Disability as a Catalyst for Sustainable Devlopment: a Policy in the Making paper (Paper 2)

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# Introduction

Lessons learnt from the experience of implementing community based disability programmes in southern Africa have potential relevance for other types of community development work with which Save the Children Fund (SCF) is involved. It is argued in this paper that the disability work in southern Africa has gone further than many other types of community development work in understanding the complex issues of participation and empowerment.

Disabled children are particularly disadvantaged, marginalised, vulnerable and discriminated against in all countries and cultures, yet few development programmes take their needs into account. Impairments may be the direct or indirect result of living in an impoverished situation or disabled people may be reduced to poverty as a result of their impairment. Caught in the poverty-disability trap, disabled people constitute the 'poorest of the poor' in most communities. They are therefore a highly deserving target group and represent an enormous challenge within all development programmes.

According to leading disabled academics, disability is socially constructed. People are disabled less by their impairments than by the negative attitudes of society which prevent them from developing their potential and from fully participating in society. Community Based Rehabilitation (CBR) workers have successfully stimulated community members, both disabled and non-disabled, to address this issue. Disabled people have been empowered as part of the community participation process and the presence of empowered disabled people in the community has had a positive effect on community attitudes.

The very nature of 'rehabilitation' means that there has to be a long-term commitment. It is not feasible to employ highly trained rehabilitation professionals in remote rural areas, so skills have to be transferred and adapted to suit the context and abilities of the people involved. It is essential that CBR is developed by people who are trusted by, and understand, their communities so that it develops in a culturally appropriate way with a strong sense of community ownership. Ownership implies participation and empowerment.

Disabled people in the North argue that they are disempowered by medical and rehabilitation professionals who want to control the rehabilitation process and by 'resource-driven' rather than 'needs-led' services. The lack of resources in the South is arguably an advantage to those CBR programmes that allow themselves to be led by the needs of consumers rather than resource driven.

SCF's disability work in southern Africa has moved away from a service delivery approach to one of community participation and empowerment, which seeks to develop appropriate and affordable solutions. In order to bring about lasting changes in the lives of disabled children it was considered necessary to raise awareness of disability issues in the whole community and to involve disabled adults in the process. Focusing exclusively on the impairments of individual children does not address the social and attitudinal barriers which cause disability. Tacklin g disability issues has proven to be an effective starting point, or catalyst, for broader community development.

The shift from Institution Based Rehabilitation (IBR) to CBR
The advent of CBR saw the wholesale rejection of any form of institutionalised provision for disabled people. 'Institutions' in this context can mean hospitals, special schools, both day and residential, and long-stay 'homes'. This was perhaps an important step initially in order to secure government commitment for changes in policy, redistribution of resources and the changing of job descriptions. However, this 'community is right, institution is bad' attitude has created a lot of problems, such as:

* The polarisation of views between the two opposing 'factions' which has caused tensions, resentment and has arguably slowed down the process of 'reaching' disabled children in rural areas;
* Insufficient training and re-training opportunities for institution-based staff which has resulted in inadequate numbers of appropriately trained personnel to implement CBR;
* Resources concentrated in institutions have tended to be under-utilised;
* Staff working in institutions who had less exposure to new ideas about CBR and Integrated Education have tended to react defensively in the face of the onslaught against them.

The lack of opportunities for the re-training of key staff meant that CBR was often poorly understood and was often narrowly interpreted as 'rehabilitation done in the community' according to the formula laid out in the World Health Organisation (WHO) manual. The enormous shift in thinking and attitudes that needed to take place to make the transition in personnel terms from omniscient professional to facilitator in the community was perhaps underestimated. Inevitably, IBR attitudes were transferred to the community under the guise of CBR, together with the 'medical model' approach of assessment, treatment and referral of individual disabled children.

This exemplifies the mistakes made in Primary Health Care (PHC) which have been repeated in some CBR programmes. However, those CBR programmes which have the benefit of hindsight of their PHC experience have been able to address some of these issues and have endeavoured to forge a new way forward. ([See Paper 1](http://www.eenet.org.uk/resources/docs/cbrthrou.php)) In order to do this it has been essential to analyse the obstacles to the practice of the PHC theory, which, in itself, is very sound. De-medicalisation and an adoption of a community development approach are essential if CBR is to succeed.

