Community Based Rehabilitation and its Emergence Through Primary Health Care (PHC) - a Policy in the Making paper (Paper 1)

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Introduction
In the mid-'70s the World Health Organisation (WHO) recommended the provision of essential services and training for disabled people through Community Based Rehabilitation (CBR) as part of the 'Health for all' campaign. The principles and reasoning behind the original concept of CBR are very similar to those of PHC. There has been a lot of discussion about the appropriateness, or otherwise, of locating CBR programmes within the context of PHC and about the relationship that should exist between the two. Opinion is also divided about whether CBR is a health issue at all and in some countries it is regarded as a social welfare or civil rights issue.

Only rarely has CBR developed from within PHC. More commonly it co-exists with PHC under separate management and tends to be seen as a low priority. It is a struggle for CBR staff to gain recognition from the ministries of health when CBR is perceived as the poor relation. Not surprisingly, many CBR implementers choose to develop services separately from PHC in order to avoid a 'watering down' of services for disabled people.

CBR has developed as an integral part of Scott Hospital's PHC programme in Lesotho. It was not 'grafted' onto PHC, but developed naturally as a result of the PHC work.

CBR and PHC have been criticised for emphasising the importance of community participation and empowerment in theory, while in practice they have too often developed a top-down approach resulting in compliance rather than participation. Lessons learnt from the failure of Scott Hospital's PHC team to develop community participation and ownership in their PHC work has had a big influence on the way they have implemented CBR. By validating indigenous knowledge and experience, the PHC team has facilitated communities to respond to the needs of their disabled members through a process of 'bottom-up' community development.

BR in Lesotho has, in a sense, been 'turned on its head' with poverty alleviation taking precedence over 'rehabilitation'. The pace has been set by the community with the help of the 'animators' from the PHC team and it is only now after seven years of implementation that the specific rehabilitation needs of disabled children are about to be addressed more systematically. It is possible that donor agencies and ministries of health would favour the speedier WHO manual approach, but the Scott 'model' is arguably more sustainable in the long-term.

Background
Save the Children Fund (SCF) has a long history of involvement in disability in Lesotho, primarily with institutional care of physically disabled children. However it was only in 1988 that a Regional Disability Adviser(RDA) was appointed with a brief to support the development of innovative community based strategies, the first of which was the Scott Hospital CBR programme.

The decision to fund the programme was a calculated risk and was based on the merits of an individual and on a well-developed PHC programme. The individ ual, a nurse with many years of community based PHC work, had completed the one year diploma course in CBR at the Institute of Child Health (ICH) in London. The project document, produced as part of the diploma, was clearly argued and the five year plan of action reflected a sound understanding of community dynamics.

It would have been preferable to fund a Ministry of Health project with greater potential impact on policy and practice, rather than a mission hospital. However the ministry showed very little interest in disability issues, considering them to be the responsibility of Social Welfare and None Government Organisations, Lesotho Save the Children, in particular. The idea of SCF supporting a pilot CBR programme at Scott, which was known for its high standards of PHC and its success rate with pilot programmes, met with hostility from the ministry. The result was that funding decisions were delayed until the ministry finally sanctioned the initiative and expressed their interest in learning from the experience of implementing a completely new approach to disability. A great deal of time was invested by the Regional Disability Advisor (RDA) during the decision making period in raising the awareness of key ministry personnel about disability issues.

Funding was minimal for the first four years (approx £5000 pa) and progress appeared to be very slow as the foundations for a CBR programme were laid. It should be recognised that when CBR is integrated into PHC the pace is inevitably slower as CBR is only one of a range of the PHC staff's responsibilities. Continuing to fund the programme from SCF's 'free' money represented a renewed risk. The approach was so unique that there were no comparisons to be made and therefore no guarantees of success, only the reassurance that a person with vision and community credibility was leading the way.

1. Scott Hospital's PHC programme
The concept of PHC was adopted by Scott Hospital in 1974 several years before the Alma Ata declaration. At that time it was called the Community Health Care programme and it had been established to combat poverty-related infectious diseases. Scott is one of nine mission hospitals in Lesotho which are responsible for 50% of health care services in the country.

