

CHAPTER 1

Some Controversies in Community Based Rehabilitation

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SUMMARY

This chapter aims to present a brief introduction to the concept and evolution of community based rehabilitation (CBR) including an overview of the changes that have taken place in the last decade. It discusses some controversial issues concerning CBR in developing countries, with particular reference to South Asia. The points for discussion are framed around 5 questions, namely, who should start CBR programmes? Will the predominance of the social model lead to rehabilitation needs being ignored? Is CBR expensive? If so, for whom? Can it realistically depend on volunteers and can it help all disabled people? The points raised are based on the work of the authors in South Asia, over the last fifteen years. The chapter concludes with a recommendation that research into these areas is required to establish constructive progress.

INTRODUCTION

CBR was promoted by the World Health Organisation (WHO) and other UN agencies in the early eighties, as an alternative service option, for the rehabilitation of people with disabilities in developing countries, who had no access to services (WHO, 1981; UN, 1983). Since these

countries had limited resources to provide high quality institutional services, the emphasis was on developing a method, which provided wide coverage, at costs that were affordable to the governments of these countries. In CBR, interventions were to be shifted from institutions to the homes and communities of people with disabilities, and carried out by minimally trained people, such as families and other community members, thereby reducing the financial costs (WHO, 1989).

In the early eighties, CBR was conceptualised and evolved primarily as a service delivery method with a medical focus. WHO recommended that it be integrated into the primary health care (PHC) system that was already well established in many developing countries. The International Classification of Impairments, Disabilities and Handicaps (ICIDH), published in 1980 by WHO, also encouraged a medical approach to rehabilitation (WHO, 1980). As a result, the early CBR programmes tended to focus on restoring functional ability in disabled individuals, in order to 'fit' them into their community. This was a sort of community located rehabilitation.

During the eighties and the nineties, there was a substantial growth in the number of CBR programmes in different developing countries. Along with the quantitative growth, there were also major changes in the way it was conceptualised (Thomas and Thomas, 1999). One of the early changes was the shift from a medical focus to a more comprehensive approach. With the realisation that stand alone medical interventions did not complete the rehabilitation process, CBR programmes gradually began to add on interventions such as education, vocational training, social rehabilitation and prevention. Along with this came the recognition that CBR needed to deal with issues relating to disabled people's lives at all times, and to change not only the disabled individual, but the context in which he or she was located. Changing contextual factors involves helping non-disabled persons in the community accept people with disabilities, promote their social integration, and equalise their opportunities to access education and employment, in the same way as non-disabled persons. Protection of the rights of people with disabilities,

and empowerment of the community to manage their programmes are other aspects of the contextual changes. These require involvement from the community, both before, during and after the formal programme phase if a philosophy of sustainability is to be embraced.

Thus, CBR today, follows a social, rather than an exclusively medical model, but there are still many questions to be answered before CBR can be implemented effectively. It may need two or three more generations before CBR becomes part of the established culture and therefore sustainable. The following discussion deals with some of the questions that need to be addressed.

SHOULD CBR BE INITIATED EXTERNALLY BEFORE THE COMMUNITY EXPRESSES ITS NEEDS, OR ONLY WHEN THERE IS AN EXPRESSED NEED FROM THE COMMUNITY?

In the earlier years when CBR was a form of service delivery, this question was irrelevant. Today, however, CBR is viewed as a development process, and the question of whether CBR should be imposed by outsiders or initiated by the community, is debated widely.

In the earlier years, CBR tended to be a form of ‘community therapy’, where services were physically shifted to the community, but the clients remained as passive ‘beneficiaries’ (Wirz, 2000). Subsequently, some CBR programmes have changed to a community development approach, where disabled persons and their families are actively involved in all issues of concern to them. However, many feel that the initiation of programmes remains in the hands of the ‘external’ facilitators because the level of awareness required for needs to be constructively expressed requires development, but that the ultimate goal should be full ownership of the programme by the clients. As it is conceptualised today, ‘Community participation’ is a central and essential tenet of the social model of CBR. In practice, however, most CBR programmes in South Asia, find it difficult to achieve this goal (Thomas and Thomas, 2001) and the challenge of promoting community initiation remains.

