

Engaging with the Disability Rights Movement: the experience of community-based rehabilitation in southern Africa

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ABSTRACT *This paper argues that unless community-based rehabilitation (CBR) programmes enter into genuine consultation with the disability rights movement they are in danger of repeating the mistakes of institution-based rehabilitation. Partnership between CBR programmes, and disabled people's and parents' organisations in southern Africa has led to the development of a more consumer focused approach to CBR. Where disabled adults and parents have been fully involved in the design and implementation of programmes, CBR workers have a clearer understanding of disability as a development issue. Education, employment and poverty alleviation have been given a higher priority than medical rehabilitation in these programmes. The evolving concept of CBR and its relationship with the disability rights movement has been observed and documented by The Save the Children Fund, and forms the basis of this paper.*

Introduction

Prevailing attitudes among rehabilitation workers tend to dismiss the strength, and thus the value, of engaging with the disability rights movement. In so doing they risk both missing out on an essential part of their education and alienating disabled people's organisations (DPOs) because of their reluctance to relinquish control of the rehabilitation process. The transition from omniscient professional to facilitator in the community requires an enormous shift in thinking and, too often, institutional attitudes are carried over. I will argue here that community-based rehabilitation is in danger of repeating the mistakes of institution-based rehabilitation (IBR) if it does not enter into genuine consultation with DPOs.

The World Health Organization (WHO) formalised CBR into a strategy for developing countries in 1976. Since then the concept of CBR has spread rapidly, though implementation strategies are diverse. Twenty years on, CBR is no longer considered to be a blue print or ready-made solution; instead, it is a philosophy

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which can be tailored to suit the cultural context in which it is applied. Greater attention is now paid to the informal CBR support networks which pre-date WHO's initiative and the need to validate indigenous practices is increasingly recognised.

In southern Africa the disabled people's movement is relatively strong and the enfolding philosophy of CBR in the region has been well seasoned with disability rights. CBR implementers are struggling to achieve a balanced perspective between delivering quality services, and empowering disabled people and parents. This struggle has been observed and documented by The Save the Children Fund (SCF) and it forms the basis for this article. In 1994, SCF brought together staff and partners working in disability programmes in 17 different countries to exchange experiences (SCF, 1994). SCF's global disability work can be divided into three categories: CBR, Integrated Education and the support of consumer organisations. A follow-up meeting was held in southern Africa to establish areas of common interest between CBR, and disabled people's and parents' organisations, develop a mutually supportive relationship and agree on a more co-ordinated way of working. The ideas and views expressed here are both a reflection of observations made by myself, as SCF's Regional Disability Advisor, and of the discussions held at the meetings.

The first section of this paper outlines some of the problems with IBR, describes in general terms the content of CBR, and stresses the need to reconceptualise CBR in the context of African communities and the collective way in which they operate. This is followed by a brief look at the way in which key writers on CBR view the role of disabled people and their organisations.

CBR is both a philosophy and a strategy for providing rehabilitation services in the community in a more equitable, sustainable and appropriate way than can be provided in a health or educational institution. Institution-based rehabilitation (IBR) in developing countries is expensive, often inappropriate and only available to a 'lucky' few. Rehabilitation services are not considered a high priority by most African governments and, even if they are, the cost of providing high quality rehabilitation institutions for those who require such services would be prohibitive. More importantly, the type of rehabilitation available in a highly professionalised institution, is unlikely to be of benefit to the majority of people whose home environment is in stark contrast to the institution. Furthermore, limited places mean that IBR is beyond the reach of the majority, and the cost of travelling long distances to and from centrally located institutions makes IBR unaffordable for impoverished families.

CBR was pioneered at a time when many rehabilitation professionals were beginning to question the validity of their institution-based work, often as a result of visiting disabled people in their communities on an outreach basis. In many cases such visits provided professionals with the information and experience required to launch CBR programmes, though many so called community-based programmes have continued to function as outreach programmes.

There are arguably as many different types of CBR as there are programmes in existence. Most CBR programmes, however, include the following activities: the selection and training of village-based CBR workers; the identification, assessment

and referral, where appropriate, of disabled children and adults; the design of aids and appliances by local craftsmen; and the teaching of simple rehabilitative techniques to family members for use with their disabled child. Awareness raising, public education, counselling, multi-sectoral collaboration, community development and the promotion of integrated education are also key ingredients of CBR programmes. CBR services may be integrated into existing health, education or social welfare structures or they may be vertical programmes run by NGOs. Increasingly CBR services are being developed at village level as part of community development programmes, with relatively little input from rehabilitation professionals. Although a CBR programme may contain some or all of the ingredients discussed above, its flavour will depend upon the cultural context in which it is implemented. Each programme is therefore unique. Differences exist not only between CBR programmes in different cultures, but also between villages in one geographical area.

