraduate degree in early childhood special education. She is head of the Special Education Unit (Integrated Education) in the Ministry of Education.

Sue Stubbs is currently Overseas Disability Advisor for Save the Children Fund (UK) and consultant for the British Overseas Development Administration on disability in India. Her background is in special education and creative arts therapy and after teaching in East London for many years, she worked in South Asia training child care workers and teachers.

Contact Address

Save the Children,
17 Grove Lane,
London SE5 8RD,
England

11

Self-directed Employment and Economic Independence in Low-income Countries

Aldred H. Neufeldt

Enrique lives in a rural area of the Philippines. His parents have little money, with family income coming from coconuts they collect from palm trees and sell on the roadside. Early in life Enrique contracted a severe infection in his ears. There was little medical help available that his parents could afford, and so he became deaf. His parents saw this as a sign from God. Although Enrique was in perfect physical shape, he did little around their small house because his parents saw it as their duty to look after him. Enrique grew up with little education and few work skills. But as his parents grew older, there was the question of how he would survive on his own.

Sawat contracted polio when he was five years old. His family lives in a small village in Thailand not far from Bangkok. His parents made their living from fishing but given Sawat's difficulty with walking, this was not a likely livelihood for him. Sawat was a proud young man and wanted to have his own source of income, but his parents had little money, so his prospects of getting either the education or money to set up his own little business seemed remote.

Nora grew up in a part of Kingston, Jamaica where it is hard to make a living. Her mother made a marginal income selling small items at the local market. Nora was born with some physical abnormalities and had learning difficulties in school. But she had determination to make it in the world. Where and how could she get help?

Nora, Sawat and Enrique are only three of more than five hundred million people in the world with disabilities. While their names and circumstances have been changed to protect their identities, they represent something of a new approach to becoming successful in generating income in regions of the world with high levels of unemployment and limited opportunity. All were born and raised in circumstances that made it very difficult to imagine being able to become financially independent. By themselves it is unlikely they would have been able to do so. Yet, with appropriate support and assistance, they managed. This chapter is about the kinds of initiatives that were created which not only helped them generate income, but did so by helping them direct their own work, rather than working for someone else.

Poverty and Disability

Poverty and disability are two words which go together. In both low and high-income countries disabled people do not participate in the cash economies of their societies to the same extent as do non-disabled people.

A study of available data shows that, in *high-income* countries, disabled people are employed at a rate roughly one-half of that of non-disabled people, and at least twice as many disabled as compared with non-disabled people are not in the labour force (Neufeldt and Mathieson, in press). Even when employed, substantially more disabled people, than non-disabled people, are under-employed relative to their levels of training. All of this is evidence of subtle forms of discrimination.

Little data is available from *low-income* countries; but it is known that the problem is even more acute for disabled people since there are no social safety nets to speak of other than one's family. So if a family can't look after its disabled member, there are few options other than starvation. If one adds the fact that in most countries people with disabilities are often treated as if they are incapable of doing meaningful work, then it is not surprising to find they are amongst the poorest of the poor.

For disabled people to participate more equitably in the cash economies of society, steps will have to be taken that are different from those in the past. To get some ideas as to reasonable approaches, a research project was undertaken beginning in 1991. Its purpose was to examine 'income generation strategies'. More specifically, we wanted to find out what kinds of models and strategies might be used to overcome the many barriers to economic self-sufficiency by people with disabilities. With the support of Disabled Peoples' International and the International Labour Organization, an international study was carried out by seventeen contributors who gathered information from 41 countries of which 34 were low-income and 7 were high-income nations. This chapter focuses mainly on results from the low-income countries.

Self-Directed Employment

The term 'income generation' often is used in low-income countries to describe small scale (micro-) enterprises, often operating in what is called the 'informal' sector. We were interested in studying projects that helped people with disabilities run their own enterprises either within the 'informal' or 'formal' economy. Another problem is that, in high-income countries, income generation can refer to a wide variety of ways in which money is earned, including salaried employment.

A term that better captures what we were looking for is '*self-directed employment'*. By self-directed employment I mean work:

> *where people with disabilities to a significant degree, have a prime decision-making role in the kind of work that is done, how time is allocated, what kinds of investment in time and money should be made, and how to allocate revenue generated.*

As a concept, self-directed employment is broader than words like ‘self-employment’. Self-employment in most places refers to a situation where a person owns and operates their own business, professional service, farm or similar enterprise. We wanted to include self-employment in our study, but also other options such as groups of disabled people operating their own business, worker cooperatives, as well as organizations of disabled persons forming business subsidiaries, thereby creating work for their members.

The Research Study

The general approach used in the study has been described previously by Neufeldt and Albright (1993). Briefly, what we did was to contract with researchers in different regions of the world to undertake a survey of the extent to which systematic efforts were being made to help people with disabilities achieve self-directed employment. We were not interested in examples where individual disabled people managed to achieve success in their own businesses by virtue only of their motivation, skill and opportunity. Harper and Momm (1989) had already described a number of such examples. In contrast, we were interested in determining the extent to which there were systematic efforts to help people with disabilities and the kinds of strategies that seemed to work.

Each researcher was asked to identify five to seven cases for study in the countries they visited. Interestingly this seemed reasonably easy to do in the low-income countries but very difficult in high-income countries. In short, it became evident that there has been much more experience in promoting self-directed employment in low-income, rather than high-income countries.

Project Characteristics

Information was collected by researchers on over 100 initiatives. After screening out those not meeting our criteria, we had a total of 81 projects from low and middle-income countries. Their characteristics are described in some detail elsewhere (Neufeldt and Albright, 1993).

Briefly, 18 of the initiatives were from South Asia, 10 from South East Asia, 12 from South America, 15 from Central America, 11 from the Caribbean, 3 from East Africa and 12 from Southern Africa. Organizations taking the lead in developing these self-directed employment initiatives included organizations *for* disabled persons (such as vocational rehabilitation organizations), organizations *of* disabled persons (self-advocacy organizations comprised of disabled people), non-governmental organizations with an interest in promoting employment opportunities for disadvantaged persons (including those with disabilities), and government run agencies.

Most of the initiatives (59%) were quite small, assisting 25 or fewer people with disabilities. Ten (14%) involved 100 or more beneficiaries, with the largest involving several hundred. The remaining projects were somewhere in the middle. About 37% focused on helping all disadvantaged or all kinds of disabled people, and 59% focused on people with physical or visual impairments. Very little attention was paid to incorporating people with hearing impairments, mental handicaps or psychiatric impairments (4%). An interesting note is that we did find several self-directed employment initiatives directed towards people with either mental handicaps or psychiatric impairments in high-income countries.

The kinds of work done varied immensely though a sizeable proportion continued with what might be viewed as fairly traditional kinds of handicraft work. Overall, 17% were involved with agricultural enterprises, 28% with artisan productions, 64% with manufacturing (usually small scale), 48% had a service enterprise and 27% had trade related enterprises. Many of the initiatives were involved in more than one kind of enterprise.

Four Cornerstones

We have carried out a detailed analysis of the various initiatives, the results of which will be coming out shortly in a book on self-directed employment. The analysis suggests there are four cornerstones that seem important to success. These are: the way in which a person thinks about her or himself; the relevant knowledge the person has; the kinds and availability of resources available; and, the extent to which the social and policy environments are enabling.

Cornerstone 1. A Self-directed Identity

Thinking about oneself as 'self-directed' is an important prerequisite to pursuing your own employment. To run a business successfully, no matter how small, requires self-confidence, energy, a willingness to take risks, skill and an intimate knowledge of the local economy (cf.ACCION International/the Calmeadow Foundation, 1988).

The first three (self-confidence, energy and willingness to take risks) are inherently related to how one sees one’s self. If a person has little self-confidence, it is unlikely that he or she will be capable of organizing a successful enterprise. The person with little self-confidence also is not likely to have the kind of energy level needed to overcome the barriers likely to be encountered in setting up a business, nor to take the risks involved.

Awareness raising or conscientisation strategies seem the most appropriate way to address this kind of issue. People need to learn what the possibilities are for the betterment of their lives, how to make their own decisions, and how to live with the effects of such decisions. These are important first steps to having the confidence that one might be able to make a go of it in business.

A number of projects we studied identified the need to challenge the existing ways in which disabled people thought about themselves so they could muster the motivation to pursue long-term objectives rather than relying on habits designed simply to help one survive from day to day. Using social animators, and encouraging development of self-advocacy organizations seemed amongst the most effective ways of promoting improved awareness.

Cornerstone 2. Getting the Right 'Know-how'

The word 'know-how' refers to some combination of knowledge and skill. Three kinds of 'know-how' are important to success: namely, literacy and numeracy, the technical skills related to the kinds of work one wishes to do, and the skills required for business practice.

Literacy and Numeracy: At the most fundamental level, it is critical to have basic skills in literacy and numeracy. Fluitman (1989), along with other writers, has made the observation that the lack of literacy and numeracy skills may be the single most restrictive barrier for people to climb out of a bare subsistence existence in low-income countries.

Limited skill with reading, writing or arithmetic, prevents people from taking advantage of formal training opportunities and seriously restricts the kind of possible employment that might be pursued. The same problem exists in high-income countries where the demand for abilities to read and to work with numbers is even greater. Normally training in literacy and numeracy is the responsibility of schools or adult education programs. None of the projects we examined spent any significant amount of energy on training in this area, though training in other areas was a very important part of development as will be seen below.

Technical Skills: The majority of initiatives we studied (75%) provided one, or more micro-level training approaches for individuals or groups. Most of these were geared towards improving the technical skill level of project beneficiaries. Such training was aimed at helping the beneficiaries do their jobs in the right way, with the right equipment. Even the simplest of tasks have technical components and with increasing dependence on technology to enhance production or services, the need for technical skill training is bound to increase. But the kinds of training required is bound to be as diverse as the kinds of products or services that are to be provided.

To be effective, then, training needs to be directed at ‘market oriented’ skills; that is, skills for the kinds of work which have a market.

Business Skills: Not only do people with disabilities often lack technical skills, the vast majority also have no prior business experience. Given that reality, and the fact that all of the initiatives we examined had as part of their aim to help people with disabilities succeed in business (rather than in wage employment), it was disappointing to note that less than one-quarter of the projects examined provided training which could be said to improve business management skills. These include business planning, market planning, financial management, personnel management among others. When it was provided, virtually all respondents considered such training essential and most felt there should be even greater emphasis on these skills. An additional 25% of respondents from other projects mentioned that a lack of business skills training was a definite constraint.

Training for Success: When we compared high success initiatives with those low in success, we found that both provided considerable attention to training (85% and 75%, respectively). But there was a significant difference in how the training was focused. Of those initiatives which provided training, all the 'low success' programs provided training only in technical skill areas. By contrast in the 'high success' programs, 41% provided training only in technical skills, 9% only in business skills, but 50% provided training in both technical and business skills. The combination of both technical and business skills was much more appreciated in high-success, than in low-success projects.

Cornerstone 3. Resourcing Entrepreneurial Initiatives

Setting up a business enterprise takes much more than just an idea (awareness) and the right ‘know-how’. It requires a variety of resources. Specifically, one is likely to need business advice and consultation from knowledgeable people, capitalization in the form of money or equipment, and help with marketing. In most cases, people setting up a business invest much more time and money in their business during the first few years than they can take out. This means the business is at risk of failing unless help with business advice, a loan or marketing assistance is available.

Business Advisory Services: Nearly half (48%) of the projects we examined made business advisory services available to new enterprises. These included advice on administrative problems, financial management, access to funding, marketing strategies, conducting feasibility studies, on-site technical assistance and solving production problems, such as product upgrading and quality control.

When we examined high success initiatives, a higher than average proportion (65%) provided such consultancy services. But 63% of low-success projects also made consultancy services available. What these data indicate is that making advice available by itself is not sufficient for success. In some cases business advisory services were promoted as a substitution for focused skill training, rather than as a complement. In other cases, it seemed that advisors did not have expertise on topics they ostensibly were giving advice on; such as the successful project developer or animator who allows himself to be drawn into the role of business advisor.

Loans and Other Forms of Capitalization: Capitalizing a new business is one of the biggest constraints to small businesses. In response to what seems to be a wide-spread conclusion, 89% of all projects we reviewed provided access to funding in the form of loans or grants. This was the single most popular strategy. Twenty-seven percent also provided equipment or other forms of capitalization (of those providing equipment most, though not all, also provided access to funding). A higher proportion of high success compared to low success initiatives (96% vs 75%) made loans available. This both illustrates the central importance that funding has in setting up new enterprises and the fact that funding by itself is not likely to be sufficient. Making equipment available did not seem very significant except in one or two instances.

There were many different approaches to providing loans. Generally it may be said that loans worked least well when they were made available through charitable organizations. Such agencies, particularly if they are church or social service related, are not very good at business. Because their job is to help the poor and weak in their personal lives, and cope with every day problems, workers in such agencies seem to have a difficult time insisting that loans should be repaid. Hence what starts out as loans often turn into grants. But grants don't teach the receivers to be accountable; rather they seem to teach receivers how to be even more dependent.

In contrast, loans work better if the non-governmental organization is expressly set up to support new business development.

A problem in both low and high-income countries is that normal lending sources such as banks, have been very reluctant to lend money to disabled people. In part, this is because disabled people are poor and have few assets which banks could use as collateral. But bankers also seem to have shared the widespread public view that people with disabilities are incapable of doing meaningful work. One project we examined was working expressly to reverse such a view.

In Kenya, the International Labour Organization arranged with Barclay's Bank to have a UNDP development fund guarantee loans made available for disabled people seeking to set up their own businesses (Metts, Oleson and Dodson-Echeverria 1993). While this project also had some problems, there was a much higher success rate of both starting up sustainable businesses and loan repayment.

One way of improving rates of loan repayment has been to make loans to 'loan circles,' rather than to individuals. Typically loan circles involve about five members. The rules of credit are that each member of the circle is responsible for every loan received by any member. No additional credit is given to any member unless everyone pays back their loans. This simple mechanism has led to dramatically improved loan repayment through peer pressure and cooperative effort. It also has had the positive effect of encouraging mutual consultation and support amongst members of the group to enhance their respective enterprises.

Marketing Assistance: Unless there is demand for the product or service being provided, business will suffer. Since new enterprises typically enter a field already occupied by established ones, an essential part of development is a good marketing plan which researches existing and future demand for one's goods or services, without cut-throat competition from the established enterprises.

Examples of different approaches to marketing in the projects we examined were:

- to set up cooperative approaches to marketing;
- using incentive systems for workers or volunteers from the community to do one's marketing;
- arranging sub-contracts or production contracts with larger firms, or entering into joint ventures;
- setting up one's own marketing arm;
- arranging government 'set asides', such as where a government commissions disabled people to operate public telephone booths, to sell lottery tickets or to sell parking spaces for cars.
- creating niche markets for new and unique products or services for which there is a growing demand.

All of these approaches worked. To make them work, though, required the right kind of advice along with persistence and an investment of energy.

Cornerstone 4. An Enabling Environment

A fourth key is to have an enabling environment. It seems doubtful that any of the initiatives we examined could have survived without one. Those low-income countries where self-directed employment took root, to varying degrees supported the idea of helping impoverished citizens generate income through micro-enterprises. There was support at the highest political level, at least to a degree; and there was some support in the local community where the people with disabilities lived.

The major difficulty facing disabled people is the narrow and paternalistic view often held about them. Such attitudes can be overcome only by attentive action. This is the lesson to emerge from high success projects and one would expect as much, given that turning a blind eye has not proven helpful over the centuries.

Two approaches to creating an enabling environment were notable. One was to use a *community development strategy*. The purpose was to engage the citizenry of local communities to be supportive of disabled people seeking to work - a community involvement strategy. Community based, vocational rehabilitation initiatives are one example. The objective was to have communities find ways of meaningfully involving all of their citizens in the life of the community. For adults with disabilities this meant, in part, finding a place to work.

The second approach took place at the state level. Governments were persuaded to develop policies sympathetic to the *rights of disabled people*. Organizations of disabled people, often affiliated with Disabled Peoples' International, usually led the drive to create such policies. It was notable that those countries, where the greatest amount of success was achieved in setting up self-directed employment, had governments that had passed legislation or policies that were supportive of treating people with disabilities with the same rights as everyone else.

Three Models of Note

Cornerstones are good for a foundation but businesses still have to be built on them. People have to invest their creativity and energy to find ways of making the most of their situation wherever they live. In scanning the different kinds of approaches taken in different parts of the world, we found a number, amongst the more successful, which might be considered 'models'. They varied quite considerably in the kind of approach used, and in the kinds of businesses they either were in or promoted. Three such 'models' are described here to illustrate the possibilities.

1. The Community Development Model - The Philippines

Many people with disabilities have little reason to believe they can get a job, let alone run their own business. If family and neighbours think that a disability is a punishment because of some sin in a former life, or that the disabled person has to be cared for all of her or his life, then all disabled people learn is that they are not destined to work.

Such has been the situation in the Philippines. Along with paternalistic beliefs, poverty also is a persistent problem amongst a large portion of the population. The Philippines is a nation of more than seven thousand islands and a population of over 61 million people. Its gross national product in 1990 was US$730 per person, placing the country amongst the low-middle income group. Despite its large population, the entire country had very few vocational rehabilitation centres or other resources devoted to people with disabilities in the early 1980s. Activity and publicity around the United Nations Decade of Disabled Persons (1982 - 1992) prompted the government to tackle some of the problems faced by disabled people. In the mid-1980s a pilot project was undertaken which has been a model of note (Delfin, in press).

The Model: The International Labour Organization, together with the Philippines Government's Department of Social Welfare Development and with technical support from the United Nations Development Program, experimented with a community based, vocational rehabilitation strategy. Its purpose was to see whether a community based approach could raise the awareness of both community and disabled people as to the possibility that full community participation was possible. The pilot project was started in four regions of the Philippines, including rural areas and parts of metropolitan Manila. This approach included the following elements:

- focusing on the community (the village or neighbourhood) with a public education message that disabled people could be part of the community;
- recruiting volunteers from people busy with their own livelihoods or domestic work. (Unemployed college students did not make good volunteers because they left as soon as job opportunities became available);
- training these volunteers to identify people with disabilities in their neighbourhoods and assisting them to make contacts and form relationships. The aim being to assist the individual and family to identify needs and plan rehabilitation goals, to identify and mobilize community resources, and to keep local community members interested and involved;
- assigning each volunteer to a maximum of 400 households (approximately 2,600 people) to find people with disabilities and initiate the community based rehabilitation process. It was anticipated that each volunteer would identify 50 - 60 people with disabilities.

A sizable portion of volunteers carried through with their tasks. By 1989, 400 volunteers had been trained, who in turn reached 1,500 people with disabilities. Of these, 289 disabled people had been assisted by 56 volunteers to engage in some means of income generation; often participating with family or other local enterprises. These included people with disabilities of all types and the degree of impairment ranged from moderate to severe.

The methods devised during the pilot project have now been extended to nearly all regions of the Philippines.

Strategies: A number of key strategies were employed. These included: awareness raising/conscientising; assistance with career search; business advice and skill training. In addition, small loans were made available through the Department of Social Welfare Development when necessary to create new enterprises or expand existing ones.

Comment: This approach was creative in a number of ways. As an illustration, volunteers were given simple rules of thumb when providing advice for seeking income generation opportunities, such as: *look for the work under your nose.* Enrique, who we introduced at the beginning, was helped to join his family enterprise when his parents were persuaded that being deaf did not mean he couldn't climb coconut palm trees, but it took community support for the parents to understand that they weren't being bad parents when they allowed their son to work. Likewise, blind people have are successfully rearing pigs.

Insert Photo - Slide 4 (pig-raising)

There also are some notable larger scale successes. For example, one rural woman wanted to buy a sewing machine so she could sew clothing for sale, and thereby supplement the small income of her husband. Training and a small loan, enabled her to begin a sewing business. Clothing sales have been so successful she now employs a large number of others. Her story is one of five told in the video, *Business as Usual* (Neufeldt, Albright and Kozak, 1994).

2. Business Subsidiary Model - DEEDS Industries, Jamaica

Disabled peoples' organizations usually have difficulty finding money to help pay for their costs of advocating for change with governments and the basic expenses of running a mutual support and public education organization. One idea that sometimes gets raised is that they should set up their own business, the profits of which would go to the advocacy organizations. A number of such initiatives have been set up; one of the oldest of which is DEEDS Industries in Kingston, Jamaica (see Baker, in press).