Developing an understanding of CBR
Communities have been responding to the needs of their disabled members for thousands of years and they continue to do so where there is no formal rehabilitation service of any kind. In 1976 WHO formalised CBR into a strategy to provide appropriate rehabilitation services to disabled people in their communities with the support of referral services at district and national level. (see Paper 1)

SCF was strongly influenced in the mid-eighties by the shift away from IBR to CBR. SCF's involvement in CBR began with the appointment of a regional adviser on disability who was based in the southern Africa region. The adviser's brief was to support the development of innovative CBR programmes that could be used as models for training and evaluation.

The traditional focus of disability work tends to be on the prevention, treatment or cure of impairments through individual rehabilitation programmes. However an increasing focus on integration, inclusion, community based services and disability rights has called into qu estion the validity of separate provision for disabled people and instead pressurises mainstream services to become more accessible.

A community development approach to CBR
An alternative approach is emerging in CBR projects which are rooted in community development principles, where the focus is on disabled people's and parents' experience of disability, rather than upon the impairments of the individuals involved. The first step in this approach is to identify the barriers faced by disabled people and develop a strategy for their removal. By removing barriers, the whole community stands to benefit both from the changes that are brought about and by the fuller involvement of disabled members of the community. The focus is therefore not exclusively on disabled people as they are not perceived to be the problem, rather the problems are located in the environment and these can be more easily and usefully addressed.

Interestingly, the need for a community 'centre' has become apparent in most CBR programmes. The creation of small, often makeshift, 'neighbourhood' centres which are community inspired and organised are increasingly becoming a feature of CBR programmes. They do not replace institutional forms of provision, as they do not only provide services, such as creches, but also essential meeting places and administrative centres. They therefore represent a new approach to service development which is more affordable, accessible and appropriate to the context in which they are situated. In fact, without such opportunities to meet regularly it may have been difficult to achieve the same levels of participation and empowerment.

Disability is a complex issue and it is potentially harmful to assume that CBR provides a blueprint for all disability work in the community. The situation of deaf people highlights some of the inadequacies and contradictions of the CBR approach. Internationally deaf people are campaigning for separate provision in order to develop sign language from which Deaf culture emerges. Inclusion and access to mainstream services are therefore inappropriate strategies for deaf people, unless there is access to sign language. Home visits by CBR workers to individual deaf children can do little to lessen the isolation they experience, particularly in remote rural areas. Where possible, deaf children and adults should have the opportunity to meet separately. This reinforces the argument for 'neighbourhood' centres within CBR, which cater for a variety of needs.

Breaking down barriers
Poverty, negative attitudes and the physical environment are three of the barriers which were identified by projects supported by SCF in southern Africa through a process of community participation. The ways in which these barriers have been tackled and the implications this has for other aspects of community development work will be described.

# 1. Poverty Alleviation

CBR in Lesotho
Poverty was identified as the greatest obstacle or barrier in the lives of disabled people and their families during the community consultation process carried out by the CBR team in Scott Hospital's PHC programme in early 1990. (see above reference to paper 1) Poverty was seen as the cause of many impairments and of further disabling conditions. Disabled people and their families were caught in the poverty-disability cycle.

The PHC programme had been established in 1974 and the staff had learned from experience that PHC initiatives have little or no impact on communities unless their views are respected and they have a sense of ownership of the programme. It was therefore decided that the CBR team should prioritise the alleviation of the poverty in which most of the disabled people and their families were living.