CBR and the Tension between the Individual and the Community

It is very important to place the development of CBR in Africa in the context of a collective consciousness. In Africa the needs of the collective, or community, are paramount, whereas in the west it is the individual whose needs come first. Although the true essence of CBR does not conflict with this cultural principle, CBR has been packaged and marketed from a western individualistic perspective and there tends to be a strong focus upon correcting or minimising the impairments of individual disabled people. Focusing exclusively upon the rehabilitation needs of individuals is likely to be counter-productive unless the informal support networks and the basic needs of the whole community are recognised and addressed. Serpell *et al.* (1993) contrast the emphasis in the West on the promotion of autonomy or independence with the tendency of African parents to cultivate social responsibility in their children, and discuss the implications of this when working with the families of children who have learning difficulties. This tension between the community and the individual, between Africa and the West would perhaps render the already contentious concept of Independent Living inappropriate in the African context. Interestingly, however, centres for Independent Living in the UK are aiming to achieve a degree of *interdependence* which is closer to the African concept, than to the western principle of independence (Barnes, 1993).

Vanneste (1995) cites a disturbing example of a CBR programme which effectively destroyed the pre-existing informal mutual support network upon which a family had depended. A neighbour had been helping the family of a severely disabled child, but when a CBR worker began to visit the child, the neighbour withdrew her support. Later, when the CBR worker stopped visiting, the neighbour refused to resume her visits, leaving the child and her family in a worse situation. This could have been avoided if the traditional coping or CBR mechanisms had been respected.

Ideally, the CBR implementer or animator should unlock and place value on indigenous knowledge about disability, and balance the local expertise with the sensitive application and adaptation of knowledge gained outside the community.

CBR can be seen as a vehicle for the exchange of information between communities and governments, and between disabled community members and national DPOs. If CBR workers are to fulfil this role for disabled people's groups and if they are to develop a co-ordinated way of working, a level of commitment to the disability rights philosophy is desirable.

A range of attitudes and ways of working with disabled people and their organisations is reflected in the CBR literature. Implementers of CBR programmes increasingly recognise the importance of involving disabled people in the CBR process, rather than seeing them as recipients of services. However, the extent to which disabled people and their organisations are actively involved in the process is difficult to determine. The Zanzibar and Mauritania CBR programmes were set up by national DPOs whose leaders are well known in the international disability movement, but unfortunately these are isolated and little known examples. Definitions of CBR have developed and changed in response to field experience and there is an arguably healthy lack of consensus. Unfortunately, though, disabled people's voices, especially those from the South, are rarely heard in the CBR debates or reflected in the literature.

The recent joint statement on CBR by UNESCO, ILO & WHO (1994) emphasises the importance of partnership with disabled people as individuals, by stressing that CBR should be implemented through the *combined efforts* of disabled people, their families and communities, and the appropriate government services. Helander (1993) recognises the value of working with local parents' and disabled people's groups, but bemoans the fact that DPOs too often develop from the top-down rather than at grass roots level.

Some writers place more emphasis on the family, rather than on disabled people. This is especially true of programmes that prioritise children and particularly children with severe disabilities, whose experience and needs tend to be neglected by the disability rights movement. O'Toole (1994) asserts that the greatest resource in developing countries for helping disabled persons lead lives which are fulfilled and productive is a well advised and supported family.

The International Labour Organisation (ILO) is concerned about broader issues such as integration and, although the main focus is on service provision, it acknowledges the increasing importance of the disabled people's movement.

A new development, which also makes its way gradually into rural areas, is the emergence of associations of disabled people. This development will sooner or later replace a patronising form of planning for disabled people by a planning process which involves the target beneficiaries. (Momm & Konig, 1989, p. 6.)

David Werner goes a step further and argues that disabled people should be in control, involvement is not enough. He recognises that families of disabled people have an equally important role to play. His views are substantiated by his experience, both as a disabled person and as a staff member of Project Projimo in rural Mexico. This is run and almost entirely staffed by disabled villagers, and maintains high standards of appropriate and affordable rehabilitation.

Only when programmes *for* disabled people are led and controlled *by* disabled people (and/or their families) are they likely to help disabled persons gain self-determination and a respected, equal position in society. (Werner, 1993, p. viii.)

