Partnership with Disabled people, Parents and the community:

Lessons from Community Based Rehabilitation (CBR) in Southern Africa

By Susie Miles

Abstract
This paper draws upon examples of where parents, disabled people, CBR workers and pre-school teachers are taking the lead in developing innovative approaches to the education of disabled children. This has led to a better use of scarce resources and the development of a more relevant, inclusive and practical curriculum for disabled children. Community participation is considered to be essential for this kind of sustainable and appropriate change to take place. Respect for indigenous beliefs and practices ensures that the best aspects of customary and formal education are drawn upon so that disabled children have access to a more appropriate education.

CBR workers are promoting the casual integration of disabled children into their local schools with the full involvement of parents and disabled adults. The sustainability of the Integrated Education (IE) approach is considered in the light of scarce resources, the low priority accorded to disability by most governments and the poverty in which many families with disabled children are living. The 'deaf' dilemma is highlighted as an example of the inadequacy of the CBR and IE approach, thus far, in developing a sustainable approach to education for deaf children. The development of a more appropriate alternative is advocated which serves to strengthen the arguments for a CBR approach.

1. The history and nature of CBR
CBR has been practised in communities for thousands of years. Families and communities have always worked out their own ways of responding to the needs of their disabled members and they continue to do so where there are no services catering specifically for disabled people.

In 1976 the World Health Organisation (WHO) formalised CBR into a strategy for developing countries by recommending the provision of essential services and training for disabled people through CBR as part of the 'Health for all' campaign. The original principles and reasoning behind CBR were thus very similar to Primay Health Care (PHC) and the relationship between the two is an important factor in the implementation of CBR (Finkenflugel 1993).

Definitions of CBR have developed and changed in response to field experience and there is an, arguably, healthy lack of consensus on this issue. The latest UN definition provides a useful summary of some of the main themes.

"CBR is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities.

CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, education, vocational and social services."

(UN Joint Statement 1994)

Whatever the limitations of CBR, both in its definition and its practice, it has provided a useful focus for fieldworkers who were disillusioned with Institution Based Rehabilitation (IBR) and who needed guidance in developing an alternative approa ch, appropriate to their context.

The first principle of CBR should be to 'unlock' and place value upon the indigenous knowledge of community members and to make full use of local professional and vocational skills. CBR workers should respect disabled people's and families' experience of disability as a valuable contribution to their programme and, where possible, empower them to develop and manage their own programmes.

CBR can be seen as a 'vehicle' for the exchange of information between communities and governments, between disabled community members and national Disabled People's Organisations (DPOs). CBR has the advantage of being able to provide access to higher level skills without compromising the customary knowledge about disability. CBR is also playing a valuable role in demystifying special education by bridging the gap between formal and customary education.

2. The role of CBR in Integrated Education
Children with mild and less visible impairments have always been 'casually integrated' into their local schools and in some countries this has been documented (Miles, Mariga & Phachaka). The support of children 'casually' integrated into schools has become an integral part of CBR in southern Africa. CBR workers are not always in a position to influence Ministry of Education policy towards integration, but they are able to work closely with disabled people, parents and teachers at community level to ensure that disabled children already in school receive the support they need and to prepare the way for the integration of children with more severe disabilities, where appropriate

In South Africa, where it is estimated that up to 50% of Black school children suffer from system-created delays, underdevelopment and underachievement, the term integration takes on a completely different meaning. Furthermore, special provision, in the western sense, is unaffordable (Kriegler & Farman 1994).

By building upon the basic principles of customary, or indigenous, education, as elaborated upon in Joseph Kisanji's paper, CBR workers can help prevent the 'dis-integration' of disabled children from their communities. Customary education is inclusive, relevant, practical and locally available and can be seen as the foundation upon which CBR workers should build. Placement in school should not necessarily be the recommended route for those children who may benefit more from a home-based approach which draws upon the principles of customary education.

