COMMUNITY PARTICIPATION: UNCOVERING ITS MEANINGS IN CBR

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ABSTRACT

The essential problem for community participation in community based rehabilitation (CBR) is that of defining the exact ‘community’ to be involved and of determining their level and method of involvement. This issue of community identification is common to most spheres of community work, however in the CBR field there are vastly different interests, for example, persons with disabilities, family members, professionals, bureaucrats, who have in turn widely varying needs, such as independence, support, management, resource development, and who then require unique methods of mobilisation, like advocacy, self-help, training, awareness raising. Perhaps the most unique challenge for CBR is in addressing the breadth of these community interests, needs, and mobilisation methods. This chapter aims to assist in identifying the opportunities and constraints which CBR faces with respect to community participation. The critical lessons from abroad can be summarised as follows: Community diversity reminds us of the disparate interests of communities and that expectations of participation can overburden specific segments of the community, especially women. Examination of the process of eliciting community needs highlights several other problems around the determination of the meaning of disability and what counts as needs. We have learned that the definition of disability is culturally constructed, as are its causes and proposed remediation. We also know that disability may not be a community priority, and what is in the best interests of individual disabled persons may not be in the best interests of the community as a whole. Finally, critical examination of community mobilisation strategies reveals that projects grounded in local participation can still be rejected. Rehabilitation may be believed to be a government responsibility, or CBR may be seen as a second-rate service in comparison to professional and institutional services. The authors show that community diversity, needs identification, and mobilisation strategies have represented considerable challenges to the development of community participation in CBR. Those interested in CBR should take note of these experiences and adapt their plans accordingly. It is asserted that knowing the communities in which we live and work is crucial to this task.

INTRODUCTION

The essential problem for community participation in CBR is that of defining the exact ‘community’ to be involved and of determining their level and method of involvement. This issue of community identification is common to most spheres of community work, however in the CBR field there are vastly different interests (for example, persons with disabilities, family members, professionals, bureaucrats), who have in turn widely varying needs (independence, support, management, resource development), and who then require unique methods of mobilisation (advocacy, self-help, training, awareness raising). Perhaps the most unique challenge for CBR is in addressing the breadth of these community interests, needs, and mobilisation methods.
It is worth reviewing the development of CBR to understand its particular challenge for community participation. The concept of CBR emerged, in tandem with primary health care (PHC), in the 1970s as rehabilitation was recognised as an essential part of the movement toward community participation in health (1). Like PHC, CBR was promoted initially as a local grassroots initiative to bridge the gap between an increasing "burden" of disability in developing countries and the scarcity of professional and financial resources. After some preliminary success in smaller projects established by non-governmental organisations, CBR was formally endorsed by the World Health Organisation (WHO) in 1978, and larger scale projects were established in Africa, India, and south east Asia. Special publications such as WHO’s CBR manual *Training in the Community for People with Disabilities* were commissioned and disseminated broadly (2, 3). The intention of WHO’s original CBR model was efficient delivery of “low-tech” rehabilitation services. Unfortunately, the results of this effort were often top-down strategies that rarely incorporated community members in CBR planning, and only marginally involved them in programme implementation (4, 5).

In the late 1980s and early 1990s, there was a dramatic shift internationally which saw the human rights of people with disabilities emerge as a community development issue. This shift, sponsored by international aid agencies and rehabilitation organisations, arose from a realisation that approaches like the original CBR models encouraged passivity among the population, not community participation. The United Nations (UN) further promoted the ideal of participation of disabled people by proclaiming 1983 to 1992 as the International Decade of Disabled Persons. Furthermore, the UN afforded the notion of CBR global recognition in its report entitled the *World Programme of Action Concerning Disabled People* (6). Finally, a Joint Position Paper on CBR, issued by a trio of multilateral agencies in 1994, proclaimed that CBR was “... a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities” (7). This document stated that a central goal of CBR in a community development model was to build genuine partnerships between rehabilitation personnel, disabled people, and their families, and to improve community attitudes toward people with disabilities. In addition, through the translation of clinical and technological knowledge into locally relevant information and self-help skills, people with disabilities and their communities were to be assisted in taking control of their health and in developing locally sustainable solutions to disability problems. In short, the ultimate goal of CBR became the improvement of the everyday lives of disabled people through basic medical rehabilitation, social inclusion, and political equality.