The Model: DEEDS (Diversified Economic Enterprises for Disabled Self-Help) Industries Ltd. is a subsidiary of the Combined Disabilities Association in Jamaica. The enterprise was established in 1983 and pursued three objectives: 1) to demonstrate the potential of people with disabilities to work alongside those without disabilities in an open employment situation; 2) to provide employment and income for people with disabilities, and 3) to provide a source of income for the parent organization.

The first two objectives have been achieved. DEEDS employs 65 workers, 60% of whom have a disability. In the past two years, the enterprise has generated income from its sale of wooden products to meet all expenses. DEEDS continues to receive some grant funding and technical assistance from an international NGO in an effort to build sufficient reserves to prepare for the withdrawal of future support. A decision has not yet been made regarding when and how the income generated will be used to support the parent organization.

DEEDS took over the premises and operations of a Salvation Army sheltered workshop. Additional equipment was purchased in order to expand and diversify production. Various wooden products are created such as clocks, wooden toys, boxes, bowls and hot mats. A new market for collapsible furniture has been identified and items are being designed for production.

Their marketing strategy is well defined. The high quality items produced by DEEDS can be found in exclusive shops which cater to tourists on the island. With help from the Jamaica Export Office, DEEDS also markets their products throughout the Caribbean and to North America. Private contracts are also accepted.

DEEDS workers reveal high levels of job satisfaction. They receive wages which are sufficient to help most of them purchase low income housing units from the government's National Housing Trust.

Strategies: The strategies used in both creating DEEDS and making it successful, include:

- accessing grant and loan funds to acquire the building, equipment and raw materials;
- training personnel in the operation of equipment, business management skills and market analysis;
- introducing sound business management procedures into the work place, such as placing an emphasis on high quality of product,
- producing products at a fast enough pace;
- having a strong marketing plan.

Applicability: Similar models have been developed with some success in other countries. In Japan a computer programming company has been established and operated by persons with mobility impairments. In Zimbabwe, the National Council of Disabled Persons has established and operates a supermarket. In Canada a greenhouse operation, involving mentally handicapped and non-handicapped workers in a co-operative, was set up in the mid-1970s which is still operating. All provide goods or services for their local/regional markets and competitive wages to participants.

Comment: Mixing business with the normal activities of disabled peoples' organizations (primarily advocacy and mutual support) is not necessarily a good idea. In fact, DEEDS Industries almost had to close down within a few years of opening. The disabled people heading DEEDS were well educated and had been strong advocacy leaders, but they had little experience with business.

When the difficulties with the business side of things were noted, the advocacy organization wisely decided to make some changes. They hired leadership with experience in running a business and with marketing. From then on, the business has continued to grow. The first lesson of this model then, is that if disabled peoples' organizations contemplate setting up a business as a subsidiary, it is critical to the success of the business that it be set up and run as a business. Keeping some distance between the business operation and the operation of the advocacy organization, is likely to enhance the well-being of both.

A second comment is with respect to the original idea that profits would be used to help the parent organization. Up to present there have been few profits to share with the Combined Disability Association (CDA). Any money made has had to be re-invested into the business. So, while the CDA has equity in a good business, its aspiration of having some of the CDA costs met has not been realized. On the other hand, a sizeable number of its members now have a reasonable income and so this has been an important gain. The second lesson then, is that - as in any business - one cannot expect profits to be available in the short term. Only in the long term is there likely to be a profit for the CDA.

3. Transitional Business Training Centre Model - Thailand

A common complaint of disabled people in many countries is that vocational rehabilitation training centres teach them few skills that are useful in the real business world. That has been the case in Thailand. The Department of Public Welfare's Vocational Rehabilitation Training Centre in Papadaeng (about two hours drive south of Bangkok), provided a course on radio and television repair. A problem encountered by graduates was that they were not able to earn enough because of the lack of practical experience in an electronic servicing business. Instruction was largely classroom based and theoretical. As well, graduates had no equipment, money or resources at their disposal on graduation with which to begin a business.

In 1981 a Christian church (the Ratchburana Church) responded to the call for activities to benefit disabled people during the International Year of Disabled Persons. Members of the church set up an electronics repair shop as part of a Christian Organization for the Handicapped (COH). Its first purpose was to assist 7 graduates from the Papadaeng Vocational Training Centre. This shop subsequently was moved to Bangkok and is now operated by the COH. Up to the time of our research, the shop had assisted 22 disabled individuals in setting up their own electronic repair businesses.

The COH has a number of income generation programs for disabled persons such as shoe repairing (2 graduates) and sewing of clothes (4 trainees), as well as other non-income related programs, but the electronic repair shop is their biggest.

The Model: The electronic repair shop is located in a three story building and is easily accessible to customers in Bangkok. Its purpose is to provide a practical bridge from vocational training centre courses on radio and TV repair to the trainees starting their own businesses. Trainees gain practical experience under the supervision of experienced repairmen. Shop trainers are all alumni of this transitional program.

Specific objectives for trainees are: to learn how to manage an electronics repair workshop as a business; to gain additional technical knowledge by studying part-time at technical schools (3 months); to learn the discipline of working together to earn money; and to save money so as to be able to start their own electronic repair workshop. The ultimate goal of the project is to produce entrepreneurs who will set up their own electronic repair shops. Trainees expect to work at this transitional electronic repair shop from 12 to 18 months.

To help trainees begin, they are given free board, lodging and utilities and use of shop equipment for the first three months. Thereafter, trainees pay for their own food from earnings in the shop. After six months, they also pay for their water and electricity. COH continues to pay the rent of each trainee.

Each trainee also gets a monthly cash advance to be used for purchasing parts for the electronic equipment being repaired. The advance must be paid back, by the end of every month, out of the trainee's earnings to ensure that the same amount will be available for purchase of electronic parts the next month.

Out of their monthly earnings trainees also contribute 10% for the maintenance of the workshop building and 1% for a vocational development fund used for additional training. The balance of the monthly earnings is divided equally amongst the participants. Then half of each trainee's share is kept in a savings account by the project manager until the end of the trainee's time at the shop. The cost of operating the shop, beyond what is earned, comes from a variety of church organizations as well as international aid organizations and other sources. Key features of this project include:

- an emphasis on improving and augmenting practical electronics repair skills;
- training and preparation in the management of the electronic repair workshop to equip them for eventually opening, owning and managing their own business, including training in customer service and customer relations;
- a focus on discipline in work and in managing and saving money for their future shop;
- advice and assistance for trainees to accumulate the basic equipment that they will need for their own workshop, using portions of their monthly earnings;
- encouragement to take additional courses at technical schools to upgrade and augment their knowledge during their spare time (usually evenings). Again these are funded by using portions of their earnings.

In the first ten years of its existence, COH helped establish 22 electronic repair shops all over Thailand, owned and managed by disabled people who graduated from the transition program. Of these, 15 were still in operation at the time of the study, 10 very successfully and the other 5 struggling financially. Seven shops had failed for various reasons and were non-operational.

Strategies: The principle strategies used in helping trainees to set up self-owned electronic repair shops are: training in the technical skills of electronic repair as well as in business skills through the tutorship of alumni from the program; additional short-term training in technical schools; business skill training in accounting, marketing, sourcing of equipment and parts, and in customer service. On-going consultation is available.

The model also is unique for its way of enabling project participants build up enough money to be able eventually to start their own electronics repair workshops. At the same time as they are being taught financial independence, discipline and money management, they are also assisted to accumulate the equipment, hardware and capital they will need for eventually establishing their own workshops. This is done through the enforced saving of a portion of their monthly earnings. Finally, alumni of the project have been formed into a club which periodically engages in alumni meetings, religious rallies and social gatherings. This provides a mutual support network. Project staff also help alumni who have set up shops, with problems such as dealing with government tax collectors and other issues that arise.

Applicability: The idea of setting up a transition business training centre has considerable potential for many places in the world. It builds on models of training that are well understood in most cultures, namely the apprenticeship model. The emphasis on promoting self-reliance and financial independence throughout the course of the training is particularly important in situations where people have had little experience in either earning or managing money. Again, this feature is a useful one for many other places.

Comment: There are several limits to a model such as this. First, the training available at a business centre such as this, revolves around one specific kind of occupation. Its long term success will hinge on two factors.

First, the people who seek training there must have the interest and personal capability of being in the electronic repair business; not everyone has the necessary traits. When people are given only one choice for improving their financial future, it is very tempting to try that career even if they do not have the attributes necessary for success. One wonders whether some of the people who failed in the electronic repair business did so because they were not well suited to this kind of work.

Attention also has to be paid to ensuring that the market does not get saturated by training too many people. Market saturation does not seem to be a problem in Thailand with respect to electronic repair as yet, but it could become one at some time in the future. Others contemplating setting up such a transition business training centre should undertake a sound business analysis in the first instance to be certain that the trainees will have a reasonable chance of success when they set up their own business.

Second, some people might be critical of the forced savings plan on the grounds that this infringes on the person's choice as to how their money is used. However each trainee knows what the rules are on entering the program; the person is not in danger of starving since the cost of food and rent continue to be subsidized and the people coming to be trained have had little prior experience in either earning or managing money. Given these factors, and the benefit of having accumulated a capital fund, such an infringement of rights seems acceptable.

Back to the Beginning

At the very beginning of this chapter three people were introduced - Enrique, Sawat and Nora. By now you may have rightly surmised that each of the three became involved in one of the models described - Enrique in the Philippines community development program, Sawat in the transitional business training centre and Nora in DEEDS Industries. All are now earning their own livelihood.

The models described are only three out of approximately fifteen different ones we isolated out of the 81 projects examined. More details on the remainder will be published shortly. The three described above are markedly different one from another. Each has its unique characteristics. Each also has potential in quite different circumstances.

Just as not every person is cut out to be in the electronic repair business or in the coconut picking business, so too each model is not likely to be suitable for every locality. The best advice for anyone wishing to set up a project promoting self-directed employment, is to begin with ensuring that the four cornerstones are in place - at least to a degree. Once there is something to work with, then the next task is to invent the best way to build a model that is appropriate to the unique opportunities within the geographic area one lives. My hope is that the fifteen models we have identified grows to ten times that number by the year 2,000.

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Aldred H. Neufeldt is a professor in the University of Calgary's Rehabilitation Studies Programme, prior to which he was Director of the National Institute on Mental Retardation (now the G. Allan Roeher Institute). His area of interests include developing and implementing innovative community-based models of service for persons with disabilities. He has extensive international experience including Canadian Advisor to the Caribbean Association on Mental Retardation and Developmental Disabilities; Director of an education programme for CBR personnel in the Gaza Strip and an external evaluator for Disabled Peoples' International. He has recently completed the large international study on employment described in this chapter.

Contact Address

Rehabilitation Studies Programme,
EDT 434, University of Calgary,
Calgary, Alberta, T2N 1N4,
CANADA

12

Mothers of Disabled Children as CBR Workers

Barney McGlade and Rita Aquino

In the Philippines, there are an estimated 4,500,000 disabled people. This figure does not include family members who are also involved and affected by the disability. Yet fewer than one per cent of disabled children attend school and at best only one in four of people with disabilities participate in any form of programme. In rural or urban poor areas, rehabilitation services are very limited or non-existent.

The Philippines has been one of leading countries in the promotion of Community Based Rehabilitation, although it is not yet part of the country's community development plans (de Jesus, 1992). A Filipino handbook on CBR implementation is currently being field tested under the aegis of the National Council for the Welfare of Disabled Persons (NCWDP) (Aportadera et al., 1994). This semi-state organisation attempts to co-ordinate the estimated 207 existing CBR programmes run by government and non-government agencies. Their plans include working closely with schools on integrating children with disabilities in mainstream education and in promoting the active participation of disabled people and their families in the decision-making, planning and evaluation of each CBR programme.

This chapter describes our experiences in developing and running a CBR programme in an urban poor area of Metro Manila which is based around mothers of children with disabilities as the family support workers.

Kasamaka CBR Programme

In 1989 the authors, along with the Columban Fathers (an Irish congregation of priests) helped to establish a small outreach programme within the parish of Malate Catholic Church in Manila. We aimed to assist local children and youth with intellectual disabilities.

At that time, we were only vaguely familiar with the emerging CBR approach. Rita had no previous experience in the field of disability but had worked extensively as a community organiser. Barney's experiences were with intellectually disabled people, but mostly in Ireland or in centre-based projects in the Philippines.

However, we were strongly influenced by the Zimcare programme in Zimbabwe (McConkey, 1988). This inspired us to consider alternative methods of meeting the needs of intellectually disabled children who could not gain access to either special or mainstream schools. Initially, we established a Portage style, home-based programme and began to train local church workers and volunteers as the 'home visitors'.

Due to work commitments, these people soon dropped out. Perhaps the inappropriate lecture-style training sessions - carried out in English - may also have been a discouragement. Or it could have been that some were not disposed to work with disabled people.

The programme was in crisis even before it had started! Rita then hit on the brainwave of enlisting the help of the mothers of the disabled children. We were soon to wonder why we had not considered this option from the onset.

With surprising ease, we soon had a core group of four volunteer mothers acting as home visitors. Training was given in Tagalog (Filipino) and became more interactive, employing a wide variety of teaching methods. It was based on the needs of both participants and volunteers, rather than some irrelevant, western, prepackaged training manual.

From this inauspicious beginning, five years later these same mothers are now running the programme. Armed with personal qualities, such as empathy, and knowledge from their own experiences and their training, these mothers are teaching classes, devising lesson plans, using physical therapy exercises, teaching sign language and Braille, counselling families, organising support groups, networking with other agencies, and preparing and implementing home based programmes in unison with the families.

They learn from each other's experiences as well as from in-service training and attendance at different courses. They are trained health workers who organise prevention and intervention workshops on disability, health and integrated education curricula for the community and local relevant professionals. They also have an advocacy role in the community; highlighting disability issues.

We learnt as we went along. What we didn't know, we sought the solution locally or through our network of appropriate agencies. The personnel in schools, hospitals and rehabilitation centres were all more than willing to offer training and advice, regardless of the academic qualifications of our workers.

Other developments also took place. While working in the communities, we met children and adults with sensory and physical disabilities and they became incorporated in the programme. We were asked to start the programme in a rural parish (Morong), and later we joined forces with a Columban priest in another province who had already initiated a similar programme.

There are now seven KASAMAKA ('you belong') CBR programmes, sharing the same philosophy and long term goals, but with aims based on the unique needs and situation of each community. The programmes have catered for 646 disabled children and adults, plus their families, on a long term basis. But whereas mothers manage and work the CBR programme in the urban setting, the six rural projects employ local community and church personnel. However, disabled people and their families are gradually gaining a stronger voice in the implementation and management of activities.

Perhaps the most profound development in all the programmes is the emphasis now placed on the active participation of disabled people and their families in the planning, decision-making and work activities; all of which are based on the self-expressed needs of the participants. In each of the seven programmes, participants have decided to form a 'peoples' organisation', made up of disabled people and their families. Non-disabled people are classed as technical advisers, trainers and supporters.

The goals of KASAMAKA CBR are those stated by Werner (1988): we aim to establish a situation whereby disabled people and their families empower themselves to live as self-reliant and as 'whole a life as possible' in the company of other community members, who, in turn, are helped to accept disabled people as equal partners, appreciating their abilities and possibilities.

In sum, KASAMAKA CBR is an attempt not only to meet the challenge of the numbers of people with a disability, but also to work for change in attitudes, access and opportunities within society, particularly in areas where there is no access to facilities or rehabilitation.

Parent Involvement

The philosophy of many CBR programmes rests on the notion of a family member being the main trainer within the home even while it is recognised that not all parents will want to be involved (O'Toole, 1993). Yet the role of parents is not clearly defined beyond this. Are they to work only with their disabled child, or should they be involved in mobilising resources in the community, or lobbying governments for facilities and services, or could their involvement be something more, as in management and implementation of the programme?

Much has been written on the difficulty of involving parents in CBR programmes (Coleridge, 1993). A primary reason could be their sense of isolation. They are made to feel different, they lack time to socialise given the responsibilities of care, and sometimes they have to suffer the misguided and outspoken advice from neighbours as well as strangers (Woolfson, 1991).

But parents are the child's first and natural teachers, and it makes sense to assist them in performing this role to the best of their ability.

The provision of home-based programmes is only a partial answer.

Opportunities are needed also for mothers, for parents and for children to meet, socialise and learn from each other. Coming together with the CBR worker and other families can provide both the support and solidarity needed by parents. Such meetings can also be the springboard for nurturing the process of 'conscientization'; giving parents a deep awareness of all the influences on their lives (Hope and Timmel, 1984).

Many of the emotional and social needs of parents may be met most effectively in parents' organisations. These can provide a forum for mutual understanding, acceptance, information-sharing and support (see Chapter 9).

In fact, group work is the root of effective CBR collaboration especially when it extends to include disabled people, communities and associated professionals and agencies. Groups are a medium for people to discuss their needs, to investigate the generative themes which influence and even control their lives, to look at ways of dealing with their situation, to learn skills, to take on an advocacy role and to act in bringing about change.

CBR Workers

Miles (1990) asserts that mothers are interested in the acquisition of information about their child's disability and what they should do but they are not concerned about where the advice is given or who is the informant. But we would contend that the identity and interpersonal skills of that informant has a major impact on whether the information will be accepted.

O'Toole (1993) states that a number of parents have mentioned the emotional and psychological support they received from their home visitor as friendships developed. The value of CBR may be rooted as much in the relationship between CBR workers and family members, as in the actual practical interventions carried out.

CBR workers have been drawn from community health workers, teachers, rehabilitation assistants and neighbours but a common misconception is that local professionals, those with formal higher education, would make the best volunteers (Helander, 1993). But O'Toole's (1991) research in Guyana found that local volunteers were much more effective and acceptable to the participants than were nursery teachers.

Thorburn (1992) claimed that the volunteer, or home visitor, could be selected from any background, but should be one who is serious about the work, is motivated to assist others in need, has an empathetic and respectful, but not pitying attitude, has good health, a stable background, and is literate only if the needs of the programme depend on that. In Thorburn's 3D project in Jamaica, most of the workers are mothers of disabled children (see Chapter 8).

Women and CBR

It is essential to recognise the sense of isolation, overwork and lack of support sometimes experienced by mothers and families with disabled children. We in CBR may have to face some difficult moral and political issues. Does CBR inadvertently prop up the traditional role of women as dependants? As Coleridge (1993) notes, there is also the issue of remuneration for volunteers. By receiving little or no salary, is CBR guilty of giving women and disabled people yet another raw deal? These issues are integral to the CBR value system and hence, its long-term sustainability.

Choice, of course, should be available, but, alas, often it is not, unless women take control. Support groups can help to achieve this. Selli-Serna (1991) stresses that the difficulties associated with rearing a disabled child should not be secluded within the family circle. Rather they should be shared with others; not only with those in the same situation but also with those who are unaware. She relates that as far back as the 1950s in Italy, it was the mothers who organised themselves, informed public opinion, looked for and got, rehabilitation services, and in the process shifted the mother's role from passivity to a more active and dynamic one.

Mothers of Disabled Children as CBR Workers

O'Toole (1991) identified a mother as one of the most effective workers in the Guyana project; her tact, devotion, sincerity, empathy and compassion made up for her lack of formal education. These same qualities were found to be more effective than knowledge and skills, when working with both families and communities, whether in Jamaica (Thorburn, 1992) or in Kenya (Oakley, 1991). Yet in the literature, only Thorburn (1992) has advocated the recruitment of parents as community workers.

When we conducted recent research on the factors influencing long-term sustainability of our CBR programmes, the mothers were perceived by the respondents (themselves mothers or fathers of disabled children) as playing a major role, second only to the acceptance of their disabled children in the community. Unity among families, disabled people and workers was also considered essential.

However, while we were able to recruit mothers as CBR workers in the urban setting, we were not able to repeat this in the CBR programmes started in rural areas. This has always baffled us: it seemed so easy in Manila! Although the rural programmes, had a very effective workforce, there has always been a problem with high turnover of staff and a lack of participation by the 'clients' of the service. Despite workshops, counselling and establishing local committees, we could not entice the mothers to become volunteers, although they were involved with their own disabled child's development.

Perhaps we failed to consider the mothers as workers when the programmes were being initiated or perhaps they preferred to wait until satisfied with the direction and achievements of the programme. But what our experiences tell us, is that if there is no other workforce, then mothers will surely get involved as they did in the city.