It is worth noting that Werner is one of very few disabled spokespersons on CBR. Sadly, there appears to be very little cross-fertilisation of ideas between CBR writers and implementers, and the disabled people's movement, and so attitudes tend to remain unchallenged. In southern Africa, however, interaction between CBR programmes and DPOs has led to the development of a more consumer-focused approach to CBR.

The Southern African Context and SCFs Involvement

This section will focus on SCFs role as facilitator and provider of technical and financial support for the work of both governmental and non-governmental initiatives in disability and development work. The nature of the support varied according to the national and political context in which it was provided, and these will be briefly described. This section will also highlight the role of the Southern Africa Federation of Organisations of the Disabled (SAFOD) as agent provocateur and ally in SCF's journey from service provision to politics. This journey, or process, has involved a redefining of rehabilitation needs through community consultation, and a greater focus on the empowerment of parents and disabled people.

The disability rights movement in southern Africa has its roots in Zimbabwe. In the mid-1970s a group of physically disabled people began to organise themselves in the institution in which they lived and worked. Charlton (1993) has charted this development through a series of interviews with key individuals, one of whom, Joshua Malinga, became the main link with Disabled People International (DPI) from its inception in 1981 and was later elected chairperson. The disability movement in southern Africa was therefore strongly influenced from its early stages by international disability politics. Malinga was instrumental in establishing SAFOD in 1986. SAFOD is the umbrella body to which all national DPOs have become affiliated and, in turn, it is affiliated to DPI. SAFOD's original aims were to support the formation of DPOs, both local and national, to strengthen existing ones, and to promote leadership training.

The southern Africa region has been fraught with political conflict, drought and an unequal distribution of resources, and it has not been easy to foster the development of altruistic and committed leaders in this context (Leaman & Fricke, 1991). Although the struggle against apartheid in South Africa has had a profoundly negative effect on the whole region, it has provided a revolutionary context from within which the disability rights movement has emerged and with which it has identified its own struggle. The relative cohesion of the region, which, ironically, is partly due to South Africa's political and economic influence, is one of the factors contributing to SAFOD's success as one of DPI's regional bodies.

It would have been conceivable, though arguably unethical, for SCF to have supported the development of CBR initiatives without reference to the disability

rights movement. SAFOD was, however, a rich resource upon which to draw in the late 1980s when CBR was a little understood concept in southern Africa. SCF's involvement began in 1988 with the appointment of a Regional Disability Advisor whose responsibility was to act as an information broker, to develop south-south networks, and to support the development of innovative community-based initiatives which would provide models for evaluation and training (Saunders, 1987).

To date, SCF has supported 10 programmes in Mozambique, Zimbabwe, South Africa, Swaziland and Lesotho. These include a national Integrated Education programme run by the Ministry of Education in Lesotho; five CBR programmes, four of which are health-based and a fifth which is located in the Ministry of Social Action in Mozambique; two institution-based outreach projects run by a local NGO in Zimbabwe, which preceded the regional disability programme; and development programmes run by two DPOs. Interestingly, only three of the 10 programmes have a national brief and are run by government ministries, only one of which is a Ministry of Health programme. This programme has stimulated thinking on disability issues in Swaziland, as has the Integrated Education programme in Lesotho, but policies have not yet been developed. The Zimbabwean government has taken the issue of disability seriously ever since it came to power at Independence and, recently, a disability act has been passed. In both Mozambique and South Africa disability policy is currently being developed. SCF has only employed two expatriates in southern Africa, both of whom were requested by government ministries: the Ministry of Social Action in Mozambique and the Ministry of Education in Lesotho.

Historically, the dividing line between SCF-supported CBR programmes and DPOs was their target groups, with SCF focusing on children and DPOs on adults. However, this proved to be a naive and unrealistic distinction as implementers of CBR programmes were faced with the changing needs of the children as they grew into adulthood. It was crucial, however, to define the CBR workers' relationship with disabled adults so that they were not simply seen as an extension of their client group, but instead as valuable participants in the CBR process.

The ILO has stressed the importance of establishing the different needs and therefore the different types of assistance required by disabled adults (Momm & Konig, 1989). Whether assistance means access to services or help with the establishment of self-help groups and/or empowerment, it is important to recognise the very different nature of the relationship between CBR workers and adults from the one that is likely to exist between CBR workers and children. Children do not have a voice and tend to be passive recipients of services, whereas disabled adults are either recipients of services, potential leaders of programmes or they may choose not to be involved at all. The difference in the relationship is arguably more crucial than the different type of assistance required.