Thus, it is just recently that issues of rehabilitation have been addressed from a community development perspective. Understandably, the field of CBR is only beginning to learn from the experiences of other community development programmes in poverty, childhood, and women’s issues. In our view, however, the international CBR experience does not fully achieve the ideals of a community development approach and requires critical re-thinking by its proponents. Appreciation of basic community development issues such as community diversity, community needs, and community mobilisation strategies are crucial. Common to all three issues is the need to understand the concept of community.

Communities, regions, and nations that consist of diverse multicultural, multiclass groups may not only understand disability differently, but also conceive of disability services in different ways. When this is the case, identification of disability needs and techniques to mobilise community participation in rehabilitation projects are affected as well. Thus, before investigating the specific
components of community participation in CBR, one must be clear about the nature and meaning of community in one’s own setting.

THE MEANINGS OF COMMUNITY PARTICIPATION

Community participation is a vast field of study which has been investigated in many sectors such as health, environment, governance, international rural development, and urban renewal. Community participation has become a central value and strategy in these sectors for a variety of reasons including efficiency, equity, and social cohesiveness (8). The phenomenon of community participation has been the subject of lengthy debates on its historical origin, its theoretical basis, and its practical application (9, 10, 11). There is general consensus that primary needs in the development of community participation theory are: to clarify concepts used to discuss participation; to delineate the factors believed to have an impact on participation; and to develop comprehensive methodologies for gathering information about participation which can be applied practically in a variety of settings (12, 13, 14).

This conceptual review begins by describing current definitions of community, before proceeding to more contentious issues of participation.

Definitions of Community

There are two ancient roots to the English word community - the Latin “communitas”, meaning common; and the older Greek biocenosis, which is an ecological term meaning “a group of integrated and interdependent plants and animals” (15).

The origins of the modern notion of community are traced to European social philosophers in the late eighteenth century. These scholars noted that the growth of capitalism, industrialisation, and urbanisation altered the relationship between humans and society in a fundamental way, resulting in the loss of inter-dependence (16). Since then, sociological research has attempted to categorise communities empirically, but with only limited success (17). Currently, the term community has two general meanings. The first refers to social ideals of solidarity, sharing, and consensus. This is a relatively recent usage. The second meaning of community refers to actual groupings of people. This is the older and more common usage, but it is also idealist in many ways (15).

Community groupings are defined usually through affinity or through geography. Affinity groups share human characteristics of ethnicity, gender, age, disablement, and sexual orientation. Occasionally, affinity includes socially defined characteristics such as education, social class, and political affiliation, but this usage is less common. It is generally the case that, the greater affinity or shared characteristics present in a group, the more cohesive is its members’ sense of community (18).

In contrast, geographically based groups use physical location to define communities and assume that physical proximity provides a set of material and social conditions which result in shared interests. Affinity and geography sometimes coexist to strengthen a community’s sense of shared interests. This is not always so, however, since many geographic communities differ markedly on many social affinity characteristics such as wealth and education. Nonetheless, geography can provide a powerful incentive for individuals to assume a shared set of interests since physical proximity increases the likelihood of social interaction (19).
Of interest to CBR, community has also been defined in terms of voluntary organisations, that is, groups which have recognised their affinity or geographic relationships and which value these enough to join together formally (20). In this sense, community implies a ‘community of organisations’, or formal associations, and the emphasis on individual community members decreases.

Cohen (19) suggests that two central ideas are found in the notion of community. One of these is aggregational and the other is relational. The former idea involves the aggregation, or grouping together, of people who have something in common. The latter idea, however, expresses the opposition of one community in relation to others that are different. This viewpoint contradicts ideal notions of community as being non-conflictual and is supported by numerous studies which demonstrate heterogeneity and conflict in communities (17, 8, 21,22).