The payment dilemma
All community development projects have to face up to the dilemma of whether to pay incentives, employ staff or manage with volunteers. Creating a new cadre of workers, with their inevitable growing demands and expectations in terms of salary, is not in the interests of sustainability. The PHC team anticipated this problem and opted to train volunteers, not paid workers. However they felt it was unreasonable to expect disabled people and parents of disabled children, who were the poorest of the poor in their communities, to work for no financial reward, especially as they had identified poverty as the single most important issue to be addressed. The following examples illustrate the way in which the PHC team tackled this issue in the pilot areas and may help other programmes which depend on the voluntary efforts of people who are already very poor.

a. Investing in local people
The training of volunteer CBR workers was carried out in the community. This was partly because it was the most appropriate location, but also in order to ensure that the wider community benefited from the CBR programme's funds. It was in the community's interests to employ community members to cook the meals for the CBR workers and the trainers, and to buy the food locally, where possible.

b. Training in income generating skills
Equipping CBR workers with the skills with which to generate their own income was considered essential if they were to be expected to carry out CBR activities for no financial reward. Candle and soap making were taught as one of the modules on the CBR workers' training course. The decision to opt for these particular income generating projects was based on proven success in other areas of the country, in the case of soap making, and the candle making was an experiment in responding to a need in the community. The experiment failed as the CBR workers ran into the practical problem of the lack of availability of a vital ingredient.

c. Individual grants
Each CBR worker received a lump sum of M400 (approximately £100) at the end of the six week training. This was intended partly as seed money for individual income generating projects and partly as security for the future. They were encouraged to deposit the money in the bank, which they all did, and were advised to save some of it for medical expenses and school fees. The rationale was that it was unreasonable to expect disabled people and parents of disabled children to work for no financial reward when poverty had been identified as the greatest obstacle to their development.

This option was considered to be more sustainable in the long-term than the payment of monthly 'salaries' to the CBR workers. It was also designed to promote greater self-reliance in the community. They should not be encouraged to rely upon an outside body such as Scott Hospital to provide cash when it was needed. The grant could therefore be drawn upon for the payment of school and hospital fees and other such expenses.

The payment of grants had other, unanticipated, effects, such as the raising of self-esteem among disabled adults who had never had money before. Parents of disabled children felt a sense of relief that at last they were able to provide for their disabled child.

d. Income Generating Projects (IGPs)
Project money was invested in the purchasing of sewing and knitting machines for use in income-generating projects. Membership of the income generating gr oups is not confined to CBR workers and other disabled people, rather it is seen as an effort to improve the economy of the whole community. Poverty alleviation is part of a broader strategy to prevent illness and impairment.

A decision has been taken by the first group of CBR workers to be trained to donate one third of their profits to new CBR groups as seed money for their own income generating. They are doing this despite the fact that profits are modest with each person only taking home approximately £20 at the end of 1994. Further research needs to be carried out into the relative benefits of this income to the families involved, although mothers of disabled children have already shown that they are now able to pay school fees, uniform costs and medical expenses for their children.

It is arguably unfair to judge this income generating initiative alongside non-disability projects as there are other agendas involved. The less tangible, but equally important, benefits of increased self-esteem and confidence and the mutual support of parents and disabled people are more difficult to measure. For these reasons time factors are not so important, as the groups are providing the dual function of income generating and mutual support

However it was recommended in the recent evaluation that further investment should be made into skills training, including business management, in order to sustain the momentum of the IGPs and the CBR programe as a whole. The evaluation revealed that the PHC team had learnt as they had gone along and in retrospect they would have benefited from training in the setting up and management of IGPs. Needless to say, training and appropriate advice is no guarantee of success in what is a notoriously difficult aspect of development work.

e. Parents' groups
The establishment of parents' groups in new areas, where work has developed less systematically, has replaced the CBR worker strategy used in the pilot areas in Lesotho. The PHC team have decided to 'go with the flow' and support the spontaneous developments which have taken place, rather than impose the idea of a cadre of voluntary CBR workers. This is likely to be a more sustainable way of developing CBR as it promotes the self-reliance of families with disabled children.

The presence of an aware and motivated PHC coordinator and the opportunity for a group of mothers of disabled children to attend a national parents' meeting in South Africa have provided the necessary impetus to the parents' groups who are the main focus of the CBR work in the new areas. A total of 69 parents from 8 different groups set up in the new areas have been orientated into CBR and disability issues through a series of four ten day initial training sessions. Disabled adults have joined the groups and as yet have not felt the need to meet as a separate interest group.