Where Integrated Education (IE) is considered to be appropriate, the role of the CBR worker could be to:-

* place value on, and 'unlock', indigenous knowledge and the practice of customary education;
* raise awareness of the need to integrate disabled children into schools in their communities;
* identify, assess and refer disabled children, where appropriate;
* prepare disabled children for school;
* introduce the Child-to-Child approach as a way of preparing schools for disabled children;
* collect and disseminate information about IE;
* mobilise communities to campaign for access to education;
* work with disabled people in the campaign for integrated education.
* challenge negative or demeaning attitudes;

In a country such as Mozambique where there is, as yet, no clear policy on the education of disabled children, CBR workers are leading the way in showing that IE is possible. CBR workers are adapting their knowledge of disability and rehabilitation and applying it to the classroom to provide the necessary support to teachers (Zinkin 1995?). In Morocco Save the Children Fund (SCF)-supported CBR initiative aims to provide a model of good practice in its support of disabled children in mainstream schools and to lobby the Ministry of Education to develop appropriate policies. (Carey 1995)

In Lesotho, 'planned' integration has been introduced by the Ministry of Education, whilst Non Government Organisations (NGO)-run CBR programmes are promoting IE at grass-roots level. Enormous gaps still exist, but it is an interesting example of CBR and IE developing simultaneously, through mutual support and a sharing of expertise. They are operating in different areas of the country, but consistency of approach is essential. This will be expanded upon in the following paper by Sue Stubbs.

The following aspects of the role of CBR in IE will be highlighted as follows: community responses to special educational needs, disabled people as advocates for IE; the importance of role models in education; and the Child-to-Child approach. Examples from SCF's work in southern Africa are quoted to demonstrate the importance of working in partnership with disabled people and parents and the communities in which they are living.

a. Community responses to the educational needs of disabled children
C ommunities that have no access to special education facilities either educate their own children according to the principles of customary education or send them to their local school. It should be the task of CBR workers to help communities adapt their customary education to the needs of disabled children and, where necessary, to develop appropriate alternatives within the community.

Disability was raised by the community as an issue that needed the attention of Scott Hospital's PHC programme in Lesotho. Community leaders felt that they lacked the necessary skills to help their disabled community members, for whom they felt a great responsibility. The Primary Health Care (PHC) team facilitated a series of community meetings to identify an appropriate strategy. The main concern of parents of disabled children was that their children should have access to the local schools and that the discrimination experienced by those children already in school should be challenged. Thus, access to education became a major focus of the CBR programme.

Opportunities for education were cited as the greatest perceived need of disabled children by community focus groups interviewed as part of an action research project in South Africa (Philpott 1995). Needs were ranked in order of most to least frequently cited: education came first and assistive devices last in a list of seven.

The involvement of the Ministry of Health's CBR team in promoting IE in Swaziland has brought benefits to the school communities and beyond. Prior to the implementation of CBR, children with mild impairments were 'casually' integrated into schools. The CBR team worked closely with teachers to prepare schools for the integration of more severely disabled children whom they identified in the surrounding areas. They have placed a strong emphasis on the preparation of the physical environment for IE with the building of simple concrete ramps and accessible playgrounds. Community 'workcamps' are organised to help with the building of playgrounds which serve to raise awareness of disability. Teachers talk of their 'repentance' from negative attitudes. They are no longer 'frightened' of teaching disabled children and they feel well-supported by the CBR team.

b. Disabled people as advocates for IE
Disabled people have articulated their support for IE through their organisations in southern Africa which together form a federation known as the Southern Africa Federation of Organisations of Disabled people (SAFOD). Speaking as former pupils in residential special schools, they argue strongly against a segregated approach to the education of disabled children. They see access to education as a basic right for all disabled children which should be realised through the equalisation of opportunities strategy.

The Lesotho National Federation of Organisations of Disabled people (LNFOD), which is affiliated to SAFOD, has played a key role in challenging the inappropriateness of residential institutions for disabled children in Lesotho and has put pressure on the government to develop a policy on IE. The integrated versus segregated education debate is discussed at length in LNFOD's "development activists" training workshops for rural disabled people based on the SAFOD model (Mbewe and Lee 1991).