Scott Hospital's Health Service Area (HSA) covers a population of approximately 170,000 people. The area covered includes villages within close reach of the main road which connects Morija to the capital, but also large areas of the foothills, situated several hours drive from the main road, where the population is sparse.

2. The process of implementation
At the time of the development of CBR, the PHC programme included the following activities:

School health;
Environmental health;
Nursery schools;
Village Health Worker(VHW) training and supervision

Home nursing which included:-
Upgrading of VHWs into home nurses;
Training of Traditional Birth Attendants(TBAs);
Care of the Elderly;
Village clinics - establishment and supervision.

All of the above activities had been implemented in response to the perceived needs of the communities which were established through the 'pitso' or public meeting.

Ten years after the initial implementation of PHC an internal evaluation was carried out to assess the effectiveness of this programme in achieving the following goals:

* reduction of sp ecific infectious diseases;
* understanding by the community of the causes of those diseases;
* health education, especially regarding nutrition and safe childbirth;
* community ownership of the programme.

The results were as follows:

* there was only limited improvement in the reduction of infectious diseases and in nutrition;
* women chose not to give birth in hospital because the nurses treated them badly and did not allow them to adopt their traditional positions while in labour;
* the community felt that the programme was owned by Scott because they had not had any input into its implementation and because many of the activities were insensitive to tradition and culture.

An example of insensitivity to culture was the construction of only one latrine per household necessitating the sharing of the latrine by fathers-in-law with daughters-in-law which is not acceptable in traditional Basotho society.

The evaluation suggested a change in approach to one of empowerment through respect for indigenous skills and knowledge upon which the PHC staff should build. The realisation that greater respect should be paid to local knowledge and practices was not unique to Scott. Lessons from PHC in general can be summarised as follows:

* The promotion of sustainable change in communities is inevitably time-consuming;
* The most effective plans are based on a knowledge of community resources and how people can best be motivated to make use of these resources;
* Key individuals are crucial, but they may not always be welcomed by their own communities;
* Projects may flourish in one village and fail in another, apparently identical, village;
* Grass roots workers usually want 'specialist' knowledge as this gives them status;
* Preventive measures such as EPI are likely to be misunderstood and may therefore have some drawbacks.

Following the Scott evaluation, Village Health Committees (VHCs) were established at the suggestion of the community in order to provide an effective mechanism for people to express their demands and needs as well as playing a decision making role. By 1989 there were more than 130 VHCs whose selection was made from the following already existing groups: traditional and spiritual healers; TBAs; Village Health Workers (VHW); chiefs; local traders; and representatives of land allocation and nursery school committees. The establishment, training and coordination of Village Health Committees were added to the PHC programme's responsibilities.

The PHC team encouraged the VHCs to identify their health problems, in order of priority, and their causes and possible solutions. It was in this context that disability was identified by the community as a priority issue to be addressed.

3. How and why CBR developed: From Care of the Elderly to CBR
Scott's pioneer Home Nursing programme, initiated in 1982, had made many of the mistakes common to the other PHC programmes. The skills of selected VHWs were 'upgraded' so that they could fulfil the role of home nurses. Their two months' training included skills such as 'bedmaking' and 'toiletting' based on hospital practice and information acquired from books. The home nurses were supposed to continue with their VHW responsibilities, using the extra skills they had learnt in their work with elderly people and with those who had had strokes. In practice, they developed s elf-important attitudes, considering themselves to be 'specialists' in this area, and neglected their other duties. The danger of creating local 'experts' who have very limited training was obvious. This was to be an important lesson for the training of PHC staff and community members in CBR.

Disability became an issue for the PHC team when the home nurses began to report information about disabled children 'discovered' during their home visits to elderly people. At the same time disability issues had come to the attention of PHC coordinators in other aspects of their work. The VHCs also identified disability as one of their health problems. The solution agreed upon with the PHC team was the training of community members in how to care for disabled children. However, the PHC team did not have the necessary skills. Prevention of disability was thus the main focus of the training provided to the VHCs until the Home Nursing programme coordinator was sent for training in CBR in London.

4. How CBR developed: introducing the concept - from theory into practice
On her return from London, the Home Nursing Coordinator, who now had the additional responsibility of implementing CBR, decided to orientate all key staff from the hospital management to the community into the concept of CBR. She felt that it was essential that the concept was accepted and understood by everyone prior to implementation. It was too complex and too different from PHC simply to be absorbed as a new programme as it required a big shift in the thinking of health staff and community members.