Further training will be provided for those parents who have demonstrated their commitment to the programme. Ideally the training will be tailor-made to the needs of the key individuals and the programme and is likely to include leadership training, income generating and simple rehabilitation techniques.

The selection of CBR workers from a parents/disabled people's group which is 'up and running' is likely to be more successful than selection that takes place pre-programme implementation. Unfortunately it is still too early to fully evaluate the relative strengths of these two different approaches, although the recent evaluation of the programme favoured the latter approach.

In South Africa and Zimbabwe parents' groups have set up their own creches to relieve women of their daily responsibility of caring for their severely disa bled children and enable them to go out to work. The birth of a severely disabled child can often lead to the impoverishment of the whole family if the mother is the only breadwinner. The setting up of creches can therefore be seen as a part of the poverty alleviation process as they help to break the poverty-disability cycle. This is, however, only one of the aims of creches which also provide mutual support to families and stimulation and basic education for children.

f. Teachers and Child-to-Child
The adoption of the Child-to-Child approach as part of CBR programmes in southern Africa has proved to be a very successful way of raising awareness and challenging negative attitudes. Teachers have been mobilised through Child-to-Child and have acted as informal community support groups for CBR. In Lesotho the CBR team has committed resources to the initial training of teachers in the Child-to-Child approach and, as with the parents' groups, they have budgeted for the further training of those teachers who have demonstrated a high level of commitment to the programme.

Teachers are a resource to be mobilised. They have status in the community and have the power to influence the attitudes of future generations. Teachers in Swaziland and Lesotho, who are well supported by CBR workers, have made a valuable contribution to the programmes.

The Lesotho National Integrated Education programme has successfully mobilised teachers in areas where there is no CBR. Teachers involved in the piloting of Integrated Education (IE) have voluntarily taken on the role of CBR workers by visiting disabled children in their homes and addressing community meetings. They would benefit from the support of a CBR programme to ensure that children have the necessary equipment, such as orthopaedic appliances, but they are managing to fulfil the other CBR worker roles.

Coming from a different perspective: a development activists' training programme
The Lesotho National Federation of Organisations of Disabled people(LNFOD) is a cross-disability national umbrella body whose member organisations represent people with physical, visual and hearing impairments, as well as those with learning difficulties and their parents. LNFOD and its member organisations depend almost entirely upon volunteers. They have only one salaried staff member, who works full-time for the organisation of the visually-impaired.

Poverty was identified by the leadership of LNFOD as a major issue for disabled people, particularly for those living in rural areas. Their response was to train 30 rural disabled people each year as development activists in a series of three one week workshops. Places on the course were shared equally between the member organisations, thus ensuring that a range of disabilities were represented, including parents, and 50% of all trainees were women. The course, which was planned, run and evaluated entirely by disabled people, included an introduction to the concept of disability as a development issue, advice on setting up committees and basic income generating skills.

The challenging of negative attitudes of disabled people towards themselves (see below) released their energy and enthusiasm and thus stimulated them to do something about their impoverished situation. In the long-term their involvement in income-generating activities and community development activities in general means that they are contributing to rather than draining the local economy.

A recent evaluation of the training programme has reluctantly highlighted the need for paid staff who can provide the necessary follow-up to the trainees in their home areas. This recommendation has been made reluctantly as the introduction of paid staff risks changing or destroying the spirit of volunteersim which is so strong in LNFOD.

# 2. Physical environment

The issue of physical accessibility for disabled people is usually associated with the provision of lifts and the adaptation of cars and houses in urban or Northern settings. In the rural areas of developing countries, however, this issue takes on a completely different meaning. Initiatives to address accessibility inevitably raise awarenss of disability issues in general and this in turn leads to community mobilisation. Some of the ways in which this issue has been tackled and the spin-offs for the wider community are described as follows:

Road building
The difficulties faced by a girl with brittle bone disease in a village in Lesotho provided the community with the necessary motivation to build a road. The community, which initially consisted of schoolchildren, teachers and parents of other disabled children, was situated in Scott Hospital's Health Service Area. The wider community is now more aware of disability issues, including problems of physical accessibility, and is currently raising money for a wheelchair.