Assuming that a more equal relationship develops, the opportunities for the greater involvement of DPOs in CBR increases. The need for positive adult role models for disabled children in CBR has prompted CBR implementers to challenge DPOs to become more involved with children's and parents' issues. However many of the region's DPOs lack the capacity to involve themselves in anything other than

the development of their own organisations. Others are reluctant to get involved because of their uneasiness about the underlying philosophy of rehabilitation, which places the power firmly in the hands of the professionals.

The continued use of the word 'rehabilitation' is, in itself, a source of conflict and debate. The following section will examine the difficulties arising from the word 'rehabilitation' and will describe the development of programmes in Lesotho and South Africa which prioritise disabled people's access to education and employment, rather than to medical rehabilitation.

CBR Without the 'R'

The ideas represented by the term CBR have sparked off disability initiatives in communities in most countries in Africa and Asia and the term has been interpreted in many different ways (Miles, 1993). For those projects that work in partnership with disabled people, it would be preferable to find a term that encapsulates the idea of a community-based strategy which promotes equality of opportunities. It should reflect the fact that disability is not only a health or social welfare issue, but also one of politics, economics, development and human rights. Community-based support (CBS) for disabled people is an example of an alternative term. It was adopted by the Ministry of Social Action in Mozambique as a deliberate move away from the medical model which emphasises the treatment and rehabilitation of impairments (Miles & Medi, 1994). In the meantime, the term CBR will continue to be used here as a catch all, but it is accepted that it may outlive its usefulness.

The adoption of a more consumer-focused approach to CBR, by the Scott Hospital CBR team in Lesotho and the Amawoti Disabled People's Association in South Africa, has enabled disabled people and CBR workers to work together on a more equal basis. By approaching disability as a community development issue, disabled adults and parents of disabled children have become active participants in the CBR process. This has resulted in a type of CBR which places less emphasis on the 'R' and instead prioritises education and employment issues.

I will now briefly describe the context in which the Scott and Amawoti programmes are working, the main aspects of the work and the similarities between the two. This will be followed by a discussion of the role of home visiting and multi-disciplinary teams in CBR. It is argued that when disabled people and parents are actively involved in CBR, the programme is moulded by the skills and interests of the people involved, rather than by prescriptive manuals and the received international wisdom on the issue.

Scott is a mission hospital serving a sparsely populated rural community in the foothills of Lesotho of approximately 170,000 people. In the mid-1980s, Scott pioneered a Home Nursing programme which targeted elderly people and those who had suffered a stroke. The need to address disability as an issue in the community arose both from the Primary Health Care (PHC) team's consultation with the Village Health Committees and from the nurses' growing awareness of disability through the Home Nursing programme. Lessons learnt from mistakes made in the implementation of PHC ensured that the PHC team entered into genuine consul-

tation with the community in order to establish community ownership and involvement in the disability work.

The long-term goal of SCF's support for this CBR programme was to provide Lesotho and the Ministry of Health, in particular, with a model for evaluation and training. This has proved to be a very slow process within Lesotho, but the impact of Scott's work has been felt both regionally and internationally, through SCF's dissemination of lessons learnt. However, the Ministry of Education's Integrated Education programme, which is also supported by SCF, is also taking the lead in promoting disability issues at a national level.

Amawoti is an informal peri-urban community situated 30 km north of Durban in South Africa. With a population of 100,000, it is a community marked by poverty and an associated lack of services (Philpott, 1995). The Amawoti Disabled People's Association grew out of the concern of one of the local civic committees about the needs of disabled people in their area. Support was provided by the staff of a community-based PHC project in Amawoti which viewed health not as a medical problem, but as a broader question of access to power.

Prior to South Africa's first elections in 1994, all pioneering work in the field of disability and development was carried out by NGOs, although between 1990–94 dialogue was initiated by the government. Since 1994, however, considerable progress has been made by the government with the support of the national DPO to develop a comprehensive policy on disability.

Scott and Amawoti are small projects which have pioneered a different approach to CBR and have had an impact on the development of thinking in the region about community disability work. Despite their very marked differences, they have the following aspects in common:

- Disabled people and parents have been involved from the beginning, many as volunteer CBR workers.
- Disabled adults are seen as partners in the CBR process rather than potential clients.
- The disability work has emerged from PHC and has a strong community development focus.
- Medical rehabilitation has not been the main priority, with education and employment issues taking precedence.
- Poverty alleviation is considered to be an essential part of CBR.
- Attitude change in the community is seen as crucial.
- The pace is necessarily slow.
- Home visiting is carried out when necessary, but is not a routine activity.