It is therefore not possible to declare that mothers, as a resource, are available to all communities. What must be considered are the cultural, familial and socio-economic conditions in each location and country, and whether local facilities and parent organisations are available.

The Personal Qualities of Mothers as CBR Workers

CBR planners have often failed to recognise the cultivation of personal qualities as crucial components in the training courses for both CBR workers and professionals, although this is well recognised in the literature on sustainable development (Oakley, 1991).

What are the special characteristics which a mother of a disabled child can offer as a CBR worker? We first realised their special contribution when we had difficulty convincing some families to work with their disabled child. But when another mother visited the family, invariably the parents paid more attention; they were more likely to listen and to follow and share suggestions.

A mother will take the time and effort to give simple explanations and be realistic in her expectations for other mothers, whereas the professional may not. Mothers may be more responsive to the needs of other mothers and less inclined to impose their own views (Thorburn, 1992). Bean (1994) expands on this theme, saying that mothers of disabled children on the 3D projects act as good role models; they accept their children and they make them feel part of the community. Moreover, the mothers are willing to share skills and knowledge, and they have become confident in doing this. They also seek new forms of solidarity and feel empowered.

In the recent participatory evaluation of our programme in Manila, the mothers of disabled children considered the home visitor's personal qualities, such as empathy, to be more important than having skills and knowledge. Nonetheless the ability to communicate and to teach were considered essential and to have personal experiences to draw on. This research also confirmed that mothers, more than most other type of worker, are willing to work collaboratively with families, thereby promoting a grassroots, participatory approach to

Consumer Participation

CBR programmes advocate community and consumer participation. But what does it mean? People can participate in the *benefits* which come from the programme or in the *implementation* of a programme; or they can be more involved and participate in the *decision making* and even in *evaluation*. Control of the programmes is not unduly upset by consumer participation at the level of benefits or implementation but when it comes to decision making and evaluation, questions are raised about who controls the programme's resources and the direction it is taking. Participation here means sharing, not only of duties, but also of power and privileges.

If consumer participation is to be more than a way of manipulating people to achieve goals predetermined by a dominant group, then its promotion must be seen as dealing with the redistribution of power within the disability field. The outcome is to enable disabled people and their families gain ownership over the conditions that affect their well-being.

Active participation takes times to develop and must proceed at the pace of the members and according to their needs. The reality has to be faced that people, educated in a long school of marginalisation and non-participation, may be resistant to change. But far from being a sign of ignorance or backwardness, it may represent a very rational response to what is unknown and unproven! Is participation what people want? Maybe they expect a service to be delivered and someone else to make the decisions. Isn't that the role of government and professional workers?

Yet disabled people and their families need a service now; they cannot afford to wait for conscientization to occur first. Our CBR programme was built around a small number of mothers coming together to determine their needs and setting about solving them. The service they deliver will attract other families. What we have then is the participatory process working alongside the delivery of a service; a service delivered by disabled people and their families.

In all the projects, we ensure that local committees of disabled people and community members are established in each district. They assume responsibility for the project's management. We also form PTA and a parents' group in each locality, as well as an association of disabled people, but this can be amalgamated with the parents' group, if members so wish.

A danger though is for programmes to become too inward looking; relying too much on their own resources and becoming isolated in the community. Participants in both our urban and rural programmes stress solidarity and teamwork, but also the need to network with local and government organisations, as part of the overall community development.

Collaboration also means working in co-operation with other marginalised groups to ensure equality for all sectors of society and in the promotion of positive personal qualities, including the spiritual. The role of the Churches is therefore very important; not only for this reason but also because of its place in the Filipino community and the infrastructure which it offers for promoting and supporting CBR activities.

Empowerment of communities also requires devolution of power by the government; decentralising authority to the local level. A start can be made by government channelling support directly to community level initiatives and helping to establish national and regional networks of support agencies.

Mobilising Mothers and other CBR Workers

How can mothers believe they will be of assistance to other families? First there is the role model of other mothers engaged in the work. There is also the support group which is set up and a belief from the organisers that mothers' personal qualities and experiences are as valuable and useful as skills and knowledge.

Yet as co-ordinators, we have made the mistake of expecting too much, too soon from mothers and our other volunteers. We have presented a series of information and training sessions aimed at 2demystifying the numerous theories and therapies. We wanted the new trainees to have as wide a range of skills as possible and for them to feel confident with the new knowledge. But after initial enthusiasm, people began to drop out. Back to the drawing board!

Had we done our pre-workshop preparation? We knew that with any community programmes, contact with the families at home is essential. Before any meeting or workshop, homes should be visited and people informed about the nature of the upcoming activity. A formal invitation is also required and maybe even a second home visit.

But all of this is to no avail if people haven't been consulted as to the relevance of any activity to their needs. And as each community is different, as the needs of each disabled person and her family are different, arriving in a community with a prepackage of activities and events spells only disaster. We must first discover what people ***need and want.*** Based on those needs and wants, we can then devise programmes and activities.

We must spend a considerable amount of time visiting homes, building relationships and trust, immersing ourselves in the life of that community and establishing local contacts. Only then can we arrange meetings. Each community will decide if they initially prefer small, intimate groups, or whether they would rather have larger groups which include all interested people in the community. Both formats have been successfully used by us.

These meetings serve to build relationships between participants, to provide the information needed, to help people analyse not only their needs but the possible solutions, and to identify possible resources. The group of informants and trainers includes mothers of disabled children as well as disabled people themselves.

By now we have established needs and are providing appropriate information and training sessions, both in groups and at the homes. Next we want to train local workers and volunteers. There is initial enthusiasm. We have chosen a time schedule that suits the prospective candidates; training is appropriate to stated needs; we have immersed ourselves in the community; people know what it is all about because the sessions are relevant to their lives; training is interactive - using a lot of group work, games, songs, role play along with theory and practical demonstration - and people still drop out!

Further analysis and experience tells us that we are still trying too much too soon. Rather than organise a complete training course, we alter our approach; minimising the number of formal sessions and instead doing the training in the family homes.

Initial training includes discussion on grassroots principles - how to establish a relationship with a family and how to listen - and information is given about disability and about the disabled child's particular needs. The volunteer is then **tasked,** that is given an activity to carry out with the family. It may be to monitor the medication of a child with epilepsy, assist with a range of motion exercises, or with early stimulation games, or accompanying the family for a hospital appointment. The activity is agreed upon with the family, something they need help with.

If the volunteer maintains this schedule and continues to show enthusiasm, the tasks are gradually increased and more theory and training is introduced. Workshops are arranged, both at the local centre and centrally (in Manila), and with other organisations and institutions.

Extended training sessions have also been organised for the workers from all the programmes (and other agencies as well). These hopefully will become an annual event - not only to develop new skills and consolidate old ones, but also to promote deeper relationships between all the KASAMAKA workers.

One final comment relating to motivation of workers. Although the CBR workers are expected to be "all rounders", they obviously have preferences for certain types of work. They may prefer to work with deaf students, or prefer the physical therapy or enjoy teaching the best. We try to respect their preferences.

Training for CBR

In this section we summarise the training we provide for our CBR workers. Although poor training is often a criticism levied at CBR programmes; the solution is glaringly simple - mobilise resources, including the professionals, to train local workers. O'Toole (1991) wonders what the minimal amount of training would be, but to consider minimal levels could create an attitude of low expectations for people. Training, we believe, should correlate with the needs of each participant and the community she lives in; it should be both practical and theory based, and on-going. Jaffer and Jaffer (1990) recommend a 'step-by-step' approach to training, growing naturally with the participants' needs, initially tackling the easy issues and working with co-operative families.

Training is founded on the premise that everyone has knowledge to offer and to share; no-one is superior. Learning about the group process is important, aiming to build on the mothers' personal qualities and experiences - and to learn from them. A grounding in basic counselling skills is provided. Training also stresses a working knowledge of the participatory process. Workers, whatever their identity, need training in how to accept, share, take advice and act on the suggestions of parents and disabled people.

The main components of the intensive training provided to all the KASAMAKA workers, including mothers and disabled people are given in Table 1. Overall, each participant received over 300 hours of training.

A wide variety of training methods should be employed: visual, participatory, 'hands on' experiences, field-work, group work and so on. Talks and lectures rarely feature!

The Role of CBR Workers

CBR programmes must be concerned with the prevention of disabilities. Hence many of our workers have been trained as **health workers,** and are aligned to both government and non-government health groups. For example, meningitis is a major cause of disability. Hence it is imperative that our workers recognise the symptoms and can inform the public about them during the community awareness workshops. They have knowledge of first aid and also the network to get the person into hospital.

Table 1
Topics covered in the Training of CBR Workers

☐ what is CBR
☐ disability: types/causes/intervention
☐ prevention and health/first aid/primary health care
☐ child development and management; early stimulation
☐ play therapy; theories of play
☐ physical therapy
☐ sign language
☐ Braille
☐ orientation, mobility and psychology of blindness
☐ principles and practice of integrated, interactive education
☐ making lesson plans
☐ assessment and devising plans of action
☐ basic counselling skills
☐ developing problem solving skills
☐ networking skills
☐ leadership and community organising skills
☐ promoting community awareness and involvement
☐ sports and leisure for disabled people
☐ making toys/classroom materials/basic orthopaedic aids
☐ promote philosophy of grassroots participation
☐ human relations training/group work
☐ employment opportunities - income generating projects
open employment; developing skills; interview skills.

Workers must also be **teachers,** as school classes are established in each community, especially for intellectually disabled, deaf and blind students. Many physically disabled children are accepted into the mainstream schools (if they can make their own way), but many receive our home tuition. They must also work closely with local schools and non-formal education groups to encourage mainstreaming of disabled children.

Workers must also be **community organisers**, knowing how to mobilise and encourage participants, as well as the community. For example, in one rural area, the workers persuaded a group of tricycle drivers to bring disabled youth to their counselling/vocational training sessions each week. CBR workers must also create a more positive attitude toward disability as they establish and maintain effective networks of community support.

Moreover, it means encouraging families and disabled people to work together, to run meetings followed by action and to utilise all local resources. Most importantly, it means encouraging the formation of 'people's organisation' so that community leaders come to see CBR as part of overall community development. The latter emphasis is the next step in the further development of our programmes.

Workers are also **disseminators of information,** producing newsletters, visual aids, media, publicity campaigns, workshops, puppet shows and dramas, child-to-child activities, talks and games. These are directed at school children, the communities, relevant professionals, as well as for disabled people and their families.

We cannot stress this enough: *information is what families say they need above all else.* With information, they can make decisions and plans. Likewise, information is also for the community, fellow groups and organisations, and the workers. We produce booklets for general information, but also for specific purposes, such as a pictorial dictionary of sign language (matching the sign to the word and its pictorial representation), cartoons on child development and on teaching self-care skills.

Lastly, all these tasks are on top of their key role as **trainers of families**; in which they are home visitors, counsellors, book-keepers, managers, and students themselves in the rehabilitation or enablement process!

Two major weaknesses exist in our present programmes. First we lack the facilities and skills to produce most orthopaedic equipment.

Another major flaw is in the area of vocational training and employment. We lack the finance to set up our own projects and can only occasionally provide capital for an income generating project. On the plus side, we try to locate jobs within the community, and we network with other agencies which may provide the training to learn the skills required.

Conclusions

Participants in KASAMAKA CBR programmes have said they want a service, but on their own terms. Parents do not want to be consulted about their child's needs and then to be handed a prepackaged rehabilitation plan to 'fit' the child. Rather, they want to participate in the formation of their child's programme, as do disabled people themselves: they want to be more involved in the planning and decision-making.

What our experiences have to offer CBR programmes elsewhere is a relatively untapped and effective workforce - the mothers of disabled children - in operating and managing CBR programmes. Whether this option will be considered, never mind accepted, will depend on professionals' willingness to give away skills, and the planners' and rehabilitation elite's willingness to give away power to disabled people and their families.

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Barney McGlade is a child psychologist from Belfast who has worked in the Philippines as programme co-ordinator of Kasamaka CBR programmes since 1988. He previously worked with the Brothers of Charity Services in Ireland and Manila before taking on his current assignment which is supported by the Irish charity, GOAL and the Columban Fathers.

Rita Aquino became a trade union and community organiser while working with a local micro-chip factory in her home city of Manila. She went on to become union vice-president and is currently in her second term as elected barangy (local district) councillor. She is also a co-ordinator of the CBR programmes and chairperson of an organisation of Day Care teachers in the Philippines.

Contact Address

Columban Fathers,
Malate Parish Church,
1016, M.H. del Pilar
1004 Malate, Manila, Philippines

13

Linking with Primary Health Care Services: Experiences from Vietnam

Tran Trong Hai and Nguyen Thu Nhan

Vietnam is in the centre of South-East Asia bordered by Laos and Cambodia in the West, China in the North and with the Pacific Ocean in the East and South. It is divided into five geographical regions: coastal regions, alluvial plains, middle region, low mountains and high mountains. It has tropical wet climate and the monsoons determine the wet and dry seasons. Two wide fertile alluvial deltas have great agricultural potential.

The population is nearly 70 million; 81% of whom live in rural areas. The growth rate of the population is 2.1%. Life expectancy at birth is 64 for men and 66 for women.

Children aged 0-16 are approximately half of the total population. The under-five mortality rate is 65 per 1,000 live births. The major causes of child mortality are acute respiratory infections, diarrhoea diseases, preventable transmissible diseases and malnutrition.

The administration is broken down into three levels: 54 provinces including 3 cities (Hanoi, Hai Phong and Ho Chi Minh); 555 districts and 9,611 communes. The local units have Provincial Councils and People's Committees.

Administrative Structures for Health

The two main tasks of the health services are Primary Health Care and improvements in the quality of health care. The concept of preventive medicine is emphasised as is the nationalisation and maximisation of local resources and maximising international assistance.

The national health policy fully endorses the Alma Ata definition of Primary Health Care with special emphasis on:

- the prevention and control of infectious diseases.
- the reduction of the population growth rate.
- the strengthening and development of the basic health services network at grassroots level.
- the development of self-sufficiency in essential drugs.
- the promotion of traditional medicine within the framework of the PHC system.
- the improvement of environmental sanitation and access to safe water.

Guidelines have recently been developed on the strengthening of district health systems, including staffing, equipment and supplies, financing, supervision and training.

Health Service Structures

The Health Care infrastructure consists of an extensive network of health facilities at four main levels - central, provincial, district and commune - with Health Steering Committees, part of the People's Committees, at each level.

Commune: A Communal Health Station is built in each community with populations of around six thousand people on average. Primary Health Care (PHC) services provided by the station include immunization, prenatal examination, delivery, minor surgery and CBR. The station is staffed with an assistant physician, a nurse and a midwife but recently, there have been reductions of up to 30% in staffing at community level.

Community Health Workers, including Red Cross, operate at the village, hamlet or co-operative level.

Relatively new are the inter-communal Polyclinics at the level between district and commune, providing basic care for about five communes (around 30,000 people) and set up to support PHC activities especially in large, under-served areas.

District: At a district level, a general hospital provides treatment and covers around 125,000 people. In addition, hygiene and epidemiological brigades serve to control malaria and provide vaccination.

Provincial: At the provincial level, there are general and specialised hospitals, along with social disease dispensaries sanatoriums, maternal protection and family planning stations and rehabilitation departments.

The health facilities network in 1990 counted 174 provincial hospitals (82 general, 92 specialised hospitals), 505 district hospitals, 676 inter-community polyclinics and 9383 community health centres.

Central: The Ministry of Health is at the top of the PHC pyramid. Some specialised institutes are attached to the Ministry e.g. the Institute for the Protection of Children's Health, the National Institute of Nutrition, Institute of Hygiene and Epidemiology.

Funding of Health Services

Health spending accounts for 3.1% of the national budget. Salaries of health staff at central and provincial levels, and part of those at district level, are paid from the national budget. All commune level salaries, however, are funded by the local People's Committee. The commune also finances the building of the community health centre and buys the essential drugs. Villagers contribute either in cash or in kind.

Disability Issues

Disability related issues are dealt with by the Ministry of Labour, Invalids and Social Affairs, the Ministry of Public Health and the Ministry of Education. The Ministry of Health is responsible for prevention and rehabilitation.

The Ministry of Labour, Invalids and Social Affairs is responsible for social welfare job replacement and it has eight rehabilitation centres and orthopaedic workshops in such major provinces as Hanoi, Ho Chi Minh and Hai Phong. There are three habilitation centres for children and one orthopaedic factory which produces semi-products to be completed as artificial limbs by the orthopaedic workshop. The factory also trains orthopaedic technicians.

In the Ministry of Education, the Special Education Section in the General Education Department administers the country's special schools. The Centre of Special Education for impaired children in the National Institute of Education and Science (NIES) conducts research on the education of disabled children and administers two schools for the blind in Hanoi and Ho Chi Minh, one school for the deaf in Hai Hung, one school for the mentally retarded in Hanoi and one school for those with speech difficulty in Hanoi.

Other special education schools and educational programmes of physically disabled children are under the Ministry of Labour, Invalids and Social Affairs. Vocational training is emphasised in education.

Disability in Vietnam

In 1983 a survey was conducted by the Ministry of Invalids and Social Affairs in co-operation with Ministry of Health and Department of General Statistics. A total of 1,485,000 disabled persons were identified; 2.7% of the population.

Of these, 55% had a motor disability, including 133,000 amputees and over one quarter of a million persons affected by polio. A further 34% had a sensory disability; including 235,000 visually impaired persons and 165,000 with a hearing impairment. An estimated 120,000 persons had a mental retardation and some 45,000 people had other types of disabilities.

It was estimated that nearly two-thirds of the people with disabilities were working. Of the remainder:

370,000 were capable of rehabilitation;
340,000 were dependent on assistance in daily life;
210,000 were unable to be independent.

An analysis was made of all the children seen at the Institute for the

Protection of Child Health in the period 1981-1993; a total in excess of 17,000. The largest proportion (26%) had motor and mental retardation, followed by those with cerebral palsy (25%) and polio (18%).

A follow-up of the latter children revealed that only 38% of the treated polio children showed some good results. For 41% no results were obtained and 21% children could not go on with their treatment.

Although the reasons for this may vary, a major factor is that parents could not afford the expense when they stay in Hanoi. The cost of 10 days in the capital might be equal to one years cost for their whole family in the countryside. That means, that parents who want to bring their child to the centre in Hanoi or Ho Chi Minh will have to do the equivalent of an extra years work to be able to spend another 10 days at the Centre. But what can a centre do for disabled children in only 10 days? Other studies have shown that follow up results of disabled person discharged from institutions is poor.

In another survey, the staff of the Rehabilitation Department of the Institute for the Protection of Child Health, contrasted the proportions of rehabilitation personnel to disabled people at four administrative levels. The results were as follows:

Proportions of Disabled People	*Level*	*Proportion of Rehab. Personnel*
1- 5%	Central	70-80%
5-10%	Provincial	5-10%
10-15%	District	1%
75-80%	Community	0%

From the above figures, one can see very clearly the mal-distribution between the rehabilitation personnel and the numbers of disabled people. The training systems for rehabilitation personnel tended to train them to help people with disabilities in the urban and more developed areas only.

Finally, institutions are expensive to build and maintain and serve only a limited number of disabled persons. Further, they depend on staff that need high levels of training which are expensive to maintain.

Given all these considerations an alternative way of meeting the needs of Vietnamese people with disabilities had to be found.

Community Based Rehabilitation in Vietnam

In Vietnam the Community Based Rehabilitation Programme was begun in 1987; sponsored by Radda Barnen (Sweden) and started by their Consultant on CBR - Dr. Padmani Mendis. The programme now goes on with national experts.

The Ministry of Health (MoH) set up a Steering Committee chaired for the first three years by Prof. Nguyen Thu Nhan, Director of the Institute for Protection of Children's Health (IPCH). Afterwards a New Rehabilitation Committee was founded in the MoH chaired by the director(s) of the Department for Health Management. Steering Committees were also set up at provincial, district and communal level with involvement of People's Committees, mass organisations, Health Services, Education and Social affairs.