The local PHC coordinator had been orientated into the concept of CBR, but had not been instructed to initiate CBR activities. ([See paper 1](http://www.eenet.org.uk/resources/docs/cbrthrou.docx)) She was aware that the girl, who has a severe physical disability, was locked in the house alone when her mother went to the fields. Her response was to encourage the mother to let her daughter socialise with other children. This was an important first step as the girl made a friend, who visited regularly, carried her around the village on her back and taught her to read, write and knit.

When the CBR team introduced the Child-to-Child approach at the local school one of the pupils mentioned 'the one who can't move'. The teacher followed this up and encouraged other children to visit the girl until she started attending school. However the girl could not be pushed to school in a small cart along a bumpy road for fear of breaking more bones. The community's response was to build a better road, from which the whole community is now benefiting.

Ramp building
The Ministry of Health's CBR team in Swaziland has become skilled at building simple ramps in schools to facilitate the integration of disabled children using wheelchairs into their local schools.

Integrated playgrounds
The Swazi team has also organised community workcamps to construct accessible playgrounds at schools where disabled children are integrated. This is to the benefit of all the schoolchildren who previously had no designated safe play area.

Pit latrines
Lack of access to basic sanitation is a major health hazard for disabled people, especially those with spinal injuries. The response of the Amawoti Disabled People's Association has been to encourage the PHC programme in Amawoti, to which the disability work is affiliated, to design wheelchair accessible pit latrines, as part of their pit latrine building programme. This is a good example of integrating a disability perspective into a general programme. Improvements in sanitation for an individual disabled person are in the interests of all family members and the community as a whole.

# 3. Attitude Change

a. Community attitudes towards disability
Attitude change is an essential element in any CBR programme. It is arguably the most difficult, the most time-consuming and, above all, t he most difficult to measure. The careful 'handling' of traditional attitudes and practice is crucial and efforts should be made to understand and work with them, rather than to condemn them.

The Scott CBR programme developed out of a request from the community's Village Health Committees for help in caring for their disabled people. Nevertheless, as in all societies, there were some negative attitudes and practices such as the sexual abuse of disabled girls, the ban on disabled heirs from becoming chiefs, the discrimination faced by disabled children in their local schools and the general lack of respect for disabled people and their parents. The first year of the programme was devoted to lengthy discussions with all the chiefs and their headmen about the way the community could respond to the needs of its disabled members, as we discussed in the first paper. Negative attitudes were challenged as part of this process.

Similarly the income generating groups have challenged common assumptions and negative attitudes towards disabled people. Set up as part of the CBR programme to address poverty, the groups supply school jerseys for the whole community and provide a much needed service to the whole community, a service which did not previously exist. As a result of their involvement in the income generating groups, disabled people and parents of disabled children feel that they now have status in the community and that their views are respected.

There is a tendency among Northern writers to make generalisations and judgements about the 'superstitious' beliefs prevalent in developing countries. Here is one example of the language used to describe the attitudes of some Northern writers towards disabled people in the South.

"The great majority (of disabled people) will live their lives without dignity, in absolute poverty, victimised by beliefs that they are possessed by evil spirits or that their very presence is proof of divine punishment."

Post-industrial societies cannot claim to have eliminated negative attitudes. Capitalism has, in fact, brought with it its own set of negative attitudes towards disabled people. While not wishing to romanticise the situation of disabled people in traditional societies, it is important to recognise the positive aspects and to build on them.

b. Disabled people's attitudes towards themselves
LNFOD aims to 'liberate disabled people from negative social attitudes'. The majority of disabled people attending the development activists' course (see above) saw themselves as sick, possibly contagiously so, and had tended to become passive recipients of charity, unable, or unwilling, to help themselves. The course succeeded in 'liberating' them from their own negative attitudes and, with a greater appreciation of disability as a form of discrimination, disabled people's attitude towards themselves has been transformed from one of shame to one of pride.

c. Anti-bias education
It is in the context of anti-bias education in the new South Africa that disability is being taken as a serious issue by pre-school teachers working for TREE (Training and Resources in Early childhood Education) in Durban. TREE, a pre-school teacher training agency, is in the process of re-writing its curriculum in the light of the need for anti-bias education. The needs of disabled children and those who are survivors of violence are being addressed simultaneously.