Usually, we assume that communities are homogeneous, cohesive and mutually supportive entities, but in reality, it does not appear to be so. They are, in most instances, quite heterogeneous, with wide differences in socio-economic status, educational status, religion, ethnicity and so on (Boyce and Lysack, 2000). This diversity sometimes causes friction and affects services, because different groups in a community have widely differing needs and priorities. Usually the needs of disabled persons, who are in a minority, are not considered as a priority by others (Thomas and Thomas, 2001).

Given this background, how does one define the 'community' in a CBR programme? Does it comprise only of the primary clients, i.e. the people with disabilities and their families? Or, does it include the larger community? If the latter, is it reasonable to expect members of the community at large, to share their resources with disabled people?

Poverty is a major barrier to participation in development programmes, as people have other pressing needs to be fulfilled before they can take charge of their programmes. Corruption and cornering of wealth by vested interests is another issue that mitigates against participation by all. People in developing countries also have difficulty with decentralisation and 'bottom-up' practices due to a cultural reluctance to take charge of their own affairs. Local communities usually expect benefits from the Government as a permanent dole, and resist suggestions about taking charge of programmes on their own (Thomas and Thomas, 2000, Boyce and Lysack, 2000, Dalal, 1998).

Consequently, the issue for debate among planners today, is whether CBR should be initiated in a community by an external agency, or whether one should wait for the local communities to start CBR on their own? The votaries of the former opinion advocate starting services for disabled individuals without waiting for community participation, as it may take a long time, and in the meantime, the needs of many disabled persons would remain ignored. They argue that community ownership of the programme, where people take on the responsibility for planning, implementing, sharing the risks of and monitoring their programme, is

unlikely to be achieved in the foreseeable future. There is also a suspicion in the minds of many people, that the rhetoric of 'community participation' is used by governments as a ploy to abdicate their responsibility, because the taxes collected are spent on causes other than development.

The opposing argument is that CBR is a developmental issue and as such, it needs to be initiated by the concerned groups themselves, who in this case are people with disabilities and their family members (Miles, 1999, Werner, 1995). If it is externally initiated, the clients will continue to remain passive recipients of services, with expectations of charity, and without the initiative to manage their own affairs and to contribute to society.

Since people in developing countries are largely ignorant about consumer ownership of development programmes, it is not feasible in most instances to begin the programme with full ownership by the communities (Thomas and Thomas, 2001). There is however, a possibility of striking a balance between the two opposing arguments. CBR programmes will need to motivate the local community to participate in their development to begin with, and over time, to shoulder the responsibilities of the programme. In this process, the community will gradually acquire the management skills to take over their programmes as well (Thomas and Thomas, 2001).

WILL THE SOCIAL MODEL OF CBR IGNORE THE 'REAL REHABILITATION' NEEDS OF PEOPLE WITH DISABILITIES?

When CBR was initially promoted by WHO, it was to be integrated into the PHC system, and thus many early CBR programmes followed a medical model, which came in for criticism in the eighties as not being sufficiently sensitive to all the needs of people with disabilities (Lang, 2000). As a result, most CBR programmes evolved subsequently as separate programmes addressing an array of needs, in a comprehensive manner. The perception then, was that unless a special focus was given to disability, the 'specialised' needs of people with disabilities would remain unmet (Thomas and Thomas, 1998). However, with the shift from

a medical model to the social model, the emphasis today is on integrating disability into development processes. According to votaries of this model, it is more cost-effective, and promotes better social integration, by ensuring that people with disabilities have access to the same benefits and services as others in the community, unlike a 'specialised' CBR programme that concentrates on people with disabilities and may actually isolate them from the mainstream (Scott, 1994). Community participation is likely to be greater in a programme that benefits the majority, rather than a minority group. At the same time, people fear that unplanned integration of disability into other development programmes can ignore 'real rehabilitation' needs, such as mobility, special education, vocational rehabilitation and so on. In turn, this can contribute to increased marginalisation of people with disabilities, rather than their integration into the mainstream (Jones, 1999).