The CBR Development Project started in six communes of Tien Giang province and one commune in Ho Chi Minh City. The following objectives were formulated:

1. To gain experience in integrating CBR within the PHC system.
2. To assess the delivery system and manpower needs of CBR.
3. To assess the effectiveness of CBR technology as described in the manual *"Training Disabled People in the Community"* (WHO, 1990) and to determine the adaptations necessary for Vietnam.
4. To evaluate the impact of CBR on the lives of people with handicaps, their families and communities.
5. To assess and develop a system for recording, reporting, monitoring and evaluating rehabilitation.
6. To develop a provincial/regional teaching and demonstration area for rehabilitation.

Introductory seminars were first held at regional and provincial levels followed by a one month training course for selected project staff during which the objectives of the project were decided. A plan of action was designed for project development for the 12 month period from March, 1987. A reporting/monitoring and evaluation system was proposed and targets were set.

The seven pilot communes were selected by the CBR Steering Committees which were part of the PHC Committee. Three categories of communes were chosen.

1. Commune(s) with very well developed PHC networks and a strong commitment from the community, whose representatives were members of the Steering Committees.
2. Communes with moderately developed PHC networks and the capital per head below 600kg rice per year.
3. Communes with the least developed PHC networks and very poor conditions.

Why three types of communes? Experiences from other programmes had shown that when the pilot areas were selected from only the 'best ones', people from poorer communes would say: "these areas are the best, we are not in that category, so we cannot follow the model they have done".

Training Manpower for CBR

With the exception of the first two seminars and training courses conducted by Dr. Mendis, the remaining courses and seminars have been conducted by Dr. Hai and his staff along with other local specialists.

The following steps have been employed to establish the CBR Programme in a locality.

1. The National Steering Committee conducts a five day seminar at Provincial level to promote CBR among representatives of all relevant Ministries, the People's Committee and local organisations. A Steering Committee is set up at Provincial Level. The Vice-chairman of the People's Committee becomes the Chairman of the CBR Steering Committee.
2. The National Committee conducts a one month training course for provincial and district level rehabilitation doctors, therapists, assistant doctors and teachers from the regular school. The WHO manual is used in this training and training at other levels.
3. Those trained in the one month course return to their district and conduct a three day seminar to promote CBR at district and commune levels. A District Level Steering Committee is also set up.
4. The same personnel also conduct a two week course for the Brigade nurses, local teachers and volunteers, such as Red Cross members, who will implement CBR within the villages or hamlets.
5. Those trained in the two week courses conduct a house-to-house survey to identify disabled people in their respective villages.
6. Training begins for disabled people who need rehabilitation. Personnel who work at village level supervise the disabled people and their families in carrying out the training.

   In most instances trainers were family members - mothers as well as fathers, grandparents, brothers and sisters. In instances where family members were not available (e.g. elderly people living alone) the Primary Health Workers have taken the role of trainers. In such cases, the workers were often relatives or very close neighbours. In the future however, the Primary Health Workers will delegate this role to others.

   In all instances where technical aids were necessary for people with mobility handicaps, the family have made them using the Vietnamese training manual as a guide. Support was available from the Primary Health Workers and, if necessary, from the assistant doctors or physiotherapists.
7. Village level personnel report regularly to the staff at the Health Station. District level staff visit the community level for

supervision every one or two weeks. Provincial level staff visit District level for supervision approximately every two weeks.

8. Records are kept at all levels so the progress of each person's rehabilitation programme can be monitored.
9. Supervision is done at each level by the appropriate steering committee.

This approach, provides coverage for a great number of disabled people in the community at a cost level that can be maintained by any community. The main goal throughout is to reinforce the family programmes for people with disabilities.

Training for Community-Level Workers

The two week training for the community level workers includes modules on the following topics:

- Objectives and orientation to the training.
- Facts on disabilities and identification of disabled persons in Vietnam and the world over.
- First-level prevention and referral pattern.
- Simple identification and rehabilitation of disabilities including moving, hearing, visual, mental and communication disorders, sensation loss, epilepsy.
- Communication and motivation techniques.
- Role of the community worker in the rehabilitation process.
- Role of the family, community and Steering Committee on CBR.
- When and how to refer disabled persons needing other services.
- Roles of other members of the rehabilitation team.

Training Methods: The methods of training generally fall into the following four main aspects:

1. Lectures, seminars, group discussion, peer learning, role-plays.
2. Use of audio-visual materials and manuals (see below).
3. Practical work in teaching rehabilitation through individual or group placements; and
4. Field study in the community.

Training for community-level workers emphasised a more practical, problem-orientated approach and encouraged the trainees' full participation. Role playing, case studies and group discussions proved to be especially effective methods.

Training Materials: From the first year up to the present, the WHO manual, *Training Disabled People in the Community* has been the most important tool for implementation of CBR. Without it, CBR could have not been successful. However, during the course of implementing CBR programmes, we found out that other materials were vital; in particular, Nancy Finnie's book, *Handling the Cerebral Palsy Child at Home* and David Werner's *Disabled Village Children.* Both these books have been translated into Vietnamese and they are used extensively for upgrading courses in all CBR programmes.

In order to help all intermediate workers to be able to teach CBR in their community, *"A Guide for CBR"* was written by Dr. Hai and others.

Impact of the CBR Programmes

Since the pilot phase, the CBR programmes has spread to some eleven provinces. The Table below summarises the activities of the CBR Programmes to date.

ACTIVITIES	*Number*
Provinces with CBR	11
Districts with CBR	23
Communities with CBR	208
Total population covered by CBR	1,643,347
Total population of Children 15 years and younger	642,381
Number of disabled children	7,649
Training courses conducted	231
Assistant Doctors trained in CBR	732
Physiotherapists trained in CBR	90
CBR workers trained	2,534
Teachers trained	70
Number of children with disabilities attending school	1

National Impact: The CBR programmes are fully integrated into the Primary Health Care system at all levels, both for referral and for services. This includes communal health stations; districts; province and central levels.

Most of the CBR workers and intermediate level workers belong to existing primary health networks which are well co-ordinated in the horizontal and vertical programmes; covering topics such as nutrition, leprosy and mental illness.

CBR has had a marked impact on Primary Health Care services as it checks up and stimulates other PHC programmes such as nutrition, education, family planning and the detection of polio.

CBR has also had an impact on the rehabilitation services. One of the most important achievements is the adoption of new curriculum for training rehabilitation technicians (formerly called physiotherapists) in three National schools (Hai Hung, Danang, Hoi Chi Minh city). Moreover, two out of the three rehabilitation schools have had major repairs carried out.

Also in medical colleges in Hanoi and Hoi Chi Minh City a new curricula in rehabilitation training has been established that is orientated mainly towards CBR.

Thanks to CBR, 77 communal health stations have been upgraded with basic equipment. This provides better working environments for the assistant doctors whose aim is the prevention of disabilities.

Sixteen rehabilitation departments in 16 districts with CBR programmes have been set up and equipped with locally made basic rehabilitation equipment.

The Rehabilitation Department in the Institute for the Protection of Child Health (IPCH) has become the co-ordinating and training resource centre for CBR in the whole county.

A major effort has gone into the production of training materials. The WHO Manual, *Training in the Community for People with Disabilities* (1989) was translated into Vietnamese and over 5,000 copies were issued for CBR in the whole country. Also 1,500 copies of the Vietnamese version of Werner's *Disabled Village Children* were printed as were 5,000 copies of the locally produced manual, *Guide for CBR*, which is used in teaching the management of CBR programmes.

Five video programmes made by Vietnamese Television on CBR have been broadcast nationally.

VINAREHA (Vietnam Rehabilitation Association) was founded in 1990 with the primary aim of promoting and developing CBR.

International Impact: CBR experiences of Vietnam have been shared in both regional and international conferences held in the Philippines, Thailand, Laos, India and Holland.

WHO Headquarters sent four Mongolian doctors to be trained on CBR by Dr. Hai for 2 months. A further four people from Kampuchia were also trained.

Changing Attitudes: In practice, this has been one of the most important difficulties and it has been a continuing problem. Attitudes need to change among disabled people themselves as well as among the able-bodied.

There are a lot of resource persons within the community, who, if mobilised, can contribute to education and changing of attitudes. For instance, traditional healers who have experienced success already in the rehabilitation or treatment of different types of disabled people. Especially important are those healers endowed by their ancestors with a high reputation in the community.

Other important allies in changing attitudes are family members with disabled people themselves who have cared and treated them for years and gained precious experiences in many aspects of dealing with disabled people.

Many disabled people themselves have overcome their disability; including the war invalid, some people with polio, those with hearing and speech problems. They can share very practical living experiences in overcoming their own disabilities.

Five Conditions Required for CBR

In summary then, we have found that there are five conditions required to start and maintain CBR programmes in Vietnam. These are:

1. Community Involvement, support and motivation from leadership (that is the People's Committee) through CBR Steering Committees which are integrated into Primary Health Care systems. Links need to be made with: People's Committees, Health section, Social affairs, Education, Mass organisations (Women's Union, Youth), Red Cross and Finance

2. Manpower is required to implement techniques of rehabilitation in CBR services. This includes:
    - Disabled persons
    - Family members
    - CBR workers (Trained PHC workers, brigade nurses, Red Cross members, teachers).
    - Physiotherapists, rehabilitation specialists.

3. Referral system need to be established at various levels:
    - Communal Health Station
    - Rehabilitation Unit in District Hospital
    - Rehabilitation Department of Provincial Hospital
    - Rehabilitation Centres nationally.

4. Training materials need to be produced:
    - Materials for making appropriate technical aids
    - Manuals for training.

5. Funds must be available to support the programmes. These have come from: Radda Barnen and from local resources.

Dr. Tran Trong Hai is Head of the Rehabilitation Department of the

Institute for the Protection of Children's Health (IPCH) in Hanoi. He has worked extensively in the area of CBR throughout Vietnam over a number of years.

Professor Nguyen Thu Nhan is the Director of the Rehabilitation Department at Bach Mai Hospital in Hanoi. Along with Dr. Hai, she is a key member of VINAREA, the NGO which manages the CBR Programme in Vietnam.

Contact Address

Institute for the Protection of Children's Health,
Hanoi,
Vietnam

14

Education of Personnel: the Key to Successful Community Based Rehabilitation

Padmani Mendis

Community-Based Rehabilitation (CBR) is a relatively new strategy which is increasingly being adopted by developing countries to improve the quality of life of their people who have disabilities. It is 'new' as a strategy and it is based conceptually on a 'new' synthesis of ideas. But many of these ideas however have been known for a long time and some have been documented in various forms by several persons at different times.

What is 'new' about CBR is this. Other approaches to rehabilitation in use up to now, focus on providing individuals who have a disability with the training opportunities and other interventions that they need to overcome the consequences of their disabling condition on themselves. The aim of these rehabilitation approaches is to enable individuals to achieve as much functional and economic independence as possible. Yet however functionally and economically independent these people become, they continue to be outside the mainstream of community life. CBR therefore seeks first to change the principal cause of the situation of people who have disability: namely the negative attitudes of individuals, communities and society-at-large towards disability and people who have disability.

CBR strives to ensure that individuals, communities and society accept the equal rights of individuals who have disability. Only then can interventions with people who are disabled bring them a place in society. CBR seeks first to promote a positive change in attitude among the people with whom individuals who have disability interact. Without this attitude change the situation of people with disabilities remains the same. As can be seen from the struggle of the disability movements even in the industrialised countries, functional and economic independence have not brought them an equal status in society.

Since it addresses this underlying social cause, CBR must then be viewed as a process of 'social development'. Other approaches we have used up to now by and large view rehabilitation as a separate programme and focus largely on individuals who have disability and on providing separate services for them.

Attitude change is of course very difficult to bring about, and especially so when attitudes towards people who have disability have deep-seated cultural and social roots. As in other development activities, experience in CBR indicates that desired social changes come about when communities take responsibility for bringing about the desired changes. Hence the words 'community-based' should be taken to mean *'community-responsibility'* for the rehabilitation of their members who have disability. In CBR, individuals and communities take responsibility for improving the lives of members who have disability and their efforts are supported by professionals who work outside these 'nuclear communities'.

Whereas before, professionals conventionally have been service providers, the role called for them in CBR is primarily a supportive one. Thus the provision of services has to be seen in a new perspective and a new sensitivity, respecting the right of individuals who have disability, their families and nuclear communities to make decisions in matters which concern themselves.

Who Needs Education?

This new perspective calls for an emphasis on education as a priority for the development of CBR. For instance, Figure 1 illustrates some aspects of the CBR Structure that we are attempting to develop in Sri Lanka; a structure that is common with many other developing countries. It is based on the needs of individuals who have a disability, their families and communities. Besides being needs-based, the programme also rests on community participation, promoted and supported by professionals, and by the local government at each administrative level. All of these groups need education in CBR.

Education first for people who have disability and their families, to make them aware of their rights, and to make available to them the knowledge and skills they need to take control of their lives.

Insert Figure 1 here

Education also for those who take leadership within communities, and for community workers, so that they may be in a position to share the processes and the benefits of development with their members who have disability.

Education too for professionals and administrators, so that they may be willing to support and to share their knowledge and skills with the groups listed above.

This paper will therefore share some of our experiences in Sri Lanka of the education of these four groups of people - individuals who have disability and their families, community workers, community leaders and rehabilitation professionals. (The education of administrators in government and non-government services is also an important aspect of the educational strategy although that is not covered here.)

Some Fundamental Concepts in Education for CBR

The process of education in CBR, as in any other field, should be dynamic; changing in response to changing situations and demands. This paper discusses educational needs in the context of the current phase of CBR development globally; that is, when programmes are being set up and while others are still in their early stages of development. As CBR grows and expands to reach more people who have disability, educational programmes will need to adapt to the changing needs of people who have a disability.

In order to ensure that the needs of people who have disability are being met in the most effective and efficient way, education must seek ways of ensuring its relevance. For this to happen, educational programmes must consider two vital aspects.

First, they must be based on the needs of people who have disability. Although there is a fundamental similarity in the situation of people who have disability in developing countries, varying social, economic, political and cultural environments have to be taken into account. Thus educational programmes have to adapted anew for each country.

Second, educational programmes must have built-in systems of continual self-evaluation so that they detect and adapt to changing needs of the people they are serving.

Both these points are largely neglected areas in present-day CBR education. Too often educational curricula are designed by those with little understanding of CBR and with little contact with people who have disability. Hence courses are based on what are perceived to be the needs of people who have disability.

Third, education itself is too often seen as a 'sharing' of information and technology (i.e. knowledge and skills) that is brought about from 'outside' or from the 'top'. Rather education should be viewed as process which leads people to grow and develop their understanding and to find their own solutions. This is facilitated through the use of 'learner-centred' teaching methods, such as discussions, problem solving and project work, rather than the more favoured lectures and talks.

These three points need to be focused on to a greater extent in order to ensure that the educational programmes remain relevant and that they will provide the necessary foresight to take CBR forward.

Education of Professionals

Professionals workers are taken up first because it is here that change is required most. This group includes any paid workers who are involved closely at present with people who have disability. They are usually employed in health, social welfare and education sectors, as well as in voluntary organizations. The group includes therapists, social workers and school teachers. People with a disability who work as professionals in any of the above sectors would also fall into this category.

Two forms of educational input are needed for professional workers. First, short courses for those already in service, to meet the immediate and urgent need for programme initiators, teachers and managers at support levels.

Second, adapting the basic curricula of existing professional education for therapists and teachers. Where no courses exist, then new styles of courses need to be considered. Professional training is required in order to meet the longer-term need for programme sustainability, especially to produce generalist workers at middle levels.

The Disability Studies Unit of the Faculty of Medicine of the University of Kelaniya, Sri Lanka, has, for the last two years, been implementing short courses for two groups of students; Sri Lankan nationals and for international participants. Some aspects of these two types of courses are shared below.

International courses

These courses run full-time for six weeks and the participants are professional workers (including administrators) who are presently working in CBR or those who intend to do so in the very near future.

In all, 44 people have participated in the two courses held thus far; a third is planned for 1995. They have all come from developing countries in Africa, South America and Asia with sponsorship obtained from various bilateral donors, UN agencies and international NGOs.

Course Objectives: The course aims at enhancing the teaching and managerial capabilities of participants. To achieve this overall objective, the course aims specifically at developing in participants the necessary attitudes, knowledge and skills so that they will be able to:

- respond with sensitivity to the needs of people who have disabilities, their families and communities, and to promote their empowerment;
- assist/support communities to plan, implement and monitor their own programmes;
- analyse community structures, activities, resources and support systems, and to facilitate and promote their coordinated use;
- make detailed plans for phased district/regional programme development;
- interact and collaborate effectively as members of interdisciplinary groups.

Course Content: Each course day consists of seven sessions of 45 minutes duration. The course content can be grouped into the following modules:

Insert photo 14.1 here

1. Disability concepts and the situation of people who have disability (34 sessions);
2. Community development and support systems (22 sessions);
3. Rehabilitation programme development (86 sessions);
4. Field work and analysis (50 sessions);
5. Adult teaching and learning (20 sessions);
6. Appropriate technical aids (20 sessions);
7. Course opening and closing, introductions, assessment of participants' learning, course evaluation (20 sessions).

Resource persons are drawn from other countries as well as Sri Lanka. Learner-centred, participatory teaching is used whenever possible. Course evaluation includes an ongoing evaluation of sessions/modules by participants, an end-of-course evaluation to give an overall perspective and a post course evaluation, 18 months after completion.

National Courses

Whereas many NGOs implement small and isolated CBR projects, the National Programme in Sri Lanka is the responsibility of the Ministry of Health and Social Welfare. At the national level, all the sectors presently involved in making opportunities available and accessible to people who have a disability, come together in a national inter-sectorial body. This includes representatives from the

Ministries of Health, Social Services, Education and Labour, as well as representatives from the larger NGOs and UN agencies. In this way, existing personnel and infrastructures are made most use of and each sector pays the salaries of its own personnel.

As Figure 2 illustrates, in Sri Lanka's CBR strategy, professional support is made available to communities at a divisional level. This is the most peripheral, administrative level; comparable to districts in most other countries. In each division, a "core team" is being educated to provide the general programme support that communities have wanted as well as the necessary technical support. The Divisional Core Team consists of a social service officer, a therapist and one other member selected by each division. The third member has most often been community and rural development officers, local NGO workers and in a few instances, planning officers. All members of teams have a basic professional education as well as varying periods of practical experience in their own fields. They incorporate CBR tasks into their existing work.

Insert Figure 14.2 here

To date, this strategy has been initiated in 20 of the 260 divisions in the country.

All training is coordinated through a central inter-sectorial body which includes representatives from Health, Social Services, Education and Labour. The Disability Studies Unit acts as a technical resource for the National CBR Programme and provides training for the the members of the core team. In addition, the Unit's programme '*Partnership in CBR*' seeks to strengthen the capacity of disability consumer organisations, and other disability-related NGOs, to participate actively in CBR.

However the education of school teachers and of vocational training teachers for CBR is being undertaken by other Institutes and will not be dealt with in this paper. Local administrative officials also have seminars and workshops on CBR.

Course objectives: The primary objective of the course is to prepare participants for the tasks which members of the divisional core teams are called on to perform. These are, to:

1. Work effectively as members of the CBR Divisional Steering Committees;
2. Carry out social mobilization of communities so that:
    a) each community will set up a community rehabilitation committee to take responsibility for the maintenance of their programme, and,
    b) the community rehabilitation committee will select volunteers

to implement the programme;

3. Organize and conduct a training course for volunteers of at least two weeks duration and orient other community members/leaders as may be necessary. (NB. The National Manual, *Training in the Community for People with Disabilities* is used as a tool for the community level. This has been adapted from the W.H.O. Manual (Helander et al., 1989);
4. Make regular home visits with volunteers so as to provide further teaching; help to solve problems and to monitor progress;
5. Meet regularly with community rehabilitation committees for support and monitoring;
6. Collect data, keep records and make reports to the divisional steering committee;
7. Assist community rehabilitation committees to communicate with education officers and obtain educational opportunities for children who are not going to school;
8. Assist community rehabilitation committees to communicate with labour officers and National Youth Service Council (NYSC) officers and NGOs, and obtain vocational training and job placement for youth and adults who need it;
9. Ensure that those who need medical interventions are referred to the Medical Officer of Health, or to other health services, and that referrals are followed up.

Course Content: The course is presently based around three modules.

