

CHAPTER 2

What is CBR in the African Context?

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SUMMARY

This chapter examines the changing concept of CBR since its introduction in the early 1980s. It recognises that initially, it was a top-down alternative to centrally provided specialist rehabilitation services. It follows its journey through to a community-based, community-led initiative, involving disabled people at all stages of the process. It suggests that the different kinds of CBR programmes in Africa today, represent the various stages of this process. The challenges faced during the development of CBR programmes in Kenya, are considered and used, to illustrate the learning opportunities offered by this dynamic process of change. In conclusion, it is suggested that all participants of the CBR development process should remain open-minded as they endeavour to seek solutions for the challenges that emerge. This is particularly essential for the professionals, who find it hard to recognise and respect the potential contribution of disabled people and their families and to give up their positions of power.

INTRODUCTION

I have been involved in CBR myself, since the early eighties, so I speak about CBR from many years of practice. My understanding and beliefs about CBR have changed considerably over the years. I remember the early days when little was known about CBR. What did it mean? Who

should be involved? How costly would it be? Would it provide a viable and quality alternative to the institutional approach? Or, was it another way of governments abdicating their responsibilities? How were predominantly illiterate communities going to carry out tasks that had taken many of us, three to four years to learn? What about our professions and professional authorities? The concerns and anxieties were numerous and perhaps some of these are still of concern to some people today.

Trends in other development programmes at this time were no different either, with increased awareness and concentration on the rural poor, as the focal point of rural development. Governments and non-governmental organisations embarked on providing social service programmes in the name of development programmes. However, these were mainly planned and implemented through a top-down approach with superficial, or no participation of the communities concerned. This practice was perhaps more pronounced in the disability field, which has been strongly influenced by the belief, that disabled people need to be cared and provided for. Within the development discourse, the change in thought and action came towards the late eighties and early nineties, with the realisation that if the subjects of development did not participate actively in the processes, change would not be realised. Sporadic voices of disabled people also started to be heard around this time, about the inappropriateness of some of the very good intentions, which failed to involve disabled people in the decision making, in areas that concerned them. In 1991, at a global meeting of disabled people, the Disabled Peoples International (DPI) was formed. The World Congress of Rehabilitation International taking place for the first time in Africa, in 1992, in Nairobi, began to strengthen the voices of disabled people in Africa.

So, for over two decades now, the trend in rehabilitation has moved from institutional management of disability to services that place greater reliance on family and community resources. The need for an approach that would be more effective, and more accessible to the majority of people with disabilities, was reinforced by the fact, that in many of our African countries, the majority of people with disabilities (about 85%)

live in rural areas or marginal urban communities. Many of them are marginalised and do not have access to any services, so any effective rehabilitation approach must include advocacy and lobbying for policy and legislation change and public education, to ensure that people with disabilities get the same opportunities, as the rest of the community members.

THE CONCEPT AND APPROACHES TO THE IMPLEMENTATION OF CBR

Over the years, a growing body of theoretical ideas has been published on CBR and practical experiences have accumulated. Some of these ideas are progressive, while others come short of viewing CBR within a true development concept. It is said, that CBR has been contextually defined throughout the world and this explains the different models and interpretations, certainly within the African region, where there are various schools of thought as to what CBR means.

Some people argue that CBR has always existed within the African context even before the ‘officialisation’ of the concept. That the families and communities, in the absence of any other services have always been the source of care and training for disabled persons. While some of the traditional practices can be termed negative, there were and still are, many traditional systems of care and management of disability and related issues, that are positive.

Another school of thought, is that CBR is the de-professionalisation of rehabilitation (technology transfer). Basing it on the model of community based health care programme (primary health care), rehabilitation is simplified to allow even the ‘non-literate’ community members to carry out therapeutic training exercises and to produce and use simple aids and devices. This model often uses, or has co-opted the ideas represented in the WHO training manual.