The last few years have witnessed attempts to integrate disability into community development projects that showed some tangible benefits for disabled people from the integration (Scott, 1994, Liton, 2000, Thomas, 2000). Many problems were also encountered in this process. Lack of organisational ability and knowledge about disability on the part of community development organisations, act as a major barrier to integration. Disability is seen as a 'specialist' issue, and hence these organisations feel that they do not have the expertise to deal with it (Jones, 1999, Thomas, 2000). Further, disabled people tend to be recognised only by their disability and not by any other parameter, such as gender, poverty level, ethnic status and so on. This results in their exclusion from the benefits of integration in a development programme. Lack of mobility, education and skills in disabled people prevents them from being a part of development programmes, while expectations of charity and poor motivation on the part of disabled people, also contributes to their exclusion (Thomas, 2000).

Integration of disability issues into development programmes implies a high degree of co-ordination and collaboration between different sectors such as health, education, employment and so on. Often, such co-ordination works better at local, 'grass-root' levels, but fails at higher

regional or national levels. Difficulties in multi-sectoral collaborations can be due to many reasons. In developing countries, programmes tend to be ‘porous’ and as a result, the different players in the field take time to trust each other (Thomas and Thomas, 2001). Secondly, there are differences in the management culture of government organisations and non-governmental organisations (NGOs), with the government operating in a top-down manner while the NGOs are usually ‘bottom-up’ and democratic in their management style. These differences can become a barrier to effective collaboration. Thirdly, under the cover of ‘collaboration’, members often try to gain control over each other rather than to work towards a common goal, and hence multi-sectoral collaborations get submerged in power and control issues between the different sectors. Lack of commitment to the goal from all partners, can also be a problem in multi-sectoral collaborations. Usually, a powerful minority controls the process while the rest are passive participants. As a result, in many instances the decisions are finalised by the minority and the majority is left to merely endorse them.

These issues need to be addressed and service development based on a comprehensive model, which includes both medical and social perspectives. This is more likely to meet the needs of disabled people. Until such time however, it may be more realistic to pursue a plan that is most feasible in a given context, focusing on the goals of the programme as the central issue at all times.

IS CBR INEXPENSIVE? IF SO, FOR WHOM?

CBR was promoted to achieve wider coverage, at costs that are affordable. This was to be achieved by shifting rehabilitation interventions to families of disabled persons, thus reducing the financial expenses on institutions and personnel, and consequently reducing the unit costs of rehabilitation. To date, very little evidence has been gathered to verify or reject the perception that CBR is a cheaper rehabilitation option particularly in remote rural settings, where costs in terms of time and transport have to be considered.

However, even if CBR does reduce the financial costs of the service provider, a question, which must be addressed, is, who carries the burden then? In reality, the costs to consumers in terms of their efforts, time and money, may turn out to be much higher than what it is generally believed to be (Thomas and Thomas, 1998). The 'cost effective' aspects of promoting community-based interventions lie in the utilisation of community resources. These, often involve different community members who volunteer their time and efforts, to help and support disabled persons and their families. The volunteers are often family members themselves, in which case another aspect for consideration might be the 'emotional cost' of this involvement. How to measure emotional costs, how to value or cost life itself, is difficult to contemplate, and how such information can be compared with a financial budget seems an impossible task.

The point then is, whether the consumers are ready to take on the additional burden of the costs of CBR interventions? Secondly, even if they are willing to do so, can they afford to do so? Many families in developing countries, who are struggling for their daily survival, feel that it is a waste of effort and money to address the rehabilitation needs of their disabled children, preferring instead, to spend on other children without disability in the hope that they would support them in their old age. In an environment of increasing competition for resources, their reasoning is that unless the other children are well placed, they may not be in a position to support their disabled sibling in the future, especially since few protective social security schemes are available in these countries (Iyanar, 2001). Until some of these issues are addressed, it is unlikely that consumers would be ready to bear the costs of the rehabilitation programme on their own.

IS CBR THE ANSWER FOR ALL DISABLED PEOPLE OR ONLY FOR A SELECT FEW?

It is estimated that 70% of people with disabilities could be helped at the community level, while the remaining 30%, comprising of people with severe and multiple disabilities, require specialist interventions that are not available in the community (WHO, 1981). Evaluations of CBR

programmes in the eighties and early nineties endorsed this view (Helander, 1999). With the change towards a social model that emphasised equity and integration, CBR as it evolved subsequently, began to address the need to include all people with disabilities within its ambit of services and interventions. In reality, however, the desired level of equity has not been achieved, leaving out some sections of people with disabilities.