Home visiting, together with attitude change and the empowerment of disabled people, has always been thought of as one of the cornerstones of CBR. Home visits provide a crucial, though time-consuming, therapeutic and support service to those disabled people and their families who would otherwise be unlikely to have regular access to rehabilitation services. While not wishing to devalue the efforts of CBR workers to provide therapy and support to individuals, I would argue that, in some cases, home visiting is in danger of becoming an institutionalised activity which has

lost sight of its original purpose. Interestingly, home visiting is given much less importance in the Scott and Amawoti projects. Some of the possible reasons are as follows:

- Home visits take place naturally as part of everyday life rather than as scheduled activities.
- Disabled adults and parents are so involved with the running of the programme that they no longer feel so isolated and are therefore in less need of home visits.
- Disabled adults and parents are learning the skills they need in other situations, for example, at community meetings, in support groups, creches or while knitting in the income generating groups.

Although the projects have prioritised attitude change, income generating projects and empowerment, home visiting has not been ruled out. In fact, home visits were made in the initial stages in order to identify disabled children and to train key workers. Parents in both projects are beginning to express their interest in learning simple rehabilitation techniques, in order to reach disabled people and their families who are not already involved in the programme. If home visiting is adopted as one of their strategies, it will be an activity defined and controlled by the community, rather than one performed or monitored by outsiders.

Similarly, roles and responsibilities in Scott and Amawoti have been defined according to the abilities and priorities of those involved, and this has led to the development of a multi-disciplinary team approach. These are not the multi-disciplinary teams associated with highly trained professionals and case conferences, but a collection of committed individuals with a variety of skills to offer. Tasks are assigned according to the abilities and interests of the individuals, in contrast to the WHO approach of training a cadre of workers who each carry out an agreed set of tasks.

In Amawoti a conscious decision was made not to train individual CBR workers, but to assign tasks according to need. The Scott project has abandoned the CBR worker strategy in favour of supporting the development of parents' and child-to-child support groups from which key individuals have emerged as resource persons and leaders. A variety of specialist services are on offer in both programmes including literacy teaching; creche facilities; examination of new-born babies; knitting machine instruction; income generating activities; the manufacture of aids and appliances; and the child-to-child approach in schools. Further training in these specialist areas will be sought, where possible, for the key individuals who have shown the greatest commitment.

Developing a Mutually Supportive Relationship

The move towards a consumer-controlled approach to CBR has necessitated the formalisation of the working relationship between CBR programme implementers and their DPO counterparts. This process is far from complete in southern Africa, but initial discussions have been held to establish common areas of interest, while

clarifying potential sources of conflict and differing priorities, for example, between adults' and children's issues. CBR workers tend to have more contact with the families of disabled people than with the disability rights movement, especially in programmes which prioritise the needs of children, and therefore do not necessarily feel that they should be accountable to DPOs. They may have contact with disabled adults as individuals or they may be involved in facilitating the development of self-help groups of disabled adults, but this does not necessarily bring them into contact with the disability rights philosophy and they may never be forced to confront their own negative attitudes.

Similarly, there is a tendency for DPOs to assume that rehabilitation workers are not interested in disability rights issues, and for the two to be perceived as being mutually exclusive or incompatible, as illustrated by the following quote:

Service providers would not be interested in the philosophy and objectives of the Movement. They suspect the Movement is there to sabotage them. (Mbewe & Lee, 1991, p. 30.)

However, the movement sees itself as a watchdog whose responsibility it is to monitor the quality and availability of services. Furthermore, disabled people feel they have a duty to educate rehabilitation workers and transform them into supporters of the movement (Charlton, 1993).

In response to proposals for funding from SAFOD, SCF produced a discussion document (Miles, 1992) to clarify SCF's disability policy and funding capacity, and to open up discussion on common areas of interest with a view to developing and formalising a mutually supportive working relationship. In 1992 SCF secured funding for two DPOs, who aimed to develop stronger links between themselves and CBR programmes. These were the Amawoti Disabled People's Association and the Lesotho National Federation of Organisations of Disabled people (LNFOD)'s development activists' training programme whose impact will be examined later.