Some conceive CBR as an outreach or extension service, with the objective of bringing professional rehabilitation services to a large number of people with disabilities, particularly in the rural areas, and to

refer those people, in need of more sophisticated services to institutions outside the community. In this model, regular and programmed visits are made to the community sometimes by a multi-sectoral team. The involvement of the community is often restricted to their participation in the outreach activities (clinics).

A fourth school of thought combines elements of institutional rehabilitation and community oriented health services. This model still lays emphasis on rehabilitation service provision, but forms a link with other services such as inclusive education, grass roots organisations of disabled people and income generation activities among others.

A fifth school of thought perceives CBR as an autonomous, empowering and inclusive process, which must be rights and development based and enable access to equal opportunities for persons with disabilities and their families. This model strives to enable people with disabilities to gain ownership of the programme and feel that they have control over their lives, as they individually and collectively with their communities, identify their needs and find solutions. This school of thought, which is more comprehensive, does not denigrate the importance, or the vital role, played by 'institutional' services.

However, even programmes that promote this more progressive idea, are often just confined to the level of the family and do not integrate or involve the wider community, though a key component of CBR has been that **the community** can be mobilised for support. In reality, many parents and families still feel isolated and are not getting enough support through care, education and training for their disabled persons. Persons with disabilities are still sidelined in mainstream decision making in most societies. There are many interpretations, as to what constitutes a community. Who plans and provides the service and what is the nature in which the service is provided?

As well as being located in the community and initiated by the community, CBR also encompasses all the exciting issues, which are being addressed in the field of disability. These include inclusive education, self advocacy, community participation, empowerment, people

centered development, humanism, access and social change. This shows the vast potential that CBR has, in addressing these issues and above all, ensuring equalisation of opportunities for disabled people and protection of their rights.

As an empowering and political process, CBR can be viewed as a threat to the status quo, as, it is about the struggle to change power relationships (those who hold power usually feel threatened by the idea of others becoming critically aware, if it means that these others slip out of their control or worse, challenge their own comfortable position). This can mean that the more powerful players may be resistant to embracing these emancipated approaches and may hang onto power and a top-down approach. Evaluation of CBR programmes is urgently needed, to provide the evidence to identify the most effective CBR approach.

EMERGING CHALLENGES AND LESSONS LEARNT

There are definitely many challenges and lessons accrued over the years. Some of these challenges may be unique to our own experiences in AMREF and in Kenya, but they are also likely to represent challenges to other CBR programmes within the region. They are considered below:

- **Infrastructure**

To develop a separate infrastructure only for CBR, is too costly and it would take too long for it to take off. The challenge in implementing a new resource into the community, is co-ordinating and incorporating it into the existing community infrastructure and hence the inclusion of CBR into existing development structures.

- **Adequate and appropriate training of personnel**

Inadequate training of personnel in CBR provides the biggest challenge in providing family/community-oriented services. CBR content and methodology need to be strengthened in the education of all disciplines of extension workers. There is need for intensive advocacy and influencing of curricula development at the central levels and provision of training opportunities, for those working at the community levels.

- **High level of illiteracy**

Illiteracy is common among people with disabilities. This affects members' ability to conceptualise their own issues and leads to a feeling of worthlessness.

- **Working with community based organisations (CBOs)**

Many programmes now recognise the importance of CBOs in respect to ownership and sustainability of CBR programmes. Capacity building of organisations of disabled people and parents means working with them to enhance their resource mobilisation and management capacities to prioritise, plan, implement and finance their activities. It also involves working to achieve unity of purpose within their membership, setting targets and objectives with specific timeliness. These are strategic issues that require long-term development support, as these organisations are usually fragile with low self-esteem and lack the wider community recognition and support.

- **Equity**

This still remains an elusive goal for many CBR programmes, which are usually on a small scale and without wider government and political support. Influencing local and national policies should form a major priority for CBR programmes.