The PHC team defined CBR as being the 'assistance given to disabled children in their families and their communities to achieve their maximum potential capability'. This definition was the culmination of PHC team discussions and was thus a combination of the external stimulus of the Coordinator's training in the UK and their local interpretation. It was crucial that CBR was a meaningful concept for the whole team prior to implementation. The PHC team had to 'own' CBR before they could facilitate community ownership of the concept and process.

The translation of the theory of CBR into practice required a high level of confidence, analysis and dynamism on the part of the coordinator. She was an individual who dared to challenge the status quo and do things differently. This was nevertheless a lonely challenge. Convincing her colleagues of the approach was necessary and helpful, but it was not sufficient as their experience of disability issues was so limited. The role of SCF's RDA in providing 'behind the scenes' support, back-up and reassurance was a less tangible, but equally important, part of the process and its value is difficult to measure.

4.1. Awareness raising
The key to the success of this particular type of CBR lies in the context into which it was introduced. The communities living in the foothills of Lesotho's mountain ranges are still relatively 'in tact'. Although many of the men work in the South African mines, life for their women and children is very traditional. The chiefs and chieftainesses are highly respected members of the community and they carry tremendous authority. It would be counterproductive for community workers to bypass traditional structures.

The process of awareness raising took place over a period of two years. The CBR coordinator was responsible for planning a series of meetings and workshops with the PHC and hospital management teams, ward chiefs, chiefs and headmen, the community as a whole and parents of disabled children. Meeting the chiefs in the whole community was a serious and time consuming business and it was an important investment for the sustainability of the programme. The coordin ator was well known to the community through her previous PHC work and therefore had a good understanding of, and respect for, the procedures.

The four ward chiefs were very enthusiastic in their initial meetings with the PHC team and this was crucial to the success of subsequent meetings as it was their responsibility to instruct the chiefs under their jurisdiction to call their communities to meetings. As the word went around that the idea of CBR was exciting and that the communities would benefit, the awareness raising and community mobilisation gathered momentum. This helped to ensure that the meetings were well attended.

a. PHC and Hospital management
Although the hospital and PHC management had the implementation of CBR as one of their objectives, they had very little understanding of the concept itself. It was therefore important to introduce them to the concept of CBR, while at the same time securing their agreement for the method and strategy of implementation.

The PHC team of 20 staff members was introduced to CBR by the Coordinator in a two week orientation course. Responsibility for the implementation of CBR rested with the Coordinator and her two assistants. The PHC coordinators based in the pilot areas were expected to take on responsibility for CBR as an additional responsibility in their areas.

b. Ward chiefs
It was particularly important to convince the most influential people in the community of the value and relevance of the CBR approach, so orientation meetings were held in each of the four ward chiefs' offices in order to give them information about CBR and convince them of its importance. The meetings were very successful and the ward chiefs in turn called their chiefs and headmen, who are powerful community leaders, in order to ensure that the information was transmitted.

c. Chiefs and Headmen
Meetings were held with chiefs and headmen to provide information about CBR, but also to prepare an entry point to the community. It was in these meetings that the chiefs identified their negative attitudes and made plans to improve the situation of disabled children in their communities. One of their recommendations was to hold community meetings in their respective villages to create awareness of disability issues. Another was to call separate meetings with parents to find out how best they could support them.

d. The community
Community meetings were most successful where the chiefs had attended the initial discussions. Community members recalled the negative attitudes towards disability from their childhood. For example, the practice which excludes chiefs' heirs (first born sons) from becoming chiefs, if they are disabled. Another example was the lack of stimulus given to disabled children, both in terms of personal interaction and in the teaching of social skills. The following recommendations were made:

* Communities should have more meetings to discuss disability issues, including the causes of disability;
* Community members should be selected and trained in the care and bringing up of disabled children.

These recommendations were acted upon and 45 voluntary CBR workers were selected and trained; 15 in each pilot area.

e. Parents of disabled children
Parents' meetings were held in order to listen to their views about disability and to help them identify their problems. These meetings were conducted separately from the other meetings because parents of disabled children are often invisible w ithin the wider community and their views not heard. Hence they rarely attended public meetings. They identified their problems as follows:

* Their children are discriminated against both by their communities and by the non-disabled children in those communities;
* Their children are rarely admitted into the local schools and, if they are admitted, they are not accepted;
* Parents do not get adequate support either from their families and relatives or from the community at large.