The trainee development activists are encouraged to take responsibility for the new generation of disabled children growing up in their home communities. With the insight gained on the training course, they are in a good position to advise disabled children and their families about the education options available (du Toit 1995?).

c. The importance of role models
The importance of the presence of disabled adults as role models in schools was highlighted by disabled people at a recent conference (ISEC 1995). A 'survivor' of IE in the UK explained that she expected to die before she became an adult because she didn't know of the existence of disabled adults.

The Scott Hospital CBR programme has recognised the importance of involving disabled adults in the preparation of schools for IE. LNFOD is called upon to participate in awareness raising meetings in the community and to address teachers and schoolchildren on the issue of IE. It is difficult to measure the impact of the personal story of a blind young woman and of why it was so important that she attended her local school. What is clear, though, is that, for the listeners, it transformed IE from being a theoretical ideal to a personalised reality.

The CBR programmes in Swaziland and Mozambique which aim to have national coverage and which are run by the government ministries of Health and Social Welfare respectively, have prioritised the employment of disabled people as an awareness raising strategy. Daily contact with disabled colleagues has effectively challenged the attitudes of the staff. This also provides positive role models for the disabled children with whom the Ministry of Health work closely on the Child-to-Child programmes in both countries.

d. The Child-to-Child approach
There is little documentation of the use of the Child-to-Child approach in CBR programmes, although it is an important part of all the CBR programmes supported by SCF in southern Africa. Child-to-Child has great potential for raising awareness of disability issues, challenging peer attitudes and preparing the ground for the integration of disabled children in schools (Zinkin & Saunders 1990).

School children in Lesotho were asked by the Scott Hospital PHC team to conduct a small 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. The main purpose of the survey exercise was to raise the children's awareness of preventable impairments and, in the long-term, to mobilise them as support groups for CBR.

This survey had some interesting results. Issues such as safety in the home, clean water supply, hygiene, immunisation and nutrition became very real issues for the children, as they saw living examples of what happe ns when too little care is taken over children's health. Their research brought them into contact with disabled children who had previously been kept away from other children. When they realised that disability was not infectious, they decided to disobey their parents' instructions not to play with disabled children, by arranging secret meetings.

This has had an immediate impact on the lives of the children involved in the survey, but there is likely to be a far greater and more long-lasting impact on the future of the community. The challenging and changing of community attitudes by children is likely to result in a more tolerant future generation.

3. Sustainability Issues
It is important to remember that the context in which we are working is one of varying degrees of poverty. The challenge facing the implementers of CBR and IE programmes is to develop sustainable and appropriate services for disabled children. Western models are notoriously expensive, unsustainable and 'resource driven'. It is not surprising that governments shy away from developing 'special education' services, as 'special' tends to imply expensive.

a. The poverty-disability cycle
The links between poverty, impairment and disability are substantial and complex (Coleridge, Philpott, Miles & Medi). Deprivation of basic needs can cause developmental delay and physical, psychological or intellectual impairment. Furthermore having a disabled child often leads to further impoverishment as expensive 'cures' are sought and extra time is needed to look after the child (Arnold 1995).

The birth of a disabled child is often a precipitating factor in the break up of marriages as children are seen as the family's future economic security. A child with an impairment is considered unlikely to become a future provider and fathers, fearing the birth of more disabled children, often simply look for another wife in the hopes of having 'healthy' children (Kisanji 1995).

It is therefore very common for women to be the sole providers for their disabled children. Not only do they have to manage without the financial support of their child's father, but they are unlikely to be able to seek paid employment if their child requires full time care. In this situation, women are often unable or unwilling to afford the school fees to send their disabled child to school and home-based educational programmes through CBR may be the only form of affordable education.