Module I - Programme Basis

- situation of people who have disability;
- attitudes towards disability and people who have disability;
- disability concepts;
- CBR concepts and approach;
- national strategy and the role of participants;

Module II - Technology

- rehabilitation of people who have difficulty seeing;
- rehabilitation of people who have difficulty moving;
- rehabilitation of people who have difficulty hearing and/or speaking;
- rehabilitation of people who have difficulty learning (mental retardation);
- rehabilitation of adults who show strange behaviour (mental illness);

- rehabilitation of people who have fits (epilepsy);
- rehabilitation of people who have multiple disabilities;
- breast-feeding of infants who have disability;
- early stimulation programmes for children who have disability;
- socialisation opportunities;
- psychosocial needs;

Module III - Programme Implementation

- interaction with individuals, families and communities (interpersonal skills);
- strategies for social mobilization;
- location, identification and assessment of needs and rehabilitation planning with and for individuals;
- education system and the role of the Ministry of Education;
- income generation for youth and adults and the roles of the Dept. of Social Services, Ministry of Labour, National Youth Services Council and NGOs;
- meeting medical needs and the role of the Ministry of Health;
- coordination with other sectors - state and non-governmental;
- information gathering, record-keeping, reporting and monitoring;
- resource analysis and harnessing;
- selection and training of volunteers;
- divisional programme planning;

Course outcomes: The impact of the training and of programme development are presently being monitored by the Disability Studies Unit and CBR Unit of the Ministry of Health and Social Welfare. This is done mostly through field visits, although a reporting system is also being developed.

At present, the preliminary course lasts 15 days, with upgrading courses to follow. Upgrading courses are being developed based on the needs detected through field monitoring.

Educating Communities - Social Mobilisation

The wider community also needs education about CBR. The objective of education in relation to communities is to procure their active participation in the CBR process. We call this "social mobilization", while in other countries it may be called social animation or community preparation.

Social mobilization is carried out by the Divisional Core Teams using non-formal educational methods as a continuous component of programme development. During their training, Divisional Core Teams learn how to approach communities and to identify persons who are most influential in each community. One method used is discussion with the formal and informal leaders in one-to-one situations or in small groups, and then reaching the rest of the community through them using the traditional communication network in each community.

Another method is to participate in community gatherings and meetings and so discuss with community members directly.

We view education or social mobilization as a process of discussion with the community leadership and membership, that will lead to the setting up by the community of a 'Community Rehabilitation Committee' who will take particular responsibility for improving the lives of their members who have disability. We have found that these Committees are vital to ensure community ownership of their programmes, as well as to both maintain and sustain the programme.

The process of education through discussion generally includes the following aspects:

- information about the CBR programme, implications for the role of the community and responsibilities;
- awareness of problems arising from a disability and the factors that cause them;
- awareness of the needs of, and a wish to improve the quality of life of community members who have disability;
- awareness of how, and to what extent, the community can use its own resources to develop programmes
- accessibility of information and technology (knowledge and skills) to meet the special needs of members who have disability;
- supports available from other levels to make accessible the services and interventions that the community cannot provide;
- examples of other programmes; the factors which account for success and constraints;
- responses to questions.

In our experience, information dissemination must be a continuous part of the CBR programme in order to maintain community participation in it.

Education of Community Workers

In Sri Lanka, community CBR workers are selected by each community and they work on a voluntary basis. They are mostly youth, although recently the middle-age group is increasingly taking on this role. Their minimum level of education is generally 10th Grade (General Certificate of Education Ordinary Level) although many have had a 12th Grade education (i.e. 'A' Level). These Community Workers most often are members of community organizations and are involved in promoting many development activities of which CBR is one. The others could include women's programmes, poverty alleviation and health promotion.

Course Length: The Introductory Course is a minimum of 14 days, followed by a continuous period of field teaching. The teaching of community workers is the responsibility of the Divisional Core Team and their training continues during regular home visits.

Course Objectives: Again, the course objectives are defined by the tasks that community workers will be called upon to perform. They have to be able to:

- involve the community in the rehabilitation programme;
- locate and identify people who have disability, and determine their rehabilitation needs, if any;
- to find a "trainer" for each person with a disability through discussion with the individual and the family, and plan interventions to meet the identified needs, using the CBR Manual as a tool;
- guide, support and motivate individuals and family members to continue the rehabilitation process until needs have been met; detect problems and constraints, and discuss these with the divisional core team who act as mid-level CBR support workers.
- seek the cooperation of school teachers for getting children into schools, and refer problems to the community rehabilitation committee;
- to find income generation activities for youth and adults through discussion with the community rehabilitation committee;
- refer to health workers those individuals who need medical interventions;
- assess progress, keep records, and report to community rehabilitation committee and to divisional core team;
- continue the programme in their own community.

NB. The Manual '*Training in the Community for People with Disabilities*' (WHO 1983), adapted to our situation, is used as a basic tool by Community Workers.

Course Content: The Content of the Introductory Training Course follows below. Field teaching continues to meet emerging needs and is used to strengthen weak areas. Further courses for community workers will follow according to need.

1. Introduction to Rehabilitation:
   (situation of people who have disability and community attitudes towards disability and people who have disability; disability concepts and rehabilitation needs; goals, components and methodology of CBR; role of community workers.)
2. Aspects of Rehabilitation which are common to the different disabilities people may have:
   (social interaction; income generation; daily living activities; schooling; early stimulation; breast-feeding advice.)
3. Meeting the special needs of people who have difficulty seeing:
   (possible problems faced by individuals, information for individuals and family, training, interventions for self-care and for orientation and mobility.)
4. Meeting the special needs of people who have difficulty hearing and/or speaking:
   (communication, communication problems and information about possibilities; communication training techniques.)
5. Meeting the special needs of people who have difficulty moving:
   (possible problems and information about possibilities; training techniques for daily living activities and for mobility including the making of simple appropriate aids and equipment; methods of preventing deformity.)
6. Meeting the special needs of people who show strange behaviour (disability arising from mental illness):
   (resulting behavioural problems and advice to family about how to deal with them; restoring daily living activities; importance of referral and medication.)
7. Meeting the special needs of people who have fits: (information about disability and advice to family about how to deal with it; importance of referral and medication.)
8. Meeting the special needs of people who have difficulty learning (disability arising from mental retardation):
   (possible problems and information to the family about how to deal with them; training techniques for children and for adults.)
9. Starting a CBR programme:
   (role and responsibility of the community and how to involve them; role of people who have disability and how to involve them.)
10. How to use the National Manual, *Training in the Community for People who have Disabilities* as a tool for carrying out the programme:

(introducing the manual and how to use it; visiting households, locating and identifying people who have disabilities; finding out rehabilitation needs; selecting training material, planning and implementing the rehabilitation programme with each individual and family; keeping records, making reports, and making referrals; how to continue the community CBR programme; role in the prevention of disability).

Education for Families and Individuals with Disability

All the educational approaches described above have one primary purpose - to reach individuals who have a disability and their families so as to empower them with the knowledge and skills that they need to strengthen positive relationships and to promote interactions among themselves and with the community.

It is at this point that CBR programme development truly begins. Individuals who have a disability and their family members are located in their homes and are helped to vocalize their needs by the trained community workers. Thereafter, the community workers share the knowledge and skills that they have and they use these in working with individuals, families and communities to fulfil the person's needs. Those needs that cannot be fulfilled at the home or community level are referred to the Divisional Core Team. Sometimes this may call for further referral to other agencies as in the case of very specialised needs. Medical needs are referred to the Divisional Health Officer.

Conclusions

The paper has emphasized that the success of a CBR strategy rests on the quality of education made available to the key implementors - individuals who have disability and their families, community leaders and membership, community workers, professionals and administrators.

Sri Lanka's CBR strategy has been developing over the last 13 years, but can be considered to be in its early stages. It is evolving as a multi-sectorial approach based on community participation and on supportive inputs at each level of the country's administrative system. It's major weakness at the present time is the limited involvement of the Organizations of People who have Disability. This will be addressed as a priority as further educational inputs are developed.

Reference

Helander, E., Mendis, P., Nelson, G. & Goerdt, A. (1989). *Training in the Community for People with Disabilities,* Geneva: WHO

Padmini Mendis worked with Einar Helander and Gunnel Nelson at the World Health Organisation on the evolution of Community Based Rehabilitation and is co-author of the manual: *Training in the Community for People with Disabilities.*

She is Course Director at the Disability Studies Unit, University of Kelaniya, Sri Lanka and visiting lecturer at Uppsala University Sweden, where she was awarded an honorary doctorate in medicine for her contribution to the global development of CBR.

Since 1980 she has been on the WHO Expert Advisory Panel on Rehabilitation and has now visited over 25 countries to promote CBR programme development

Contact Address

Disability Studies Unit, Faculty of Medicine,
University of Kelaniya
P.O.Box 06, Ragama,
Sri Lanka

15
Funding Services

Bill Brohier

Money is said to be the root of all evil. However, this is a misquote from St. Paul's letter to Timothy which reads: *' the* ***love*** *of money is the root of all evils'.* The very sad fact is that 'the **love** of money' is the driving force behind much of the world's development projects. An even sadder fact of life is that these development projects appear, on the surface, to be for the betterment of the people when, in reality, they are often at the expense of the majority. This results in the unequal distribution of wealth to the extent that, in some countries, between 10-20% of the population own around 80 - 90% of the wealth! Where do people with disability stand in such a global scenario and what are their chances of competing on an equal footing, or even of surviving?

The World Summit for Social Development **(WSSD)**, which was concluded on March 12, 1995 in Copenhagen, held out much hope for people with disability because its three core themes were:

- Poverty Alleviation,
- Increased Productive Employment, and
- Social Integration

The great importance of the above issues cannot be over-emphasised for people with disability, especially the millions who barely subsist in the teeming masses of Asia, Africa, Latin America and the Caribbean. Therefore, in preparation for the World Summit, six disability, non-governmental organisations which operate internationally (INGOs) submitted the following statement to the Organising Committee.

> *The disability INGOs know from the direct experience of their members that disabled people are the poorest of the poor - segregated and isolated in their communities. The three core issues of the Social Summit are particularly relevant to disabled people everywhere. Disabled people are a significant proportion of every other group in the world.*
>
> *The resulting experience of discrimination and oppression make it imperative that disabled people are included wherever there is reference to marginalised, disadvantaged or impoverished people. There should also be particular recognition of disabled people's experience of social apartheid, the exciting solutions that disabled people have found for themselves and the monitoring and*

> *evaluation mechanism put in place by the UN itself in the Standard Rules on Equalization of Opportunities for Persons with Disabilities.*
>
> (Extract from the Statement prepared by: Disabled Peoples' International, International Council for Education of People with Visual Impairment, Nordic Council of Organisations of Disabled People, Rehabilitation International, World Blind Union, World Federation of the Deaf, January, 1995)

For the first time at a summit meeting, *people* were being placed at the centre of development. There was great expectation that the participating Heads of State would make specific commitments and ensure the funding which would result in direct benefit to people with disability, who after all account for ***'10% of the world's population'*** (UNESCO, 1993).

The World Summit was somewhat disappointing in realising the above hopes. But as with the *International Year of Disabled Persons* (1981), what it did do, among other things, was to focus global attention on the growing needs in the developing and developed countries as well. The facts are these:

- The population of the world is still increasing too rapidly.
- As a direct consequence, the demands on both developing and developed countries have increased, as have the numbers of people who are disabled, often as a result of wars, armed conflict, anti-personal mines and a variety of easily preventable causes.
- The above increases have resulted in an ever widening gap between the ***haves*** and the ***have-nots***.
- Unfortunately, in view of the world's economic situation, available resources, especially financial, cannot keep pace with the above demands.
- In fact, less funds are available for the escalating needs, resulting in keener competition for the same dollar and the need for a more professional approach to programme management and to fund raising.

Although 'the love of money is the root of all evils', money itself - like love - makes the world go round and can be put to very good uses, including the support of services to people with disability.

Partnership for Progress

The introductory paragraphs are deliberately not very encouraging because the task of funding services for people with disabilities is not easy. There are innumerable demands on the limited resources.

However, the challenge can be met and success is not impossible.

Gone are the days when Non-Governmental Organisations (NGOs) from developed countries merely donated large sums in support of residential or centre-based programmes. Two main factors account for this; the current economic situation and a deeper understanding of the real needs and aspirations of people with disability.

Hopefully gone too is the purely ***charity*** approach to services for those with disabilities which resulted in over-protection and mere 'hand-outs'.

Today, service programmes are preferred which adopt a developmental approach and have built into their plans time-bound phases towards becoming self-sustaining. Such services, if they are affordable and appropriate, are assured of continuity which, in turn, ensures long-term benefits to people with disability. In order to plan and implement such programmes, the local NGO needs:

- to totally involve people with disability themselves, their families and the community in the planning and decision-making process from the beginning;
- to provide a local counterpart either in cash, kind or in terms of human resource, coupled with a commitment to increase it annually as donor assistance is phased out;
- to call on professionals and technical experts to assist in drawing up the plan and its implementation, if necessary; and
- to attract the necessary funding from local, national and overseas sources.

Such a partnership for progress is assured of success, particularly if it forms part of an overall community service, be it in health, education or welfare.

International NGOs

The International NGOs which support services to people with disability should ***not*** be looked upon only as donor agencies which can provide financial assistance annually for an indefinite number of years. This would merely reinforce the dependency syndrome. Moreover, as stressed earlier, they no longer function in such a way, so to look to them in this light would be futile.

It is also worth noting that INGOs today tend to collaborate and co-ordinate with each other much more than they ever did. This ensures that there is no double funding and that the limited resources are maximised through pooling together whatever they have to offer. An excellent example of international collaboration and co-ordination is the *Partnership Committee of NGOs dedicated to the Prevention of Blindness and the Education and Rehabilitation of the Blind* which in

1994 had 18 full members, four associate members and ten with observer status. Their numbers are increasing.

As partners, INGOs can play important roles and assume certain responsibilities in furthering the cause of people who are disabled. For example, they could:

- Assist the local NGO in pioneering appropriate and cost-effective development programmes with, and for, people with disabilities. This can be done by providing essential initial funding, professional and technical support as necessary and the required equipment/materials if they are not available locally.
- Support public awareness campaigns to change negative attitudes towards people with disabilities and build instead understanding and acceptance.
- Guide organisations of, and for, people with disabilities in providing their governments with professionally sound advice for the amendment and/or enactment of legislation concerning the rights of people with disability and the implementation of the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations General Assembly Resolution 48/96, adopted in December 1993).
- Support programmes on the prevention of the causes of the various disabilities and their cure if possible.

Above all, INGOs should guide and assist their local partners in the monitoring and evaluation of programmes to ensure that there is real growth and an improvement in the quality of life of the individuals in the programme.

What is obvious is that INGOs should ***not*** take over local initiative and effort. Rather, in true partnership, they should be available to support the programme as, and when, necessary but having first thought through the plans thoroughly with the local NGO(s) and agreed on very clear terms of reference, including any financial commitments.

In the following sections information is given about possible funding agencies and the procedures required to access funds or technical support.

Types of Funding Agencies and Organisations

In addition to the numerous international and national NGOs which, as direct service providers also fund organisations of, and for, people with disabilities, there are several service organisations, such as Apex, Kiwanis, Lions, Rotary, Soroptomists and Zonta Clubs, which are usually very supportive of programmes by, and for, people with disabilities. Moreover they often fund projects aimed at preventing the causes of disabilities.

There are also a host of Foundations - both national and international - which have been established with very specific mandates. Some of them are open and sympathetic to sound social and educational programmes which are either disability related or which could include such programmes into their general mandate.

Inter-governmental development agencies, which have bilateral and multi-lateral relations between countries, are another potential source of funding, but NGOs normally have to get their applications processed and approved by their government, which then forwards the request for consideration.

In addition, there are the Specialised Agencies of the United Nations (UN), such as:

ILO, (International Labour Organisation),
UNESCO, (United Nations Educational, Scientific and Cultural Organisation) and,
WHO, (World Health Organisation).

It should be clearly understood that these and other UN specialised bodies are **NOT** funding agencies with the exception of UNICEF, the United Nations Children's Fund. However, technical co-operation can be obtained for an approved project which usually has to be recommended by the appropriate government department of a country. In addition, it is possible to call upon the competent Specialised Agency to execute operational projects which are funded by outside organisations such as an International NGO or one of the other categories of organisations referred to in the preceding paragraphs.

Criteria for Funding: In terms of funding services, it is important for the NGO asking for support to know the ***profile*** of the funding organisation to which a project proposal is to be submitted, for example:

- What is its main mandate, i.e. its aims and objectives?
- Is it just a funding body, or a developmental organisation, or a technical co-operation agency which does not provide funds?
- Does it consider only capital grants and, if so, only once, or annually, or after an interval of how many years?
- Is it a developmental organisation which also approves running expenses? If so, what sort of recurrent costs can be included?
- What are its priorities for funding given the nature of the specific project, its criteria for eligibility of a grant, and any limitations and/or conditions?
- What project proposal forms, if any, have to be completed and what additional information must be forwarded with the request

for funding, and in what format, before the application can be given consideration?

Funding Cycles: Likewise, from the timing point of view of an application, it is useful to know the answers to the following questions:

- When is its financial year?
- What is its funding cycle, i.e. does it consider applications every year, or every two years, or only once in three years?
- Should the grant requested be for only a year, or for two years, or more?
- By what date must the proposal be submitted?

Meticulous attention to all the above details, when preparing and submitting a project proposal, would ensure that the application is given careful and sympathetic consideration. The converse is equally true: a slipshod request would not make a good impression with the recipient organisation.

Compendia: Most developed countries and some agencies have compiled lists of organisations which specifically support programmes of, and for, people with disabilities in developing countries, or which do include such programmes within their general funding support. They are a useful resource when seeking funding for services. A few such examples are:

Listing of Organizations Working with Persons with Disabilities in Developing Countries, The Hesperian Foundation, P.O. Box 1692, Palo Alto, CA, 94302 USA.

Handbook on Funding and Training Resources for Disability-Related Services in Asia and the Pacific, United Nations Economic and Social Commission for Asia and the Pacific (ESCAP), United Nations Building, Rajdamnern Avenue, Bangkok 10200, Thailand

A Directory of British Development NGOs supporting Education in Asia, Latin America and Africa Published by Voluntary Service Overseas, 317 Putney Bridge Road, London SW15 2PN

*The Foundation Directory 1994 Edition,*and *Foundation Grants for Individuals,* The Foundation Center, 79 5th Avenue, New York, NY 10003

Directory of International Corporate Giving in America and

Abroad, The Taft Group, 12300 Twinbrook Parkway, Suite 520, Rockville, MD 20852.

Included as appendices to this chapter are a sample Proposal Form and Letter of Enquiry which have been taken from the Handbook produced by ESCAP (United Nations Economic and Social Commission for Asia and the Pacific). These are a useful guide for new NGOs.

Independence and Sustainability

Is it possible for an NGO in a developing country to attain independence and ensure sustainability of its programmes for people with disability? The answer is a clear '***YES***', in spite of the economic situation referred to earlier in this chapter and the numerous constraints with which NGOs are confronted, especially the self-help groups in developing countries.

In order for the funding of services to be adequate and continuous, several things have to be in place. If they are not, the NGO concerned should work towards them immediately. The conditions which follow are ***not*** listed in any prioritised order because they are all inter-related, but it is obvious that unless certain essentials are already in force, the rest cannot happen.

Ownership of the programme: NGOs which are ***not*** self-help groups must ensure that adults with disability and the parents of children who are disabled are at least part owners of the programme and directly involved in the decision-making process. The community too should be brought into the programme from the beginning. This is necessary for a number of important reasons:

- Unless there is direct involvement in, and support of, the programme by the people named above, true independence of the programme and its sustainability cannot be guaranteed.
- The commitment of those with disability, their families and the community should help to develop appropriate services which are needs-based and needs-led and which are also fully integrated into the existing infrastructure and life of the community right from the start.
- Such a partnership makes it possible for existing local resources - both human and material; no matter how limited they may be - to be tapped to the full. Such resources will remain available even after any INGO support is phased out.
- Although the disability itself does not automatically qualify an adult or the parents of a child who is disabled to play an active role in the decision-making process of an NGO, their inclusion on the Board would strengthen the organisation because of the

valuable insights they would be able to share from deep personal experience.

- Shared ownership within an NGO increases its credibility and political stature as a genuine service provider and pro-active advocate.