When first challenged to address the needs of disabled children, the teachers' attitudes were negative. One of the reasons for their reluctance to have disabled children in their classes was their perceived lack of 'specialist' skills. In order to address this issue, the teachers looked to the community, the local Disabled Peoples Organisation and the parents in particular, for the expertise they felt they lacked. They have learned a great deal through this process of community consultation and have come to realise that their skills as pre-school teachers have great relevance to the so-called 'special' needs of disabled pre-school children.

d. Teacher's attitudes
The Ministry of Education in Lesotho has initiated the in-service training of primary school teachers in the principles of inclusive education. By raising their awareness of the needs of children with a range of disabilities, teachers have become more aware of the individual needs of all the children in their classes. Prior to this in-service training they confess that they used to tease and even beat children for failing to answer simple questions correctly. In their words, they have now 'repented'. The training has equipped them with the skills to cater to individual difference in the classroom and they now work overtime in order to plan lessons more carefully and to visit disabled children in their homes. They feel that they have not only become better teachers but also better people.

e. Children's attitudes
The Child-to-Child approach has proved to be very effective in raising awareness about disability and promoting positive attitudes among teachers and pupils. This approach has been used by the CBR programme in Lesotho to mobilise school communities as part of CBR.

The awareness raising was done firstly by a disabled person from LNFOD who was invited to talk to the oldest children in each school in the pilot area. Then the children were given the task of conducting a survey of the number of children who had been burned during the winter season and who had had bouts of diarrhoea in the rainy season.

Issues such as safety in the home, clean water, hygiene, immunisation and nutrition became very real issues for the children as they came to realise the causes of burns and of diarrhoea. More importantly, when the children realised that disability was not infectious, they began to visit and play with the disabled children in their area, thus disobeying their parents' instructions. The challenging and changing of community attitudes by children is likely to result in more tolerant future generations.

This echoes the experience of the national IE programme in Lesotho where the children in the pilot schools have said that they don't ever want to be separated again from disabled children, as they feel they 'need each other'.

Conclusion
The examples discussed in this paper have shown that CBR should not only be seen as a strategy for providing services to disabled people. The crucial factor is that it should seek to address disability issues in the context in which disabled people are living. In most cases, this involves the alleviation of poverty, the challenging of negative attitudes and the removal of physical barriers in the environment. There are clear benefits to whole communities from looking at the needs of disabled children holistically rather than simply in terms of their rehabilitation requirements.

Some of the perceived benefits to the whole community are as follows: the construction and improvement of community facilities, such as roads and playgrounds; the improvement of teaching methods in schools to create greater awareness of individual difference; the mobilisation of disabled people, who had previously been passive recipients of charity, to become community leaders and active participants in development programmes.

A strategy that su cceeds in empowering disabled people, who are among the least powerful members of society, should also succeed in empowering other sections of the community. The CBR approach therefore sheds light on the development of potential work with other marginalised groups, such as women and people living with HIV and AIDS. Recognition of the fact that disabled children are also members of a whole range of target groups, such as refugees, streetchildren and survivors of violence and sexual abuse may be a good starting point, as this demonstrates the fact that disability is a cross-cutting theme and attempts to single out disabled children are artificial and impractical.

The CBR projects described began by singling out disabled children before coming to the realisation that this is helpful initially but counterproductive in the long-term. The transformation of teachers' attitudes towards disability is unlikely to have taken place through professionalised individual support to disabled children. The teachers claim that they have become better people as a result of the IE initiative and this will have a far reaching effect on all school children. By addressing practical problems rooted in people's everyday reality, the disability work has proved to be a catalyst for the broader development of the whole community.

SCF's role in this development has been characterised by the minimum involvement of ex-patriates; a willingness to trust local initiatives and to take risks; and the provision of relatively long-term, 'behind-the-scenes' support.

**Reference:**
**Title:** Disability as a Catalyst for Sustainable Devlopment: A policy in the making paper
**Author:** Miles, S
**Publisher:** Save the Children
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