**Definitions of Participation**

Participation has a variety of meanings, focused on sharing in activities by entitlement or right, which derive from basic constructs of democratic theory (23). The notion of participation is used widely, often with an imprecise or no definition, to include almost any situation in which some minimal amount of interaction takes place. Such interaction can imply little more than the presence of a particular individual at a group activity. Pateman (24) suggests that suitable definitions of participation must include four elements - participation by someone, participation with someone, participation in something, and participation for some purpose.

Participation excludes the following situations: where an individual merely takes part in a group activity; where an individual is merely given information on a decision affecting him/her before it is executed; or, where an individual is present at a meeting but has no influence.

A definition of community participation for use in CBR is proposed:

*Community participation is the organisation of activities by groups of persons who have disabilities (or their family members/friends), in conjunction with others who do not, to increase their ability to influence social conditions, and in doing so to improve their disability situations.*

This definition reinforces the central issue of power in community participation. The outcome of participation is influence over resources and programs by disabled persons. The community is not seen as a cohesive whole with mutual interests, but rather as a constellation of distinct advantaged and disadvantaged groups. This definition is consistent with the principles of community development to which CBR supposedly adheres.

**Concepts of Community Participation**

Having defined community and participation, there are still two central and linked conceptual questions in community participation:

- Is community participation a means or an end?
- What are the purposes of participation? (See Figure 1).
Participation, like other social phenomena such as education and employment, can be conceptualised as both a means and an end in itself. When understood as a means, (instrumental participation) the process of involvement achieves some predetermined common social goal or objective, such as the establishment of a technical aids centre. Participation becomes a way of utilising the existing physical, economic, and social resources of people to attain a valued outcome or benefit, and is also a means to achieving efficiency in project management. This form of community participation tends to be short term and does not necessarily lead to an increased capacity of individual persons to participate.

In contrast, when understood as an end (transformational participation) a longer term process develops and strengthens the self-capabilities of people to be involved in social development. An example of this style of participation in CBR may be through the development of a disability policy paper. Participation in this sense promotes goals such as social justice, equity, and democracy (25).

The ends and means distinction is linked to the issue of purpose in community participation. Currently, there are three broad purposes, or functions, of community participation (Figure 1).

1. Community participation as ‘contribution’ is the voluntary donation of people’s resources to a common good or goal (participation as an instrumental means). This purpose values the efficiency obtained in meeting project objectives through people’s own efforts. It implies that community interests are cohesive and that internal, community conflicts can be resolved through democratic processes. Participation as ‘contribution’ is intended to be initiated by the authorities in a top-down fashion and does not necessarily imply that control and direction of activities pass to the local people (26). Any barriers to participation are commonly addressed by educational and motivational strategies.

2. Community participation as ‘organisation’ is the process of organising or arranging people in common activities (participation as both means and end). In this purpose of participation, the origin and form of the organisation are crucial. Some community organisations are conceived and introduced by external agents such as the government bureaucracy, while others emerge and take form from the process of community members’ own involvement (27). In either case, this purpose of participation values the process of organisational development to achieve social integration of disabled individuals, group cohesiveness, and common objectives (24). Any barriers to participation are believed to be derived from operational problems and are usually addressed by technical and resource mobilisation strategies.
3. Community participation as ‘empowerment’ is a more recent purpose and implies both the
development of management skills in local people and the ability to make decisions which
affect their lives (participation as a transformational end). Empowerment assumes that people
have a right to self-organise and that internal conflicts between social groups are able to be
resolved at the local level (28). Rifkin (21) identifies the core concern: “To address the issue
of participation, is to address the issue of power” (p.243). This empowerment purpose of
participation acknowledges the need for community members to exercise power and values the
social equity which is achieved when this happens. Any barriers to participation are believed
to derive from social conflict and are often addressed through compromise on conflicting
policies or by removal of social barriers through political reform (14,22).

Unfortunately, these different purposes of participation are often not clarified in project planning,
thus creating the potential for the rhetoric of ‘instrumental participation’ to mask the maintenance of
inequality in community activities (22). In practice, community participation activities often
emphasise more than one purpose, although not often all three. Oakley (13) suggests that a broad
distinction can be drawn between projects which emphasise the purpose of participation as
‘contribution’ and those which focus on the purpose of participation as ‘empowerment’.