Many CBR programmes are assisting with the payment of school fees for disabled children whom they have integrated into local schools. This usually happens because disabled children come from the poorest families, but also because parents are often reluctant to spend their money on school fees for a child who is unlikely to become a provider in the future. In most cases this involves relatively small amounts of money for primary school fees. However this creates a precedent which may be difficult to follow when the donor funding ceases. It should be seen as a short term measure to ensure that the principle of IE is accepted, while recognising the lack of sustainability in the long-term.

In Lesotho income generating schemes have been set up as part of the Scott Hospital CBR programme to ensure that costs such as school fees, medical expenses and the purchase of assistive devices can be met by families with support from their community.

b. Training
The lack of locally available training courses and the high cost of specialised training overseas are two major obstacles to the development of a sustainable approach to the education of disabled children. Special schools staffed with relatively highly trained teachers co-exist with community-run integrated creches whose teachers have only a basic level of training. There is a need for less specialisation and more good quality generic in-service training.

In Durban, a pre-school teacher training agency, TREE (Training and Resouces in Early childhood Education), was challenged by the donors in 1992 to address the needs of disabled children and to introduce IE into the pre-schools. The budget for the project was small and the teachers resisted the idea of integration. 'It is illegal' and 'we are not specialists' were some of the responses elicited during the first disability awareness day for pre-school teacher trainers.

Following a period of research in the community, which involved extensive consultation with parents through community meetings and with the local branch of the national DPO, the pre-school teachers' curriculum has been modified to include special educational needs. Special needs in this context includes the needs of children who are survivors of violence. This has been done with a minimum of resources and in a way which is meaningful to the teachers. Parents and disabled people are seen as a valuable resource in the designing and teaching of the new curriculum.

4. The 'deaf' dilemma
Special schools and CBR programmes, as they are currently run, are failing deaf children. Deaf children who attend special schools are isolated from their families and communities and receive an education that is largely inappropriate to their needs.

Despite the fact that most children who attend special schools have to live away from their families, organisations of deaf people argue for separate educational provision. Even some CBR documents concede that children with severe hearing impairments may need more specialised services than those offered by the CBR approach (O'Toole 1991 & Salamanca 1994).

There is an urgent need to demystify deaf education in order to encourage the involvement of communities, parents and deaf people themselves. The challenge is to develop an appropriate and sustainable approach to the education of deaf children. The author contends that this is not possible without the development of sign languages.

Where deaf people have formed their own organisations they have prioritised the development of sign language and an improvement in the standard of education for deaf children. Deaf adults tend to show more interest in the education of deaf children than any other group of disabled people. They recognise that without language and education there is no culture and that it is essential to start developing Deaf culture now by investing in the younger generation. If education is to improve, fundamental changes need to be made in schools for deaf children and in the training of teachers (Miles 1995).

In Mozambique deaf adults play a major role in the Ministry of Social Action's national Community Based Support (CBS) programme. Two deaf adults are employed by the ministry to support groups of deaf people and to develop sign language. In an urban informal settlement on the outskirts of the capital, Maputo, they teach small classes of deaf children as part of the CBS programme.

CBR workers are in a key position to link deaf children and their families with organisations of deaf adults. They can help raise the profile of deafness and dispel some of the misunderstandings surrounding it. Together they could lobby for change in the education of deaf children and the development of sign language and interpreting services.

Conclusion
Partnership is the key to progress. Communities, parents and disabled pe ople are potential resources to be drawn upon through a process of community consultation. CBR workers are in a key position to liaise between the key players, but they should be encouraged to share this responsibility with teachers.

The educational needs of deaf children can be addressed more appropriately by applying the principles of customary education with the support of CBR programmes. This will inevitably involve challenging current practice which invests in an unsustainable way in a minority and excludes the majority. However, without sign language, inclusion and access to mainstream services are arguably inappropriate strategies for deaf children. Communities need to be helped to regain confidence in their own ability to educate their deaf children, whilst drawing upon the expertise of deaf people and sign language experts from the wider national and international community. CBR workers can provide the necessary support to the setting up of community alternatives to institutional provision for deaf children.

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