How best to work with DPOs had become a major issue for CBR workers throughout the region and attitudes to this varied enormously. The need to consult and confront DPOs about the role of CBR in the disability rights movement came about through discussions between project staff and SCF's advisor which culminated in a series of meetings held both regionally and globally (SCF, 1994) to review SCF's disability work. An interesting comparison was made at the final regional meeting between the very similar aims of the CBR programmes and DPOs represented. A sharing of resources and the development of a more co-ordinated way of working seemed the obvious way forward, but first differences in philosophy and approach needed to be discussed as honestly and openly as possible. From the CBR perspective it was felt by some that DPOs tended to be undemocratic, disorganised and led by elite groups of physically disabled people. It is difficult to encourage the development of decentralised and egalitarian DPOs when their membership and agendas are urban-based and largely middle-class (Werner, 1995). The tendency was to bypass them, or to inform them of CBR activities, but not to enter into genuine consultation about the needs of their common target groups. An example of a more co-ordinated approach to the needs of rural disabled people follows.

Where There is No CBR: the Role of Development Activists

This section highlights the role that DPOs can play in promoting the concept of CBR in the absence of CBR programmes. The mobilisation of disabled adults living in rural areas through LNFOD's development activists' training workshops has resulted in their increased confidence and motivation. A good working relationship between LNFOD, and the CBR and National Integrated Education programmes in Lesotho has ensured that disabled children's issues are high on the agenda.

LNFOD is a cross-disability national umbrella organisation and since 1993 it has consisted of four member organisations, representing people with physical, visual and hearing impairments, and learning difficulties (and their parents). Over a 3-year period LNFOD has trained 30 rural disabled people per year as development activists in a series of three 1-week workshops. Places on the training programme were shared equally between the member organisations and 50% of all trainees were women. In addition, the CBR programme was allocated places for disabled adults who were potential leaders in the programme.

The courses included an introduction to disability as a development issue, consciousness raising on disability rights issues, advice on how to set up and run local committees, and ideas on income generation. There was also some orientation on disabled children's issues and visits were organised to both segregated and integrated schools. The organisation of these courses and the follow up in the communities were the responsibility of the one salaried person within LNFOD and its volunteer committee members.

The main impact of the training has been in the raising of self-esteem and confidence of the individuals trained. The mutual support systems which have developed through the workshops and subsequent local meetings have fostered a greater sense of self-worth in the trainees and of control over their own lives:

We used to feel isolated and suffered in silence—now we meet and make our own decisions. (du Toit, 1995.)

Similarly, the parents who have been trained have experienced a change in their attitude towards their disabled children and a greater appreciation of disability issues:

Being involved with disabled people has taught me to handle my situation. My disabled child is now active in my family. (du Toit, 1995, p. 18.)

Finally, disabled adults now feel committed to CBR-type activities such as the challenging of negative attitudes, and the counselling of other disabled people and their families about education, employment and rehabilitation issues. They consider themselves responsible resource people in their communities and in particular they are concerned to support parents of disabled children:

I now have the courage and understanding to approach parents to change their view of their children with disabilities, to seek education for them and to organise for self-help. (du Toit, 1995, p. 17.)

The development activists have formed support groups in which they plan their

activities, such as holding community meetings and establishing self-help groups. Their awareness of CBR issues has given them the confidence to provide advice and information to families, and in this way they are performing part of the function of CBR workers. In fact, LNFOD has taken over the management of an NGO run CBR programme in the south of Lesotho and this provides them with the opportunity to integrate the two approaches.

The following section describes the reverse situation, where CBR workers are involved in setting up local disabled people's support groups, often with very little input from the national DPO.

The Role of CBR Where There is No DPO

CBR programmes invariably operate in communities where there is no DPO and CBR workers are often instrumental in facilitating their development. In the following examples the CBR workers provide a vital link between local groups and the national DPO and relevant government departments. They act as a channel of information and ideas, and are therefore in a position of power. The way in which this is handled is crucial to the long-term sustainability of the local group. Local DPOs are in danger of either becoming totally dependent on the CBR programme and, therefore, being ineffective, or of being left to develop so independently that they lack support and resources and so flounder.

One of Africa's earliest rural CBR programmes in Kibwezi, Kenya, began without the involvement of disabled people, but its staff have come to realise the drawbacks of this way of working. The Kibwezi programme targeted disabled children up to the age of 16 and neither provided services for adults nor considered helping them to set up a local support group. In 1990 the programme was evaluated and this lack of involvement of disabled adults was highlighted as an issue of concern (Saunders & Zinkin, 1990). As a result of this a local group began to meet as a separate entity from the CBR programme. The co-ordinator of the programme is now convinced of the importance of starting CBR programmes with the full involvement of disabled adults, if they are to be sustainable.