Leadership: Total commitment to the cause is an obvious prerequisite. At the same time, while an individual with charisma can play a key role in terms of attracting funding for services, there is grave danger in leaving the task to just one leader however effective and successful that person may be. A strong team approach is more likely to ensure:

- independence and sustainability;
- the pivotal role in spear-heading advocacy programmes and running essential services;
- good stewardship and accountability as a result of careful planning and proper budgeting, and ***not*** just good accounts;
- programmes which are based on real needs and which are cost-effective as well as appropriate.

Corporate image: In today's highly competitive world, it is imperative that the NGO develops a good corporate image. To achieve this, it has to have long term plans and clear objectives against which the success of its programmes can be measured and demonstrated. The leadership style referred to above, will result if the organisation is headed by a good cross-section of committed and knowledgeable professionals and public-spirited individuals who really believe in the cause, and become directly involved in it and not just lend their name to it. Such management will also go a long way in establishing the credibility and professionalism of the NGO which are so important if it is to enjoy a good reputation. This, in turn, enables it to attract funding both from the government and the private sector; nationally and internationally. The end result is an organisation that is independent and sustainable and one which commands respect in the country.

The Government: Ideally, services to people with disability should be an integral part of any public service because these men and women are found in every walk of life. Their needs should be automatically included in the government's national plans for health, education and social services, for example. If this is not the case, then the NGOs in the country should join forces to advocate for the inclusion of the needs of people with disability in all public programmes so that they are given the priority they deserve. This can be achieved only if there is the ***political will***.

Such inclusion would ensure sustainability and would enable NGOs to complement, and supplement government efforts within a ***National Plan of Action***. Wherever possible, the NGOs concerned should obtain government funding, however nominal and/or inadequate this may be. If this is not possible because of a government's severe budgetary constraints, then at least the government's 'blessing' of the NGO's programmes will go a long way in supporting efforts at raising funds locally and abroad.

Fund Raising

There are several essential elements which have to be borne in mind when mounting a campaign to raise funds for services to people with disability. Some main points for consideration follow:

- The dignity and self-respect of a person who is disabled must ***never*** be compromised.
- The secret of success is knowing how to persuade the viewer, reader or listener to make as generous a donation as possible, often to the extent of giving sacrificially to a worthy cause.
- The appeal should be cleverly packaged to present the need clearly and, in every case, it must reflect an honest requirement which is presented truthfully.
- It should appeal to the heart of the donor initially, but it should also be educational because an informed contributor is more likely to become a regular donor than one who responds emotionally only to a heart-rendering story.
- 'Strike while the iron is hot'. Be an opportunist on the look-out for the right time and the right occasion to launch the campaign, using the most appropriate dignitary and place for the ceremony.
- Look for windows of opportunity. For example if the government is running a campaign on saving the environment, ensure that your campaign incorporates and advances the theme.
- It is important to make the giving process as simple as possible so that people can respond easily and immediately.
- While it is important for the public to see the 'big picture' and to understand what the ultimate aim is, the appeal should have the effect of identifying a beneficiary in need with the donor, of impressing on the donor how important and significant his or her gift is and of making the donor feel pleased to have been able to help. The NGO is the 'conduit', the important and essential link between the two.
- In order to build up a donor base of regular friends of the NGO, a close relationship has to be developed with donors, particularly those who can make substantial contributions and who are likely to give regularly. This requires careful planning and handling, and time needs to be devoted to it.

- When the profiles of key supporters have been built up and good rapport has been established, the more targeted (specific) the appeal is, the more generous the contribution is likely to be.
- If specific appeals are being made to a particular profession, e.g. doctors, educators or lawyers, try to identify a distinguished individual of that profession, who is already a supporter or who is prepared to back the campaign, to make the approach.
- In addition to being the opportunist referred to earlier, try to be different and to present each appeal in a new way. NGOs can learn a lot from commercial advertising in terms of creativity and innovativeness. Study the psychology they use to launch a new product or to boost sales. Their one aim is to get more members of the public to buy more of their product. Is this not what fund raising is all about?
- Be prepared to spend some money on making the appeal attractive and eye-catching but the costs of doing this should be no more than ten to twenty percent of the projected gross sum which you are trying to raise.
- Do NOT use commercial fund raising organisations which take more in commission than what is given to the project.
- Provide for the future by starting an Endowment Fund into which donations to commemorate a birthday, wedding anniversary or death, are put and from which only the interest earned is withdrawn while the capital keeps increasing.
- Gifts in kind can also be encouraged, such as food and clothing, or people might give of their time for voluntary work.
- Always have the fund raising accounts audited by a reputable firm or by an individual from such a firm. He or she may be prepared to do this on a voluntary basis or at a nominal fee.

The golden rule of successful fund raising is to show personal appreciation. ***Never fail*** to say, 'thank you very much'!

Conclusion

In summary then, the following factors all combine to make the funding of services easier and more sustainable:

- A good corporate image,
- Developmentally sound and sharply focused aims,
- Transparent accountability and excellent stewardship,
- Appropriate, affordable and accessible services to children and adults who are disabled,
- Maximum use is made of available resources, both human and material,
- Commitment and professionalism,
- A team approach,

- Dynamism and innovation.

NGOs are in the happy position of being pioneers who can respond almost spontaneously to a need. As catalysts, they can demonstrate successfully to their government what can be done, at a relatively modest cost, to prevent the causes of disability and to improve the quality of life of individuals who are disabled. They can maximise resources and minimise costs by establishing close linkages and networking with others.

In all of the above, adults with disabilities and the parents of children who are disabled must play a key role in the planning, implementation and management of the services. In the final analysis, their total empowerment is the ultimate goal. To achieve this, they must be given positions of leadership and responsibility. In fact, INGOs and other national funding organisations should give serious thought to providing more direct funding support to self-help organisations in order to accelerate the process and correct the grave imbalance which exists in the equalisation of opportunities for people with disability.

The wise Chinese proverb has often been quoted: 'Give a man a fish and you feed him for a day. Teach him to fish and you feed him for life.' How true, especially in the context of the empowerment of people with disability. However, as service providers and in the context of funding services, please ***never forget*** two important assumptions without which so-called empowerment becomes mere tokenism:

* there must be 'fish' to catch; the more the better!
* the trained person with a disability is also *allowed* to catch the 'fish'!

Bill Brohier currently works for the Christoffel-Blindenmission/ Christian Blind Mission International (CBM/CBMI) as its Education and Rehabilitation Consultant for Asia, particularly in the field of blindness. Previously he was CBM's Regional Representative for 14 years and he concurrently held a similar position for Sight Savers International. In 1987, he became the first Asian to be elected President of the International Council for Education of People with Visual Impairments and is presently serving a second five-year term. In 1992 he was awarded the P.J.M. by His Excellency the Governor of Penang for outstanding service.

Contact Address

37, Jesselton Crescent,

10450 Penang
Malaysia

APPENDIX

Sample Letter of Enquiry

Requesting Organisation's name, address and date

Dear ....

I am writing for information on the possibility of funding assistance for a project that we have identified in collaboration with (*name of disabled group or community with which you intend to undertake this work or which you intend to serve*).

The project is concerned with (*give title or brief description of the project idea, including its objectives, expected activities, outcomes and estimated budget requirements*).

We would be grateful to know if your organisation would consider providing technical or financial assistance for such a project. If so, how could we apply for the needed assistance. Please provide us with the necessary application forms, if there are any.

Should you not be in a position to help us, we would be grateful if you could recommend other organisations that may be interested in our proposal.

With appreciation,

Yours sincerely,

(*name and position within the organisation*)

Sample Proposal Format

Requesting Organisation:

Provide the full name and address of your organisation.

Objectives and Activities of the Organisation:

Briefly describe the type of work you do.

Project Title:

The title should be brief and descriptive of the activities that the project will undertake.

Objectives of the Project:

State clearly and concisely what you expect the project will achieve. Objectives should be feasible and measurable. Do not make your objectives general or unobtainable. For example, do not say that you will create employment for all disabled people!

Need for the Project:

Describe the situation and the problem(s) which give rise to the situation.

Project Description:

Describe the activities of the proposed project. Activities should be linked clearly with your objectives. Detail what the project will do, who will do it, where it will be done, who will benefit from it and the time-frame for its implementation.

Evaluation:

Detail how you will assess if the project has been successful in achieving stated objectives. What criteria will be used?

Budget:

List in detail the types of things you will spend money on (e.g. staffing, travel, equipment) and the expected cost for each item. It is important that you specify the kind and amount of assistance and expertise requested from the external agency. Do not forget to list the contribution (both financial and in-kind) to be made by your own organisation.

16

Evaluation Based Planning for *Rehabilitation Programmes in India*

Maya Thomas and Maliakal Thomas

This chapter describes how the concepts of monitoring and evaluation in rehabilitation programmes were introduced into various non-governmental organisations (NGOs) supported by the Disability Division of ACTIONAID-India. Most of the literature on evaluation deals with the methodology and outcomes of evaluation, rather than the process preceding the evaluation. Here we attempt to delineate the process of attitude change that was brought about in the NGOs towards the concept of evaluation and describe how they changed from a stage of resistance to one of acceptance and active involvement.

What is Evaluation?

According to the World Health Organisation (WHO, 1981):

> *"Evaluation is a systematic way of learning from experience and using the lessons learned to improve current activities and promote better planning by careful selection of alternatives for future action. This involves analysis of different phases of a programme, its relevance, its formulation, its efficiency and effectiveness, and its acceptance by all parties involved".*

Another working definition proposed by Krefting (1994) states:

> *"Evaluation is the systematic collection, analysis and interpretation of information about the activities and outcomes of CBR programmes in order for interested people to make judgements about what the programme is doing and how it can be improved."*

In many instances, the words *monitoring* and *evaluation* tend to be used together or interchangeably. However we take ***monitoring*** to refer to a continuous mechanism of observation, recording and checking of programme implementation. ***Evaluation***, we view as a periodic exercise carried out during, or at the end of, a programme, to assess the worth and/or impact of a programme.

The data gathered for monitoring purposes are of value in an evaluation exercise. Both monitoring and evaluation have to do with inputs, processes, outputs, outcomes, impact and effectiveness, though with differing emphasis. Monitoring helps to follow-up and watch over while evaluation helps to take stock of a programme.

The Background

The field of rehabilitation is in an evolving stage in many developing countries, including India. Over the last decade in India, many programmes and approaches are being promoted by the government and by the NGOs, to reach the large numbers of disabled people in the country. The Community Based Rehabilitation (CBR) approach occupies an important position among the wide ranging activities.

There are two major reasons for the promotion of CBR. One is the availability of appropriate know-how for the care of disabled people in the community, and the consequent shift from 'professionals' to 'non-professionals' in community care programmes. An important advantage of this shift towards decentralisation is the availability of services for the majority of the population within a reasonable period of time and in a form that is acceptable to them.

The second reason for the promotion of CBR is the national commitment for universal provision of services and the shift from 'everything for a few' to 'something for everyone', (Murthy, 1991).

In 1990, the Disability Division of ACTIONAID-India began to actively promote CBR projects through NGOs in different parts of the country. Currently the Division supports 15 CBR projects based in rural as well as urban slums. These projects are managed by people from different backgrounds; some are disabled people, some are family members of disabled people, some are religious and charitable organisations, some are rehabilitation professionals and some are social workers. Most of the people do not have professional qualifications in the field of rehabilitation.

The CBR programmes encompass various components including prevention, medical rehabilitation, education, vocational training/income generation, social rehabilitation and awareness building (Thomas, 1993).

In the national commitment to, and in the promotion of CBR, it is important to keep in mind that rehabilitation is culture dependent, especially if it is to take place in community settings. It will be difficult to have a centralised plan, particularly in a country as diverse as India. A centralised national plan can only provide a framework. There has to be specific decentralised planning for service provision in accordance with local cultures.

In order to ensure that such decentralised programmes are effective, especially if they are carried out by non-professionals, it is necessary to equip the implementers of CBR with the skills of monitoring and evaluating their work. The relevance of the CBR approach has to be evaluated in each area and community. The only way to know that CBR benefits disabled people, their families and the wider communities is to continuously monitor and evaluate the different aspects of CBR programmes.

From the beginning, the Disability Division of ACTIONAID-India recognised the fact that CBR was in an evolving stage and that it had to be evaluated in its different contexts in order to study its impact. The Division started on the premise that monitoring and evaluation must be seen as integral parts of any programme. We believed that the projects supported by us, should develop the capability of integrating into their programmes procedures for monitoring and evaluation, and of using the results obtained for their own future planning. Our goal was to upgrade the technical skills of project staff so that they could introduce their own monitoring and evaluation into their programmes rather than have external evaluations mid-way through the programme.

In the initial stages, the NGOs supported by ACTIONAID concentrated primarily on service provision. Their programme planning did not include monitoring and evaluation as integral components. However, from ACTIONAID's point of view, the concepts of monitoring and evaluation of programmes were important and we had to persuade the programmes of their worth. It was not to be a centralised plan of monitoring and evaluation, but one that was done by the local programmes. The aim was to have monitoring and evaluation as integral parts of the programmes. Primarily to feed into the development and future planning of the programme and only secondarily for the purposes of the donor agency or other external bodies. The stages of the process through which we attempted to achieve these outcomes, are detailed in the following sections.

Phase of Negotiation

A situation analysis was carried out as a first step at the different partner organisations in order to assess their opinions and impressions of the concept of evaluation. Most NGOs were found to have resistance to evaluation for various reasons.

Many felt that they were too busy with programme implementation. Others voiced their ignorance and lack of skills to carry out evaluations. Yet another group cited the lack of financial and technical resources. Some resisted the idea because it came from a donor agency, fearing that adverse findings would affect future funding.

All this clearly pointed out the need for an attitude change towards evaluation and to promote its acceptance as important in programme planning and effectiveness. It was important to convince the NGOs that:

1. evaluation would address primarily their need and not the needs of external agencies;
2. evaluation could lead to better and more cost-effective methods of service delivery;
3. the funds utilised for evaluation could be recovered by ensuring that failures were minimised;
4. evaluation was not as difficult a process as they thought.

Phase of Passive Co-operation

One of the first stages in this process of bringing about attitude change was the starting of a newsletter to disseminate information on contemporary issues in rehabilitation.

ACTIONAID Disability News was started in 1990, as a biannual publication meant for concept clarification and highlighting of issues to be addressed in the field of rehabilitation. The newsletter was aimed at implementing agencies, donor organisations, policy planners, administrators and professionals involved in rehabilitation.

The rationale for starting the newsletter was this: projects are more likely to get interested in trying to innovate in their own programmes when they knew where they were in relation to the global situation in rehabilitation, and what they should do to catch up with what was going on. Once there are innovations in a programme, the implementers would also want to know how effective they were, thus generating an interest in evaluating the approaches adopted.

In the first year, the initial issues of the newsletter attempted to provide a holistic picture of the field of rehabilitation and its various aspects, including methods of service delivery, manpower training, development of technical aids, evaluation and research.

With the first few issues, there was a perceptible change in the NGOs, from active resistance against new ideas, to passive acceptance, though scepticism remained. A readership survey which was conducted at that time showed that a majority of the respondents read more than 75% of the newsletter (see ACTIONAID Disability News, 1993). The changes noticed in the NGOs supported by ACTIONAID included attempts at decentralised planning of programmes, more active promotion of community participation and examination of viable income generation activities as a contribution to the sustainability of programmes.

Phase of Active Co-operation

Evaluation and research in rehabilitation became the major focus of the information dissemination effort in 1991-92. It was a pro- active and planned effort with definite goals, though the ideas were consolidated through a democratic, bottom-up and consensual method.

The ACTIONAID Workshops for project holders of rehabilitation programmes had evaluation issues as the main topics for discussion. At these Workshops, key people from allied fields were chosen to sensitise the project holders to the need for documentation, monitoring, evaluation and research. This was done in a collective, democratic set-up with plenty of time for debate and clarifications. Some of the project holders who had been introspecting and experimenting on these issues were also invited to share their preliminary experiences and to make recommendations for future action.

By 1992, a consensus had developed in the project holders regarding the need for evaluation and research in their programmes. There was also consensus on the need for specialised technical inputs on these issues. Around the same time, two Symposia were organised on evaluation and research for a larger audience which included the project holders. This was an attempt to bring in experts in the field of rehabilitation, to share their experiences in evaluation and research and to identify critical issues for further research in the field of rehabilitation. The topics included the experiences of research and evaluation of the Government of India, UNICEF, one of the Indian institutes on disability, the 3D projects in Jamaica and the Disability Division of ACTIONAID. Arising from the discussions there was an agreement that research and evaluation were necessary to increase the efficacy of CBR programmes and that implementing agencies needed to be trained in operational research. It was also agreed that research should be specific and relevant to the given sociocultural situation (Prabhu, 1993).

The stage was thus set for spelling out ACTIONAID's strategies for documentation, evaluation and research in the supported projects (Pruthvish and Thomas, 1992).

Furthermore, the technical inputs requested by the projects were provided by bringing in a Programme Advisor specifically to co-ordinate issues related to documentation, monitoring, evaluation and research in CBR projects. Finances were also allocated for this purpose in the project budgets. At this stage, the NGOs had moved from the stage of passive acceptance to active involvement in specific assignments related to research. This was carried out in a collective manner, though some degree of scepticism continued to linger.

Throughout the stages in the first two years, the emphasis was on attitude change before initiating action. It was recognised that if evaluation was imposed on the projects without changing attitudes, they would become averse to the idea of evaluation. Further, any future attempts to evaluate programmes and to use the results to improve their efficacy would also fail.

Phase of Initial Action

One of the first assignments undertaken jointly by the projects and ACTIONAID was the identification and needs assessment of disabled persons in all the CBR programmes. The tools used to do this included questionnaires for

1) obtaining a community profile;
2) door-to-door survey for identification of disabled persons, and
3) needs assessment of identified disabled persons.

These tools were first tested in a pilot study in one of the CBR projects. After this, all the project holders met together and jointly field-tested the tools in another CBR project. After modifications and translation into local languages, the tools were used by the project holders for data collection in their respective projects (Pruthvish and Thomas, 1993). (Copies of the questionnaires are available from ACTIONAID India.)

By early 1993, all the CBR projects had completed the identification and needs assessment surveys in their areas. This exercise was neutral and did not expose any shortcomings, yet was useful to all projects in establishing baseline data in their respective target areas. Besides, the project holders were actively involved in the methodology planning, data collection as well as the analysis and interpretation of findings, thereby improving their own technical competencies in this neutral area of research.

With this exercise, the scepticism slowly disappeared. There was also some uniformity across projects in terms of the methodology adopted, which led to the possibility of compiling comparative data across different projects. The possibility of publication of the survey reports also acted as a positive reinforcement.

By this time, computerisation had been effected in most projects, improving their ability to document, store, analyse and retrieve data more easily. Much of the information disseminated through the newsletter was also absorbed by the projects. Slowly the need to learn more about evaluation and the need for more external expertise in this area began to come up from the projects. Evaluation was accepted by then as necessary and important but the projects lacked the know-how to carry it out in their programmes.

The need for some uniformity in the recording and information systems used by CBR programmes was also beginning to be voiced, in a tentative fashion. However even at this stage, the NGOs were not ready to examine their failures or to let others do so, nor were they concerned about preventing others from repeating their mistakes. It was therefore necessary to guide them towards this frame of mind, and to have them look at positive and negative aspects of programmes, in order to improve the planning and effectiveness of their own programmes and those of others.

Phase of Examination and Acceptance of Corrections

An on-going CBR project, located near Bangalore and supported by ACTIONAID, which was more open to evaluation was evaluated in late 1993 (Rajendra, Abraham and Thomas, 1993). This project started in 1990 and covers 140 villages with a total population of 100,000. In all, 825 persons with a disability receive help from the project, such as vocational training, medical rehabilitation, education, social rehabilitation and prevention.

A pilot methodology was evolved jointly by the project and ACTIONAID, to carry out the evaluation study on a small sample. In this effort, scientific accuracy was sacrificed in the interests of a simple and easy to comprehend methodology. The reliability may not have been high but the study was nevertheless valid because of the wealth of information that was generated and which helped to modify strategies for the future.

The major advantage of this study was that it helped to demystify the process of evaluation for the implementing NGO, convincing them that an evaluation was a relatively simple exercise which can be easily integrated into the on-going project activities. Besides, the results of the study helped the NGO to plan new strategies to overcome identified weaknesses and to prepare a better perspective plan for future programme implementation.