It is estimated that about 20% of the disabled population that requires interventions from a CBR programme are people with severe disabilities, many of whom would also have multiple disabilities (Rajendra, 2001). In poorer communities, the percentage of people with severe disabilities is low, as the families may not seek help for their survival. In some communities, mortality of children with disabilities reaches almost 80%, leading to a 'weeding out' phenomenon (Rajendra, 2001). However small their number may be, CBR programmes face many difficulties in dealing with the impairment aspects of severe disabilities. Many programmes are initiated by external agents, who need to build a rapport with the community and show quick results. They often achieve this by working with mildly and moderately disabled persons. As a result, people with severe disabilities tend to be left out of interventions. Most CBR programmes also do not have personnel who are adequately trained to deal with this group. Sometimes, in the process of promoting 'community participation' and 'rights' of disabled persons, the impairment needs of severely disabled persons get neglected. As yet, there are no valid methods to effectively address the needs of this group at the community level.

Women with disabilities are another group whose needs are not adequately addressed by CBR programmes, particularly in traditional cultures. Although disability leads to segregation of both men and women, women with disabilities face certain unique disadvantages, such as difficulties in performing traditional gender roles, participating in community life, and accessing rehabilitation services which are dominated by male service providers (Thomas, 2001). Concerns of women with disabilities also tend to get neglected, in organisations of people with disabilities that are usually dominated by disabled men. Even the women's organisations in developing countries consider these women

as disabled first and as women only secondarily. CBR programmes will need to develop appropriate strategies to address issues related to traditional, social and cultural perceptions. Strategies, such as awareness building, to dispel misconceptions about disabled women's gender roles are needed, along with skills development training, to carry out their tasks and home adaptation where feasible. Training of women and CBR staff, provision of educational and employment opportunities for women with disabilities, sensitisation of women's organisations and disabled persons' organisations to include the issues of women with disabilities in their agenda, can all help to reduce the inequality between women and men with disabilities.

CAN VOLUNTEERS IN CBR 'AFFORD' TO VOLUNTEER?

In an international workshop on CBR in 1998, participants from twenty-two CBR projects were asked to identify the major challenges facing them. Problems linked to community volunteers were identified as one of the significant issues by almost all of the participants. The problems had to do with difficulty in finding new community volunteers, fast turnover of volunteers, need for additional resources for continuously training new volunteers, lack of motivation among volunteers, and need for paying incentives or small salaries to volunteers (Deepak and Sharma, 2001).

The role of community volunteers is perceived as one of the major issues for CBR projects in different parts of the world, particularly in the light of the current emphasis on 'community participation'. There are examples of CBR programmes that have successfully used volunteers (O'Toole, 1995), but these are probably the exception, rather than the rule.

The point of debate is, can there be true voluntarism in developing countries where a majority of the population cannot afford to 'volunteer'? The dictionary defines 'volunteer' as a person, 'who voluntarily undertakes, or expresses a willingness to undertake a service while having no legal concern or interest'. Thus, the term has a dual connotation, that of, 'own free will' and of 'without interest or payment'. Though the term 'volunteer' is used often in CBR, in reality, it covers a variety of identities and roles that do not conform to the definition of the term (24). Thus,

there may be persons who have the time to dedicate to their chosen task, or may have some time in specific periods of the month or year, or may be available only for a limited period of time. In the last decade, with a move to market economies in many developing countries, most people need paid employment to survive and are therefore less able or willing to volunteer. Those who do volunteer, often use their training and experience as a stepping-stone to paid employment. Under these circumstances, expectations of free work over a long period of time from volunteers, in the same way as paid CBR workers, may not be realistic or sustainable.

CONCLUSION

After more than two decades of CBR in different parts of the world, many people believe that it may be an appropriate approach for people with disabilities, in developing countries. But many controversies and questions remain about different aspects of CBR. If sufficient attention and resources are allocated to research in this field, it is possible that some of these questions may be answered in the coming decade.

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