In Mozambique, the community-based support (CBS) team attached to the Ministry of Social Action in Mozambique provided a meeting room for a group of deaf school leavers who had failed to make their voices heard in the national DPO. The group prioritised the development of a national sign language and became involved with teaching small groups of deaf children as part of the national CBS programme. The group will soon form itself into an association and will apply for affiliate membership to the national DPO. The CBS team played a crucial role in supporting a neglected group of disabled people who, in turn have made an invaluable contribution to the community disability work by supporting the development of groups in many different provinces.

In South Africa a working relationship between disabled people and occupational therapists has existed since the mid-1980s with the advent of an organisation known as Rural Action on Disability (RURACT), which is affiliated to the national DPO. Its responsibility is to promote CBR, and develop networks through-

out South Africa and the surrounding countries. RURACT has provided a useful forum for the development of thinking on CBR issues in the context of the disability rights philosophy.

The Alexandra Health Centre's CBR programme in South Africa had, as one of its original aims, the establishment of a support group of, and for, disabled people. The process of facilitating the development of the Alexandra Disability Movement (ADM) has been documented from the point of view of the CBR implementer (Cornielje, 1993). The creation of a body of disabled people to whom rehabilitation workers would be accountable was one of the original objectives. Despite the difficulties of working in a politically divided society and the lack of quality leadership, ADM is increasingly playing a vital role in the development of rehabilitation services.

In Amawoti, disability was identified by the local civic committee as an issue to be addressed and a committee was formed of concerned persons which included disabled people and parents of disabled children. Sub-committees of interest groups have since been formed so disabled people meet separately as a sub-group, but they come together with the parents and civic committee members to form the Amawoti Disabled People's Association as they do not wish to isolate themselves from the rest of the community. They consider it their role to raise awareness of the fact that disabled people are members of the wider group of disadvantaged and impoverished people in Amawoti and they encourage others to be inclusive in their approach to development (SCF, 1994).

In Lesotho the Scott CBR programme established contact with the national DPO, primarily to solicit help with the training of CBR workers and teachers. Close contact between the CBR programme and the DPO has been possible because Lesotho is a very small country and because of a good working relationship between the respective leaders. Parents' groups have been set up and, as membership is open to disabled people, the need for a separate DPO has not been identified.

In the above examples, the CBR programmes have provided the initial funding for the establishment of local DPOs and parents' groups, and it is unlikely that these groups would have been set up without this support. The local groups all have a role to play in the CBR programmes with which they are associated. In the case of Alexandra, this role was predetermined and with the others it is being defined as the programmes develop. The Amawoti programme is somewhat different as it does not use CBR terminology and it is a single organisation which is fulfilling both functions. Finally, membership of local DPOs is not always restricted to disabled people, and it is very common for disabled adults and parents to work together at a local level. The CBR programmes described are moving towards greater partnership with disabled people and parents. This is a dynamic process which necessitates the continual re-appraisal of roles. One of the main purposes of SCFs regional meeting was to clarify the role of CBR workers in relation to DPOs and it was agreed that this should be as follows (Miles, 1994):

- Mobilisation of parents and disabled people.
- Help with the formation of local parents' and disabled people's groups.

- Networking and dissemination of information between local and national DPOs.
- Empowerment and capacity building of disabled people and their organisations.

The greatest and most urgent need was considered to be the capacity building of DPOs. DPOs, especially at a local level, tend to lack funds, administrative and logistical support, and are generally less well-resourced than CBR programmes. More co-ordinated planning in the deployment of scarce resources would improve the situation, but the empowerment and capacity building process will inevitably be slow—slower than most donors are likely to tolerate.

Parents as Activists

This final section addresses the issue of parents, their involvement in both CBR programmes and the disability rights movement and the way in which they have come to realise their common oppression with disabled adults. It is recognised that there are important differences between the experience of disabled people in Africa and that of disabled people in the UK, for example, and that very real, often insurmountable problems and conflicts exist between organisations of and for disabled people in industrialised countries. Similar tensions and conflicts have already arisen in southern Africa, and attempts have been made to understand and resolve them.

In southern Africa, the term 'parents' rather than 'families' tends to be used, as they have organised themselves into pressure groups, and are active in promoting and implementing CBR activities. In practice, they are primarily mothers' groups, as many women are abandoned by their husbands as a result of the birth of their disabled child, or upon diagnosis (Kisanji, 1995). Economic pressure to produce healthy children is very strong.