At this stage, the change in attitude to evaluation was from analysing neutral information to objectively analysing the positive and negative aspects of a programme. Secondly, from mere analysis of data, there was a shift towards utilising the data to modify strategies and to plan for the future. The summary report of the evaluation study was published in ACTIONAID Disability News for wider coverage and dissemination, so that others could also learn and be further motivated to evaluate their own programmes (Rajendra et al., 1993).

Phase of Collective Evaluation and Sharing Information

By this time, the implementing NGOs were ready to accept the need for evaluation and had largely overcome their resistance to the idea. In addition, they were willing to objectively analyse the positive and negative outcomes of an evaluation, and to utilise the results for future planning and action.

The time was then right for the introduction of standardised, internationally accepted methodologies of evaluation, so that different projects could be evaluated and the results compared. With this in mind, a Workshop on *Evaluation Methodology for CBR projects* was jointly organised by ACTIONAID and the UNDP Inter-regional Programme for Disabled People, Geneva. Participants were drawn from ACTIONAID supported CBR programmes and from Government sponsored projects.

The Workshop attempted primarily to address the question of

"How to Evaluate". Its objectives were to finalise a methodology for evaluation and to help participants to plan for the evaluation of their programmes. The "Operations Monitoring and Analysis of Results" (OMAR) software which has been developed by the UNDP for evaluation purposes was demonstrated at the Workshop (Jonsson, 1994). This was subsequently used in a modified form by two CBR projects although both found some of the computer software difficult to use.

The report of the pilot evaluation conducted earlier was also extensively discussed, particularly with regard to the process, the practical difficulties encountered and the outcomes. At the conclusion of the workshop, the participants agreed that the process of evaluation had been further demystified and that they were enthusiastic about planning for evaluations of their own programmes.

The Lessons Learnt

After five years, this is the stage we have reached. There have been some major lessons learnt in this entire exercise, as summarised below:

1. Any attempt at introducing monitoring and evaluation systems will be rejected if attitudinal changes have not been effected.

2. Improved availability of information to service providers can help in changing attitudes to evaluation.

3. Attitude change is brought about more easily if implementing agencies are able to see evaluation as of some direct benefit to themselves.

4. Though lack of time and money are often cited as reasons for resistance to evaluation, they may not be the major reasons. A major cause of resistance at the project level is reluctance to expose failures.

5. Methods of monitoring and evaluation are not as simple as the implementing agencies would like them to be, though ACTIONAID had thought that it would be simple and easy to introduce them at the beginning of the exercise.

6. The technical upgrading of research skills in the programmes is often necessary before local personnel can take up evaluation on their own.

7. Some aspects of monitoring/evaluation are easy to introduce into programmes, while others are more difficult. Quantitative indicators, such as prevalence rates and coverage of services are easily obtained

but qualitative ones, such as changes in the quality of life and the efficacy of interventions, are more difficult.

8. Measures of disability which are easily observable and quantifiable and are culture-free, can be easily introduced into a programme, e.g. questions relating to mobility: does the person stand, sit, walk with/without help? Such measures can also contribute to the evolution of standardised evaluation methods.

9. However the measurement of handicaps, which is mostly culture dependent and not easily observable or quantifiable, are generally difficult to introduce into programmes, and they cannot be standardised across projects. These include measurement of acceptance by the community and self esteem of the disabled person. Resistance from projects will be greater if these measures are introduced in the initial stages.

10. It may be preferable to have an independent and skilled research team to work on culture dependent and qualitative parameters of evaluation, using small samples drawn from the projects, rather than getting the projects to do this sort of work on their own.

Future Plans

In the next stage of our work, it is proposed to develop further the idea of evaluation and research, with the objective of improving programme effectiveness. As part of this work, ACTIONAID and the International Center for the Advancement of Community Based Rehabilitation (ICACBR) of Queen's University, Canada, jointly organised an Asian Regional Symposium on Evaluation and Research in CBR. This brought together the viewpoints, experiences and information on research and evaluation in CBR from different parts of the world.

The intention was to stimulate implementing agencies to move from the broad areas of evaluation of overall programmes, to take up intensive research pertaining to specific programme components that will further improve programme effectiveness. To achieve this, it is also proposed to bring in technical expertise, both from within the country and from outside, to help local implementing NGOs upgrade their research skills.

It is also proposed to set up a CBR research team for the purpose of continually studying CBR in its different aspects and to utilise the results obtained to modify future programme strategies as well as to feed into national and international level policies and planning in rehabilitation.

Through all these efforts, we expect the following outcomes.

1) Implementing organisations would develop a positive attitude towards monitoring, evaluation and research,

2) They make monitoring, evaluation and research an integral part of their work without difficulty,

3) These organisations will move towards evaluation based planning and base their future programmes on the results of their monitoring and evaluation efforts, and

4) They would share their experiences with others in the field and thus contribute to policies and planning at a more global level.

The entire exercise of introducing evaluation based planning in rehabilitation started in a small way, with emphasis on the whole process being carried out by the projects themselves. Special care was taken to ensure that attitude change took place prior to action and to involve projects early in the process, rather than imposing ideas on them from outside.

The ACTIONAID India Disability Division helps other organisations interested in the evaluation of their programmes in India and elsewhere. The support includes:

- the supply of background materials and literature,
- arranging exposure visits to projects which have been evaluated or which are in the process of undertaking evaluations,
- invitations to participate in workshops on evaluation and research,
- and in some instances, project staff can be involved in the process of evaluation of a project.

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Maya Thomas is an executive of ACTIONAID India and holds the position of Director of the Disability Division; a post she has held since its inception in 1988. She has a doctorate in clinical psychology and is an associate member of ICACBR, Queen's University, Canada and foreign corresponding member of the American Academy of Cerebral Palsy and Developmental Medicine.

Maliakal Thomas is a Senior Psychiatrist in Manipal Hospital, Bangalore, India. He assists ACTIONAID as the editorial advisor for 'Disability News' and also in research and evaluation. He is on the governing body of Community Health Cell, a unique Indian NGO which is involved in the development of community medicine.

Contact Address
ACTIONAID - India,
P.B. No.5406,
No.3, Rest House Road,
Bangalore - 560 001, India

17

Changing CBR Concepts in Indonesia: Learning from Programme Evaluation

Handojo Tjandrakusuma, Douglas Krefting
and Laura Krefting

CBR programmes are founded on basic ideas or concepts that vary significantly between countries and organizations. These ideas and concepts change through time as new information is obtained. Often trial-and-error experiences prove that the initial ideas were wrong. One of the best ways of examining the effectiveness of CBR programmes, and the concepts on which they are based, is through evaluation.

This chapter draws on our experiences in Solo, Indonesia at the Community Based Rehabilitation Development and Training Centre (CBRDTC) to describe a process where changes in programmes and concepts have resulted from evaluation. This will hopefully help others to learn ways to change their own ideas, concepts and CBR programmes.

CBRDTC is a not-for-profit, non-governmental organisation (NGO) that is part of Yayasan Pembinaan Anak Cacat (YPAC), which is the Indonesian Society for the Care of Disabled Children. CBRDTC's mission statement is:

> *Improving the quality of life of people with disabilities in their own families, communities, and countries by developing, implementing and sharing knowledge about community action programmes that focus on disability issues.*

CBRDTC is primarily an applied research and development organisation who, in order to learn how to do CBR, has established CBR community development projects in Indonesia (Central Java and North Sulawesi) and Bangladesh.

Other facets of their work includes the production of training manuals and organising international workshops for CBR initiators.

Their work is funded on an individual basis by a number of different international donor organisations while funds for core operations are raised locally.

The chapter is divided into four main sections.

In Section 1 we present a summary of the evaluators' understanding of what CBR was and could be. This provided the 'standards' against which the projects were then judged.

Section 2 describes the formal evaluation process which was used to systematically obtain information about the outcomes and results of four CBR programmes started by CBRDTC in Central Java.

In Section 3 we describe the concepts on which CBRDTC's new CBR programmes are based. We explore some of the hidden problems that were brought to light by the evaluation and examine their underlying causal factors.

Finally in Section 4 the general conclusions reached as a result of this complete evaluation process are described.

First though a word about the evaluation team. This consisted of personnel from Yayasan Indonesia Sejahtera (YIS), an NGO that works in the field of community development in Indonesia, along with staff from the Faculty of Rehabilitation Medicine, University of Alberta, Canada. The University had helped to develop the first Indonesia Academy of Occupational Therapy and had gained an understanding of disability and rehabilitation in the country. Part of their Canadian aid funding had been ear-marked for CBR and they chose to use it in the evaluation of CBRDTC's projects in Central Java. The University also selected the appropriate Indonesian evaluation consultant, thereby ensuring that this partnership was completely independent of CBRDTC.

Section 1: Evaluators' Understanding of CBR

Before beginning the evaluation, the team had to first learn what CBRDTC's concept of Community Based Rehabilitation was and what it could be. The following information describes the evaluators' understanding of CBR after they reviewed existing documents and they had interviewed staff and others involved in the development of the CBR field programmes.

The basic CBR concept underlying the implementation of the field programmes was to change the community's perception about the problems; the socioeconomic, sociocultural, medical and psychological problems of people with disabilities.

CBR sought also to encourage the community to provide an atmosphere in which people with disabilities could solve their problems and improve their lives. The larger idea behind it involved giving authority to community members to collectively make decisions about their future.

The seven key strategies that were considered necessary for CBR implementation were:

1. **Integrating CBR into Community Activities:** In order to minimize the funding required, CBR activities should be integrated with existing services wherever possible.
2. **Entry Point:** The best way to enter a community was through demonstrating how it was possible to help people with disabilities in a way that motivated the community to get

involved from the beginning.

3. **Maintenance:** It was important to encourage community members to take responsibility for CBR's continuation.
4. **Realization of Goals:** It was impossible to simultaneously achieve all of the goals CBR set for itself. But success in early detection of disabilities was an immediate CBR priority because it would reduce future demands on related services.
5. **Spectrum of CBR Activities:** The types of *community activities* that should be included in the CBR field projects are:

- Helping an existing community organization develop activities to improve the welfare of people with disabilities.
- Financing field activities.
- Encouraging proper attitudes among people with disabilities.
- Undertaking disability prevention.
- Providing home treatment.
- Detecting and reporting disabilities.
- Conducting community training.

The *Rehabilitation activities* that could be conducted by specially-trained community members were thought to be:

- Simple rehabilitation, such as walking exercises, making tripods, and explaining their use.
- Providing information and motivation, as well as illustrating various types of exercises to community members.
- Organizing continuity of service.
- Monitoring, recording and reporting.

The *Supportive activities* which health care professionals or institutions could provide would include:

- Supporting the technical and managerial aspects of CBR services.
- Providing referral services for medical intervention and complex medical rehabilitation services.
- Organizing and conducting research activities, developing CBR implementation, etc.
- Developing a general understanding of the health aspects of disabilities.
- Teaching of disability prevention.

6. **Economic Aspects:** CBR did not limit itself to vocational rehabilitation, but took income generation as one of its starting points. It was envisaged that the activities related to the economy and to income generation should include:

    - Supporting the family economy.
    - Training by local community members in business skills.
    - Encouraging new initiatives in the village economy.
    - Training in micro-economy management.
    - Developing effective marketing techniques.
    - Initiating a cooperative economic enterprise.
    - Providing local jobs for people with disabilities.

7. **Involving People With Disabilities In the Programme:** It was envisaged that community members and people with disabilities would all be involved in the managing of CBR so that they could become the programme's subjects, not simply its targets.

Section 2: Evaluation Methods

Data were collected through a series of interviews (both informal and guided) with key personnel and through direct observation of all CBR activities. Detailed sampling techniques focused on two villages in each regency. The data were validated by:

- **Triangulation:** Data were collected from different people and from different perspectives. Information from one source was thoroughly compared with information from other sources.
- **Key Informant Review:** Key informants were asked to review the information in the draft report.

In order to understand CBR's strengths and weaknesses, the evaluation considered the following key issues:

- The number and diversity of field activities in relation to the programme's overall goals.
- CBR's effectiveness as perceived by all those involved with it and who were affected by it.
- Village volunteer training activities in the community.
- Existing community mechanisms relating to CBR programmes.
- The extent and nature of community knowledge of, and participation in, CBR at the village level.
- The community's perception of CBR's achievements.

- The extent of government awareness of the CBR approach.
- Whether an NGO such as CBRDTC was better equipped than a government development project to become a catalyst for community-based development.
- The determination of objective indicators for future research.

The main model of analysis was interactive, where the activity of data collection interacted with the three main analytical techniques (data reduction, data display and conclusion drawing). This model was applied to each case or unit of analysis.

Evaluation Results

Evaluations were carried out in four regencies (districts) in the province of Central Java where CBR programmes had been established by CBRDTC. The findings for each regency are summarised in separate sections. Further details are available (see Note at end of chapter).

1. BANJARNEGARA REGENCY

Background: The 1980 census revealed 1056 people with disabilities in the regency's 278 villages but data obtained later from social workers increased that number to 4,134. Early detection in 4,000 children under the age of 5 revealed that 142 (3.43%) had disabilities. To coordinate all activities for people with disabilities, the BANJARNEGARA local government founded the Supervising Board of Rehabilitation for People with Disabilities which involved 30 institutions and offices related to disabled people.

CBR Programme Initiation Process: The Rehabilitation Board soon after its founding, cooperated with CBRDTC to draft a plan of activities, known as the Disabled Rehabilitation Development Project. The plan called for activities in 10 villages in four locations: two valley sub-districts and two in the mountainous area.

Evaluation was conducted in two valley villages which became the project locations between 1986 and 1989. Initially CBRDTC was dominant but its visits then decreased, the last one taking place in June 1990. This influenced the development of the programme and in one of the two villages selected for the evaluation, the CBR programme came to a halt after June 1990.

The training given to local volunteers created a local work force to nurture community enthusiasm and to undertake both the initial census of people with disabilities and the early detection efforts. The training was also to enable the volunteers to spread the idea that people with disabilities were not simply the responsibility of the government.

In April 1986, a CBR team was founded in the village of Medayu. Funds were derived from the re-sale of community-donated rice and from sources such as divorce fees paid to the government. But according to both the village head and a village volunteer, once the initial project finished, the activities stopped.

In two other valley villages there was training in early detection. Yet the head of one village said he had never heard of CBR and that none of its activities were carried out there. There was not a single document about CBR in the village office.

The Rehabilitation Board's activities at the sub-district level were similarly unorganized. In addition, the CBR team felt it had little involvement in the project because CBRDTC went directly to the field without coordinating with the subdistrict CBR team. This direct handling from CBRDTC in Solo meant that once the project was finished there could be little coordination among the village and subdistrict teams and their supervisors in the regency. It was also clear that the people in the community, who it was hoped would handle the treatment of people with disabilities, could not do so without outside assistance.

Present Condition of the Programme: Although the CBR programme ran well between 1986 and 1989, informants said it ceased to function after that point.

Conclusions: During the term of the project, trained village volunteers performed as expected.

Community leaders and village volunteers thought the programme dealt effectively and quickly with disabled people. On the other hand, programme planners and government officials thought the programme was ineffective.

CBR was handled by only one institution and did not fully involve the community. People became involved because of the village head's decree, without necessarily knowing what CBR was. They were volunteered rather than volunteering through their own interest.

Government involvement needed improvement. Many Rehabilitation Board members neither knew about nor became involved in the programme. There was little coordination between the levels of authority.

2. SUKOHARJO REGENCY

Background: Sukoharjo Regency's 676,482 inhabitants live in 167 villages. According to 1989 statistics, there were 5,462 people with disabilities in the regency; 0.8% of the population. Of those, only 1,938 (0.3%) had been medically or vocationally handled by either government or non-government agencies.

Programme Initiation Process: Discussions between CBRDTC, local governments and the District Head led to the choice of three villages as CBR try-out areas. Each had a great number of people with disabilities, and in each the village heads and staff from the Women's Family Welfare Movement were already active in a variety of development activities.

The CBR team, formed after a 1987 decree from the subdistrict head, involved subdistrict agencies and the Departments of Education and Culture. The village volunteers worked in their communities with funding and direct supervision from CBRDTC. Between 1987 and 1990, 17 (14%) people with disabilities in the three villages underwent medical rehabilitation while 36 (29%) underwent thorough medical, educational and vocational rehabilitation.

Financial contributions for CBR came from a variety of sources: local communities in which people with disabilities live; the families of people with disabilities; related agencies such as the district government, the Department of Social Welfare and the Department of Health and from private sector sources such as CBRDTC and the Disabled Children's Foundation. Although increased community funding was a goal, CBR activities still depended on outside sources (in this case CBRDTC). Related institutions had little identifiable role, simply following the recommendations of the implementation team.

There was a great degree of highly dedicated village volunteer involvement in the implementation. All levels of government acted to support their work but it was felt that coordination between various government sectors could have been improved, especially at the regency level.

Present Condition of the Programme: The rehabilitation statistics reported above, led to the start-up of CBR activities in a further twelve villages. Activity in the three try-out villages, however, decreased significantly. Between 1990 and 1993 only one person was medically rehabilitated.

Conclusions: The work done by the village volunteers in early detection and fund-raising was successful. But, because of the limited nature of the funds that came from the community (even if fund-raising was successful) the desired level of rehabilitation could not be undertaken without the involvement of CBRDTC or other external financial resources.

In general, those involved in CBR at all levels agreed that the programme was effective. The Government was enthusiastic because the private sector had become involved. Informants using three different yardsticks (the level of community involvement, the amount of funds raised and the village volunteer activities) all stated that the programme ran well during the try-out phase. Doubts about the programme's sustainability seemed borne out by the later disintegration of coordination and the drying-up of funding.

Village volunteer activities were varied and, on the whole, effective because they were conducted by people already involved in community health activities and because they were incorporated into existing health programmes. Community involvement was good, especially in so far as it marshalled the support of existing community agencies for CBR activities. However, it was felt that community involvement in CBR activities had decreased because CBR was fully understood only by a few members of the community, most notably those actively involved in it.

At the institutional level, the understanding of CBR was weak. At the regency level, some government employees cited the lack of a standard curriculum as an obstacle. There was a better understanding at the subdistrict level, where people were more intimately acquainted with the day-to-day work of the programme.

CBR activities declined for a number of reasons, among them the loss of the person who was the key motivator for the programme and a reduction in the involvement of related institutions and the private sector.

Suggested Improvements: In order to increase the probability of success in developing CBR programmes in the future, interested parties at both the regency and sub-district level, among others, made the following suggestions:

- The roles and functions of relevant institutions needed to be clearly defined and a routine meeting schedule should have been established.
- Private sector, non-organizational funding should have been more energetically pursued.
- There was a need for more skilled and qualified field workers at the village level.
- The mass media should have been employed to spread information about CBR across Indonesia.
- CBRDTC should have allocated more funds for the management and motivating of teams.
- Top leaders should have offered more encouragement and provided better examples for those below them.
- There should have been more monitoring of people with disabilities after they left the programme.

3. SRAGEN REGENCY

Background: Sragen Regency's 207 communities (all primarily agricultural) were found to contain 44,707 children under the age of five. Of these nearly half had undergone screening for the early detection of disabilities at over 1,000 of the regency's 1,136 Integrated Health Service Posts. It was found that 182 of these children (0.8%) had some form of disability. The early detection programme, which later developed into the CBR programme, was coordinated by the Women's Family Welfare Movement which dominated CBR implementation in the regency. Both local government and CBRDTC became involved when it developed into a full CBR programme.

Programme Initiation Process: Four villages were chosen as try-out areas, in part because all were easily reached from the regency capital. Evaluation of CBR programming took place only in two villages; those with the highest number of people with disabilities.

Early detection activities in the regency took place between 1987 and 1990, following a CBRDTC training attended by people from a variety of relevant agencies.

After training, early detection activities were undertaken with the full support of the District head and the Women's Family Welfare Movement. The latter organisation trained village volunteers at the subdistrict level in early detection techniques, conducted early detection every three months at the Integrated Health Service Posts and sent those found to have disabilities to the Community Health Centre for examination and classification. Data about disabilities was recorded at, and reported to, all levels of government.

Present Condition of the Programme: There are currently no CBR programme activities being carried out in this district. All activities ceased as soon as CBRDTC withdrew from the programme area.

Conclusions: According to an informant, 61 people with disabilities were detected in one village in 1990 and 77 in another. Due to limited funds from the regency and from CBRDTC, the number of people rehabilitated medically, educationally or vocationally was very low. Those who were treated were handled by the government sector; that is, sent to institutions related to their disabilities.