The parents recommended that the PHC team should discuss with and teach communities, teachers and school children about disability issues.

4.2. Selection of pilot areas and CBR workers
CBR was first piloted in three areas in the Scott HSA in 1990 in order to closely monitor its implementation. The identification of the areas was based on the interest shown by the attendance at public meetings, which ranged from 300-500 people in the three pilot areas selected.

a. Parents of disabled children and disabled adults
The community decided that parents of disabled children and disabled adults should be given priority in the selection process. The reason given for this was that they understand the daily struggle of disability and would therefore be in a good position to teach communities about disability and to support families with disabled children. The validity of this rather vague criteria has since been questioned. See Paper 2 for a discussion of this issue.

b. Village Health Workers (VHWs)
It was decided that in each of the pilot areas one VHW should be selected because they are already involved in health matters and are always consulted by their communities when someone needs help. It was essential that they understood the concept of CBR as an integral part of PHC.

c. Traditional Birth Attendants (TBAs)
It was also agreed that one TBA in each area should be selected since they are present at home deliveries. They would therefore be in a good position to identify babies with problems at birth and provide both rehabilitation and support services to the families.

4.3. Training of CBR workers
The training took place over a six week period with a two week practical block. The medium of instruction was Sesotho, the national language, and no training manuals were used or handouts given. The curriculum was designed by the team with input from community development workers and representatives of the national Disabled People's Organisation (DPO). Income generating skills were taught as part of the course, as it was considered unreasonable to expect the CBR workers to work for no financial reward. Each CBR worker received a grant at the end of the period of training, which was to be used partly as seed money for income generating and partly to cover the medical and educational expenses of the disabled person in the family. 4

4.4. Child to Child approach
The Child-to-Child approach was adopted as the most appropriate strategy for the raising of awareness of disability issues among teachers and children, as had been suggested by the parents. It was envisaged that school children would form another support group within the community for disabled children. The teachers' role is to support both disabled children and their parents.

Interestingly, in the non-pilot areas CBR workers have not been trained, instead the PHC team provide support to groups of parents and teachers inv olved in Child-to-Child work. See [Paper 2](http://www.eenet.org.uk/resources/docs/catalyst.docx) for further discussion of the two approaches.

Conclusion
The philosophy of CBR is so similar to that of PHC that it should be relatively easy to integrate the two, providing that there is sufficient political will and that there is a broad interpretation of the PHC philosophy. To confine CBR to the health sphere is to limit, rather than equalise, disabled people's opportunities. However PHC can provide a good starting point for CBR and it makes logistical and financial sense for it to be an integral part of PHC, rather than a separate programme.

CBR has been successfully integrated into Scott Hospital's PHC programme and the key to its success lies in an analysis of the pre-conditions and the process of implementation. Scott had developed a high standard of comprehensive PHC, but the vital components of community participation and ownership were missing. CBR had the benefit of this hindsight. The CBR Coordinator has a balance of appropriate training, community health experience, vision and a willingness to do things differently. The area served by Scott is characterised by its 'in tact' communities with their powerful and effective traditional structures. This made it possible for the PHC team to raise awareness and mobilise support groups from within the community, thus fostering a sense of community ownership.

Disability had been identified by the community as a priority PHC issue which they needed help in addressing. But the pace has been slow. An appreciation of the complexity of disability issues by everyone concerned was considered essential and this orientation process was very thorough and therefore time consuming. A slow pace is inevitable and necessary in disability work as it requires an enormous shift in people's thinking, not unlike the dismantling of apartheid. To fully integrate CBR into PHC also implies a slower pace as PHC staff have responsibility for a range of programmes, not only CBR. It is in the interests of sustainability to ensure that everyone is 'on board' before embarking upon a radical departure in policy and practice, as the more vertical CBR programmes have found to their cost.

A key factor in the success of the programme was the role that SCF played in allowing a flexible funding arrangement with no rigid requirements whilst at the same time providing discrete, but consistent, technical and moral support.

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