Although mothers have been extremely effective in organising themselves into support groups, they have not achieved the same levels of recognition or success as the disability rights movement and what they have achieved is poorly documented. A major reason for the disparity between the two groups in southern Africa is undoubtedly gender-related, as DPOs tend to be led by men and parents' groups by women who are primarily the sole breadwinners for their families (Miles, 1994). SAFOD's progressive gender policy will in time redress this imbalance, but the fundamental inequalities between men and women in relation to childcare are likely to continue.

As parents have become more involved in the setting up of their own organisations and in CBR programmes, they have come into contact with broader disability issues. Parental involvement in the struggle for disability rights has effectively challenged the predominant attitude in SAFOD that parents neglected, over-protected and discriminated against their children. This attitude had been compounded by the lack of interest shown by DPOs in children's issues in general, but more specifically in those with profound and multiple disabilities and in the consequences

for their families. Not surprisingly, parents were unsure of their role and did not see disabled adults as their natural allies.

A lack of concern for children's issues among DPOs is not peculiar to southern Africa as the following quotation from the UK illustrates:

I had been active in disability politics for more than ten years, but it was only when I became a parent that I realised that the moves forward that we have achieved for ourselves as adults with disabilities have not reached the lives of disabled children at all. (Rieser & Mason, 1992, cover note.)

In Lesotho and South Africa parents have argued that they are disabled by virtue of being the full-time carers of severely disabled children and that, together with their children, they are affected by the stigma of disability. As a result parents' organisations have been accepted as affiliate members of DPOs which enables them to pursue their own agendas, which are quite distinct from those of disabled adults, while maximising the opportunity of being an ally of the disability rights movement.

Parents also have a role to play in service provision. CBR implementers have trained mothers of disabled children as CBR workers in Lesotho and South Africa and in many instances they have proved to be more effective and more dedicated than health workers, as McGlade & Aquino (1995) testify from their experience in the Philippines. Ideally, both parents and disabled adults should be employed as CBR workers, or as CBR team members.

In this way the needs of disabled children for role models and of parents for support are more likely to be met. Tensions inevitably exist between the two groups, especially where resources are scarce. However, through a process of constructive dialogue and a commitment to working in partnership, a mutually supportive relationship can be developed through which disabled adults and parents can teach each other a great deal.

Conclusions

The long-term goal of all CBR programmes should be to facilitate disabled people to take control of their own lives and to play a decisive role in any services that are created. In a recent survey of people living with acquired impairments in the UK, services were seen as tending to remove choice and control because they were provided by others on their behalf (Todhunter *et al.*, 1995). There is enormous potential in developing countries to leapfrog over the professional hurdles created by the rehabilitation industry in the West and to work directly with disabled people and parents to ensure that the services which are created are those that are most needed. The cultural bias in Africa towards collective, rather than individual, needs and responsibilities, should be fully exploited by CBR.

Resource-driven service provision, based on the western model, is not sustainable and is of questionable value. Disabled people need access to mainstream services and to appropriate information in an accessible form. CBR has the potential to unlock and validate existing indigenous knowledge and information systems while facilitating access to relevant information and ideas outside the community. I have

argued that this should be done with the active participation of the consumers themselves and with an understanding of disability as a development issue.

The danger inherent in CBR is that it may simply become a community version of IBR with the power still firmly in the hands of professionals, and with disabled people and their families in the role of passive recipients. It is important that programmes strive to develop services which have appropriately high standards while at the same time ensuring an equal partnership between consumer and professional. This will inevitably call into question some of the fundamental aspects of CBR, such as the practice of home visiting. The development of a mutually supportive relationship and an honest discussion of the different agendas of CBR workers, parents and DPOs have helped in redefining CBR as a consumer-focused strategy in southern Africa.

In summary, CBR workers have a key role to play in the development and capacity building of DPOS, especially at community level. They have access to information and resources which need to be shared. By feeding information about disability work at community level to the policy makers at national level they can provide an essential link between local and national issues. CBR teams should work together with DPOs to address poverty, and to tackle education and employment issues. At a political level, they can support the efforts of DPOs to run advocacy programmes and to develop policy and legislation on disability. It is crucial that CBR workers and donors recognise that the pace will inevitably be slow and that it is in the long-term interests of disabled people to work with, rather than against, the disability rights movement.

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