After data was compiled and reported, and people with disabilities were examined, there was little effort on the part of the community members or the CBR team to impart skills to them. Only skilled village volunteers carried out the disability detection and intervention activities, because untrained village volunteers were afraid of making mistakes. Trained village volunteers found they still had problems motivating and organizing the community. Many parents of people with disabilities still felt ashamed of their children.

Among community leaders and village volunteers, there were differing opinions about the programme. The head of the CBR team in one village felt that CBR was an effort to give people with disabilities the same status as people without disabilities. The secretary of CBR activities in another village felt that CBR was an effort by non-disabled people to help people with disabilities enhance their self-image. A subdistrict official understood CBR to be an effort to motivate community members to take part in the handling and treatment of its people with disabilities.

Village volunteers were involved in the programme but village leaders were often otherwise occupied with their own duties. Agencies involved in CBR handled only those aspects of the programme relevant to their previous duties. This suggests that the division of tasks for CBR team members was not explicitly stated.

Community members in general, and people with disabilities in particular, did not receive much benefit from the programme. The level of medical rehabilitation was low, while educational and vocational rehabilitation was not carried out at all.

From the point of view of services received, Institutional Based Rehabilitation was superior because people with disabilities were placed in institutions with complete facilities. CBR, on the other hand, suffered from poor funding and a consequent poor level of service. On a social level, CBR was considered superior because people with disabilities could stay with their own families.

4. WONOSOBO REGENCY

Background: Most of the 670,000 people in Wonosobo's 263 villages are farmers whose income is low by Central Java standards. In 1990, the Regional Office of Social Service reported 2,182 people with disabilities, mainly in rural areas. Few of them had been served by any related programme.

Programme Initiation Process: CBR teams at all levels started their work after a training session in November 1988. The CBR teams visited villages and Community Health Centres, usually accompanied by Social Service officials. Their initial commitment, and that of CBRDTC, were not matched by a commitment from other institutions.

Wonosobo's CBR programme started in 1990. A series of meetings was held, during which relevant Wonosobo institutions and leaders were addressed by CBRDTC and by those who had implemented CBR programmes in other regencies. Three villages were later selected as try-out areas.

CBR village volunteers, carrying out early detection discovered 181 people with disabilities. The detected disabilities were reported to the Community Health Centre. Of the total, five persons were rehabilitated; four medically and one vocationally.

Present Condition of the Programme: The CBR motivator team conducted public education sessions with the village volunteers, a process enhanced by periodic visits by a CBRDTC team. At the beginning of the programme, this and other activities ran efficiently, even though lack of equipment was a chronic problem. Over time, however, activities slackened.

Conclusions: The CBR programme was introduced to participants at all levels, using discussions, information meetings and comparative studies. However, the involvement at all levels was not uniformly intense and this greatly influenced the programme's success.

Only one coordination meeting was held, seven months after the issuing of the decree calling for the formation of the CBR supervisor team. Supervisor team members felt insufficiently informed about their positions on the team, even though some had been intimately involved in the programme's start-up stage. Misunderstanding arose about an appropriate level of involvement. Some personnel from related government agencies, for instance, still felt that primary responsibility for the programme should belong to the Department of Social Welfare. Another team member, who had been asked to provide instructors and conduct training for people with disabilities, was nonetheless entirely unaware that the government agency for whom he worked, was involved in the programme.

Because the team members responsible for motivating the community were expected to have more contact with the community, more preparation was made on their behalf. They held discussions and informal meetings, and helped to introduce the CBR idea to the community. As a result, they had a significantly higher degree of understanding about CBR and their roles in it. Yet they faced some of the same stumbling blocks encountered by the supervisor team. Some agencies were more active than others. Also, there were widely differing perceptions about the programme among the team members.

Despite their small size, the village-level implementation teams had more success in understanding the programme and increasing community awareness. Some members fully comprehended CBR as an effort to make people with disabilities fully self-supporting. Others continued to see CBR only as an attempt to medically rehabilitate people with disabilities.

The only activities included in the outline of the CBR programme that were never carried out, were the programme evaluation and the educational rehabilitation. These activities occurred only at the preparation stage and at the programme start-up. The only activities that remained were early detection and the collecting of funds, which were considered inadequate for the programme's needs.

So far, there has been a noticeable attitudinal shift in the community. Some have begun to see disability not as a curse, but as something that could happen to anyone. People with disabilities have become more a part of daily life. Some community members now employ people with disabilities or purchase products made by them. But the community members saw CBR as involving little more than early detection and medical rehabilitation. It was more difficult to change the attitudes of people with disabilities themselves, as well as those of their families.

The CBR mechanism, from early detection and identification through to the eventual handling of the cases by the Community Health Centres or by CBRDTC, took a long time. Activities were constrained by lack of funding and lack of equipment. Technically, most of the village volunteers were capable of performing the tasks for which they had been trained. They could do early detection and give recovery training to people with disabilities, both without awkwardness. But they felt they had not been adequately prepared for activities that involved informing and motivating the community, both of which are important for the programme's success.

It was clear that all related institutions had to be consistently involved in CBR if it was to reach all its short- and long-term objectives. This did not happen, in part because leaders delegated responsibility to unprepared subordinates. It was also clear that the intervention programme did not fully succeed in making people with disabilities self-supporting. This suggested there were still weaknesses in CBRDTC's attempts to prepare people with disabilities for full economic participation in the community.

Evaluation Conclusions

Village volunteer activities, such as early detection and intervention, and the collection of funds, were the most consistently maintained activities in the CBR programmes. Village volunteers still report their findings to the villages.

Government staff from related institutions found the programme largely ineffective. They felt that medical rehabilitation had been insufficient and the CBR mechanism in general had not been implemented.

The programme was found to be most effective while still in the try-out stage. When CBRDTC staff were no longer involved, CBR activities declined. This suggests that the community never felt it owned the programme or had responsibility for developing it. In part, this was because village volunteers were not given the kinds of training that would keep the programme healthy.

Community members had few opinions about the programme because they knew little about it and had not been noticeably involved. Village volunteers felt the programme was effective in so far as it led to better early detection of disabilities.

Although village-level programmes still existed, at the regency level, related bodies carried out their own programmes with little coordination.

Community knowledge about CBR, even among those involved in it, seemed limited to the feeling that CBR was an attempt to serve only people with disabilities. Most people saw CBR as an attempt to help people with disabilities live more normal lives. Negative perceptions were held by those who did not yet understand CBR's aims. The highest degree of understanding about CBR came from the staff of the local government welfare office. Elsewhere, awareness was lower.

People living in districts surrounding the project areas, especially in Sragen regency, expressed a desire for CBR programming but activities were limited to early detection, without formal organizing along CBR lines.

CBRDTC, an NGO, had some advantages over government institutions for carrying out CBR programmes. It is more flexible, better able to tap a wide variety of funding sources and can work more effectively at the grassroots level to help people develop an awareness of sustainable development.

In general, it can be said that the sequence of CBR activities was in line with the strategy outlined in the CBR concept. Good use was made of parallel activities in the local Integrated Health Service Posts.

There was misunderstanding about the role of the regency-level supervisors. They, not the community, were expected to develop the programme, an idea that ran counter to the CBR philosophy. This misunderstanding had a great impact on the sustainability of the programme.

The programme's biggest problems concerned funding and community support. Most efforts to collect public funds resulted in only small amounts of support. Alliances with other NGOs in more imaginative funding campaigns, and a more thorough canvassing of private sector sources, were felt to be necessary.

The decrease in field activities tended to limit the programme to its medical aspects and stopped it short of its ultimate goal of encouraging both financial self-sufficiency in people with disabilities and an overall community development.

Another important problem was thought to be inadequate monitoring and evaluation of the programme by CBRDTC.

A final point of discussion involved the top-down nature of CBR implementation. Most of the efforts on the part of the CBR organisers seemed aimed at forming structures removed from the overall communities. A more appropriate approach would have been a participatory approach that allowed ideas and perceptions to rise up from the bottom.

In conclusion, the problems associated with CBR implementation in the four regencies included:

- Decreasing intensity of programme activities;
- Lack of organizational coordination at the subdistrict and regency levels;
- Limited knowledge and understanding about CBR;
- Insufficient development of people's attitudes, knowledge and skills;
- Insufficient community funds available for CBR;
- A limited number of services available for people with disabilities;
- The passive role of people with disabilities;
- Insufficient monitoring and evaluation.

Recommendations

The following suggestions were offered by the evaluators, although some may present problems when they are implemented in the field that make them inappropriate or in need of rethinking.

- There is a need for a guide book to CBR implementation, which could be divided into three parts:

  - ☐ *Part 1: A guide for organizations to be used by agencies at the subdistrict and regency levels.* It would include information on CBR concepts and strategies, suggested organizational structure (including the number, roles and responsibilities of involved personnel) and a working mechanism for coordinating the various teams, with job descriptions and suggested activities for all participants.
  - ☐ *Part 2 - A guide for village volunteers and all village-level participants.* This section should include job descriptions for village volunteers, village office staff and community leaders and suggestions for fund raising.
  - ☐ *Part 3 - A training manual.* The information in this section should be geared towards encouraging the development and passing on of skills without the need for a specific team of outside experts.

- A complete system for monitoring and evaluating CBR activities in a community should be created. It should include:

  - ☐ A system for regular registration and reporting.
  - ☐ Strategies for reporting feedback.
  - ☐ A strategy for internal programme evaluation.

- CBRDTC needs to develop liaisons with other NGOs involved in community development to exchange information and encourage mutual support. It is not enough for CBRDTC to work simply with government institutions or with the local Health Service Posts.

- Some consideration must be given to modifying the implementation strategy to allow for more bottom-up planning, that is from the village level, rather than coming down from the subdistrict and regency levels. Well-known techniques of "Participatory Rural Appraisal" might be useful in this regard.
- Training should be more frequent and better material should be developed for that training.

- A firmer organization is needed to encourage the proper training of CBR staff. For instance "field care-takers" should be created to oversee implementation, and further staff should be appointed to handle monitoring and evaluation.

Section 3: Changing the Concepts of CBR

This evaluation indicated that there was something seriously wrong with the CBR concept proposed by CBRDTC and the reality of the evaluation came as a shock. The outcomes were not at first accepted or acknowledged.

Previously evaluation at CBRDTC was simple and very informal. Usually villagers would make casual comments or tell stories to visitors who would pass them on to the staff or sometimes the staff would make casual comments about what was happening in the field. These informal evaluations were not based on a systematic process of data collection which would allow managers to determine what objectives were not being met and the changes in concept which might help to meet these objectives. Nevertheless these informal evaluations did lead to the formal evaluation.

Of particular concern was the large difference between the description of what the evaluation team had learnt CBR was supposed to be (as summarized in Section 1) and what had actually been done in the field (the reports by programme recipients given to the evaluators and summarised in Section 2). To address this, a secondary analysis was necessary in terms of the overall work of CBRDTC. This would identify any intangible benefits that would not be apparent at the local level where the first evaluation had been carried out. The main conclusions reached are described below.

After completing this, the changes needed in CBRDTC's concept of CBR, and CBR programme design, could be considered so as to address the major recommendations of the evaluations.

Putting evaluation into context

The development of CBR programmes needs to be looked at in the larger context of the overall development of CBR itself. CBRDTC develops CBR programmes in order to learn how to do CBR. Implicit in this major objective was the secondary objective of sharing what was learnt with as many others as possible, mainly through international workshops which started in 1992 and international networks of organizations to which CBRDTC belongs.

One example of the changing of CBR concepts in the greater context is the development of CBR by the World Health Organization (WHO). Because CBRDTC were testing their concept in the field programmes, they were able to make some contribution to bringing about a changed point of view. Their major focus was advocating that CBR should be seen as a community development programme rather than as a rehabilitation programme. In 1994, WHO changed their definition of CBR to a *"...strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities"* (see Note 2).

Another indicator of CBRDTC's influence is the inclusion in the current national, five year plan, by the Indonesian Department of Health, of CBR as a national strategy for providing rehabilitation assistance at the community level. CBRDTC staff are often requested to advise the Department of Health on community level rehabilitation problems and have frequently used these opportunities to advocate for CBR as a national strategy.

Implications for the CBR Programmes

In this section we attempt to analyse some of the underlying causes for the problems identified in the evaluation, and to outline the changes in concept or process that have been adopted to overcome them.

Aims of CBR: The evaluations teams's description of the concept of CBR was fairly accurate. However there were several areas where the description did not match with CBRDTC's concept. The most important aspect of CBRDTC's concept that was not considered by the evaluators was the idea of trying to find a way of doing CBR on a large-scale; the macro approach.

Also a comparison of the evaluator's description and what they found in the field, indicated that there was an even greater difference between what was being said and what actually was done. Subsequent discussions with some of CBRDTC's staff indicated that this mismatch happened because not all staff were aware of the concept being promoted. In a few cases, staff members did not agree with the CBRDTC concept and had described to the evaluators what they thought CBR should be, rather than the CBRDTC concept.

In order to try and solve this problem, CBRDTC tried to get more of the staff involved in programme design. Another approach was to replace some of the staff who would not change their ideas. This difference in opinion is, to a certain extent healthy, and is still present in CBRDTC. However when the difference is too great, it decreases the overall effectiveness of the organisation and the programme.

Latterly, CBRDTC have found that this emphasis on focusing on the community, while very important, is not sufficient. They have recently changed their concept to include a double focus which first emphasises the focus on community, in terms of changing the environment in which people with disabilities live, and second, emphasises the focus on people with disabilities themselves, in order to decrease the effects of their impairments on their lives and on those who support them (i.e. families) thereby minimizing their handicaps.

Government Involvement: One of the major problems indicated by this evaluation was lack of coordination with and/or involvement of government employees. The underlying problem is government employee job descriptions and rates of pay. At the community level, most government employees are under-paid and over-worked. To expect them to take on extra work, without additional pay, at the request of an NGO or the community is unrealistic. In some cases, it has been found that they will not attend CBR coordination meetings unless they are paid transportation money. It seems that achieving the levels of cooperation required to make this type of CBR programme workable and sustainable is not possible unless the national government changes job descriptions and adds additional staff at the local level. With the current state of the economy this does not appear to be possible.

Nevertheless it is important to note that many government employees, usually at lower levels, were willing to cooperate and worked very hard with no expectations of extra pay or benefits. However, there were not enough of them to ensure sustainability.

To try and overcome this problem at a community level, CBRDTC have placed full-time paid field workers in the target villages. One of the tasks of these field workers is to try and get more government employees interested and involved in the CBR programme. Experience indicates that this approach is somewhat more successful.

Another significant factor in programme sustainability is continuity of service by staff. Often CBRDTC have found that the government people who get trained in CBR are later transferred, then the programme has to start all over again. Again the solution is to have government employees officially designated as CBR workers with a government programme to train them and their replacements when they get moved. All CBRDTC can do in this regard is to continue to try and lobby the government to change their approach.

The lack of government involvement and concern presents a major problem if CBR is to be developed for an entire population. In a country like Indonesia, it is impossible for NGOs to do this. Fortunately government services are starting to move in this direction and in order to further shift opinion, CBRDTC are now trying to develop a model of CBR, as well as the necessary training materials, that could be adopted by the Government on a larger scale.

Funding: In several places in the evaluation, there are references to the dilemma of finding funds in the villages for needed medical rehabilitation. These are not only one-off funds needed to solve current problems but also include funds that will be required for the foreseeable future as the occurrence of disability will not stop once a CBR programme starts.

The finding of funds is not only a problem for the villagers, it is also a problem for the NGOs, like CBRDTC. If we pay for the rehabilitation this time who will pay next time? If it is always to be CBRDTC, how long will we be committed to this obligation? CBRDTC have no immediate solution to this problem and are still trying to find ways to overcome it.

The other aspect of medical rehabilitation is the cost and availability of referral services. Medical services are not free and they are not always available close to villages. What do you do when there are no services or people cannot afford them?

As noted above, CBRDTC now recognize that this problem is as important as the involvement of the community and will soon be including in their CBR programme, a second type of paid field worker who will be trained specifically for rehabilitation rather than community development.

Programme failure: The evaluation noted that the effectiveness of the programme declined after the try-out stage. This phenomena could be a function of human nature - new project, new ideas which equals lots of interest as opposed to, old project, old ideas and a problem that never goes away, which results in boredom and a desire to go on to something else.

The evaluation further noted that after three years of project time, the programmes had failed in all of the villages examined. CBRDTC have given serious consideration to project duration and now feel, after looking at similar programs in other areas of community development, that a much longer time period will be required to firmly establish a programme so that it will be more sustainable without external NGO support.

Section 4: General Conclusions

The basic evaluation design, field work, and analysis were completed by a team of Indonesians. The input of staff from the University of Alberta consisted of a general review of, and comment on, the methodology and editing of the final report.

It was a big advantage having an evaluation team that were familiar with the local scene. During the course of the evaluation they were able to maintain their independence from CBRDTC as they could obtain all of the permits required to do this research on their own and were able to talk directly with the relevant government officials and community members in their own language without using interpreters. The team's awareness of and their ability to understand local needs and conditions, was considered to be the primary attribute.

One consideration regarding the team's effectiveness was their unfamiliarity with any aspect of rehabilitation. Given the terms of this evaluation this unfamiliarity was seen to be an advantage as the team focused on, what was to CBRDTC, the most important parts of the evaluation, namely the effects of the programme on the community and the programme design itself. However, the lack of knowledge about rehabilitation had a disadvantage in that the evaluation did not consider the direct effect of the programme on the individual lives of people with disabilities.

Overall the team did an excellent job in a relatively short time. They found the major problems and clearly stated them without reservation, both of which are essential if an evaluation is to be of any use.

CBRDTC's experience of non-formal evaluation had proved inadequate for properly designing and implementing programmes. A formal process of evaluation at key points in time, for example evaluating old programmes before starting new ones, can result in development of new CBR concepts and models. However, model changes will only happen if close attention is paid to the evaluation itself, and time and effort is taken to put the evaluation into its proper context in terms of the overall activities of the organization.

The final, and most important conclusion reached by CBRDTC as a result of this evaluation process, is that CBR projects must have a much longer time frame than the three years used in the programmes that were the subject of this evaluation. In fact, there is now considerable doubt as to whether a CBR programme can ever be fully self-sustainable. External inputs in terms of funds, training and monitoring will be required long after the programme has been implemented. This is an important area where solutions will only be found through close cooperation between governments and NGO's.

Notes

1. A fuller account of the evaluation and its outcomes is given in the report: *An Evaluation of Community Based Rehabilitation in Banjarnegara, Sukoharjo, Sragen and Wonosobo, Central Java, Indonesia*, prepared by Heribertus Sutopo of Yayasan Indonesia Sejahtera (YIS) in cooperation with the University of Alberta, Canada. The evaluation was conducted between March and October 1993 and the funding was provided by the Government of Canada through a grant from the Canadian International Development Association (CIDA).

2. *Community-Based Rehabilitation For and With People with Disabilities,* 1994 Joint Position Paper, International Labour Organization (ILO), United Nations Educational, Scientific and Cultural Organization (UNESCO) and World Health Organization (WHO).

Dr. Handojo Tjandrakusuma has been the founder Director of CBRDTC since 1989. On graduating from medical school, he became involved in rehabilitation, joining YPAC in 1967 as a volunteer. By 1975 he realised the limitations of institutional based rehabilitation for people with disabilities in rural areas and he started to organize a community development approach. In 1992 he was awarded the Sasakawa Health Award by the World Health Organisation (WHO) for his contribution to the conceptual development of CBR.

Douglas Krefting is a medical anthropologist, working for CBRDTC as a CBR Management Consultant. He has been a colleague of Dr. Handojo since 1986 when he first learnt about CBR. Since 1992 he has lived in Solo and has managed the development of CBR projects in Java and Bangladesh. He assists with the development of new concepts, ideas and proposals, including the organisation and management of international CBR workshops.

Dr. Laura Krefting is an occupational therapist who has used her background in medical anthropology to specialise in cross-cultural disability. She has been involved in the development of CBR since she learnt of it from Dr. Handojo in 1986 and moved to Solo to work with CBRDTC as a volunteer in 1992. She coordinates the development of training manuals, trains the field workers in all CBRDTC projects and facilitates and directs the international CBR workshops. She is a consultant to UNICEF and WHO.

Contact Address

CBR Development and Training Centre
JL. Adisucipto KM 7,
Colomadu, Solo 57176, Indonesia