- **Disability issues**

These are ranked low, not only by the communities, but also by the Governments and even NGOs, who purport to work with the 'poorest of the poor.' In many cases, when one sits down with the communities to discuss their needs and priorities, one finds that they are usually concerned with issues such as supply of water, the disease that is killing their cattle etc, instead of the concerns of disabled people. The challenge is in finding ways to embed the process of rehabilitation of persons with disability, in the every day life of the family and community.

- **Equal opportunities**

Although we desire equal opportunities for people with disabilities, we are working in an environment where there is extreme poverty. Opportunities are scarce for everyone, including people with disabilities. Even opportunities for income generating activities are remote. What this implies is that poverty reduction remains part and parcel of any credible CBR programme.

- **Dependency**

Due to the fact that disability has traditionally been seen in line with charity and welfare, a large part of the communities and even people with disabilities themselves have continued to exhibit a high sense of dependency. This in itself has been the greatest hindrance to community participation and sustainability of CBR. The issue and challenge lie with perceiving CBR as a development issue. Enhancing self-esteem for self-reliance through education and economic empowerment has been instrumental in changing these attitudes. Use of role models is a key strategy.

- **People with mental illness**

In many CBR programmes, the issue of people with mental illness is not adequately addressed. Communities seem unsure about their role in rehabilitating someone with a mental illness. Most people with mental illness are usually identified at very late stages and as a result, the only intervention at that time is usually institutionally based. Stigma and attitudes prevent the establishment of community based post institutional care. This requires intensive and long term community education and mobilisation.

- **Women with disabilities**

Another challenge is the issue of women with disabilities. They are still under-represented even within the disability groups. Women in our societies have low status and if one is a woman and at the same time has a disability, the situation is even worse. Women with disabilities often miss out on basic rights, such as, to choose marriage and bring up children.

- **Collaboration and networking**

As the CBR movement within Africa expands, the need for collaboration, sharing and networking emerges and must be emphasised. Emerging projects will require support in terms of staff capacity building and development of project designs.

- **Sustainability**

This remains a challenge for CBR, as for many community based programmes. Many of us see the responsibility for sustainability of CBR, as lying with the institutions of disabled peoples' organisations (DPOs). However, these organisations are fragile with low self-esteem and lack the wider community support. We need to emphasise capacity building of these organisations through training in leadership, small enterprise development, organisation and management, communication and advocacy skills and linkage with other established organisations.

- **Sexual issues**

Another challenge is that of how CBR programmes respond to sexual issues, what access do disabled women have to antenatal care and information? To what extent are they included in HIV programmes? How best, can they be included?

In conclusion, the challenges outlined above, are still part of an evolving process. CBR is not static and as we endeavour to seek solutions to these challenges, open-mindedness is essential.

Equally important, is the analysis of the community structures within which CBR is embedded. The existence of a power structure: the difference between disabled and non-disabled, men and women, disabled men and disabled women, are glaring realities. The recognition of these differences is crucial for CBR, as for any community-oriented programme.

For any CBR programme to be autonomous, the involvement of people with disabilities should be central. The *empowerment* of women with

disabilities and other vulnerable groups, such as people with intellectual handicaps should form priority agendas of CBR programmes. An autonomous CBR programme does not exclude professionals. However, the professionals' role should not only be seen as that of 'transferring technology', but should begin with the recognition and acknowledgement of the rights, power and ability of the people. This basically means that people with disabilities, parents and the community, have knowledge and skills too, to share with professionals.

I would like to end this chapter by saying that the overwhelming strength of CBR is that it provides a vehicle for embarking on the four guiding principles for developing services, as documented in the World Programme of Action Concerning Disabled Persons.

- a) Disabled persons should remain within their own communities and share ordinary lifestyles, with necessary support;
- b) Disabled persons should take part in decision-making at all levels, both in general community affairs and in matters that particularly concern them as people with disabilities;
- c) Disabled persons should receive the assistance they need within the ordinary structures of education, health, social services etc.;
- d) Disabled persons should take an active part in the general social and economic development of society, and their needs should be included in national planning. Disabled persons should have adequate opportunity to contribute to national development.

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