In many development sectors, the purpose of community participation is claimed to be
‘empowerment’ of disadvantaged groups, such as disabled persons. This implies that there will be
a transformational phenomenon influencing the process of community decision-making. If so, there
are a number of implicit assumptions (29,30, 12). First, there should be a basic right of disabled
persons to participate and the objective of participation should be to introduce change in social
conditions. Second, active participation of disabled persons should improve relationships between
them and other community members, and thus reduce their alienation and stigma. Third, through
participation, disability groups should gain access to resources and positions of influence. Finally,
participation should result in attitudinal changes towards disability in community members,
organisations, and society at large.

The theme of participation for disabled persons has recently emerged as a major concept in
disability categorisation. In contrast to the initial medically-oriented categories of the International
Classification of Impairment, Disability, and Handicaps (ICIDH), the new categories address
impairment, activities, and participation (31). This shift suggests not only a more positive set of
disability concepts, but also a clear challenge to clarify the elements of participation. However,
we must also be aware that WHO’s focus is on assessing and classifying the participation of
individuals, and not the participation of communities which are crucial to the success of CBR projects.

**COMMUNITY PARTICIPATION IN CBR**

Few studies exist of community participation in disability and rehabilitation (32). This critique
will also focus on the area of health as a close comparison of community participation mechanisms
and dynamics.

Contemporary types of community participation in health and social development activities
can be organised into three strata and analysed across a number of features (purpose, benefits or
motivation, opportunity, control, and perceived effects) (33, 34, 35, 36, 37, 38, 39) (Table 1).
Table 1. Types of Participation in Disability Programmes

<table>
<thead>
<tr>
<th>FEATURE</th>
<th>MASS PARTICIPATION</th>
<th>TRADITIONAL VOLUNTARISM</th>
<th>SELF-HELP/ ADVOCACY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purpose(s) of Participation</td>
<td>Contribution</td>
<td>Contribution Organisation</td>
<td>Empowerment Organisation</td>
</tr>
<tr>
<td>Primary benefits or motivation</td>
<td>To benefit oneself and one’s</td>
<td>To benefit another group</td>
<td>To benefit oneself and one’s</td>
</tr>
<tr>
<td></td>
<td>wider community</td>
<td></td>
<td>group</td>
</tr>
<tr>
<td>Opportunity</td>
<td>All can participate in theory.</td>
<td>Elite members with extra resources</td>
<td>Disadvantaged members, need support</td>
</tr>
<tr>
<td></td>
<td>In practice, many do not and some are excluded</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>By organisers</td>
<td>By volunteers and organisers</td>
<td>By disadvantaged and organisers</td>
</tr>
<tr>
<td>Perceived effects</td>
<td>Efficiency in achieving goals - instrumental - means to an end</td>
<td>Efficiency, Equity of situations and groups</td>
<td>Equity, Involvement - transformation - end in itself</td>
</tr>
<tr>
<td>Examples</td>
<td>Immunisation programsDisability campsInternational Disability Day</td>
<td>Local CBR SupervisorsLocal disability committeesCharitable fund raising</td>
<td>Self-help groupsAdvocacy groupsSupport groups for disabled personsParents’ groups</td>
</tr>
</tbody>
</table>

Proponents of ‘Mass Participation’ advocate the participation of everyone in improving the health of the community through immunisation programs and disability camps. In national disability programs, the involvement of virtually all sectors of society is advocated in awareness campaigns such as International Disability Day. This aim, however, is at odds with the widely observed phenomenon of non-participation by the majority of community members, both disabled and non-disabled. ‘Traditional Voluntarism’ is another type of participation which has extensive roots in most societies. Altruistic in philosophy and often focused on target groups such as disabled persons, voluntarism alone does not allow a transformational process nor an empowerment experience for disadvantaged persons. Finally, there are ‘Self-Help and Advocacy’ types of participation. Primarily small scale in design, these approaches aim to balance their limited numbers of participants with a wider impact due to transformational processes and to public advocacy.
Numerous contradictions have been noted about community participation in health development projects (40). For example, many projects utilise forms of community ‘health education’ which emphasise personal behaviour change alone and do not address social determinants of health and disability, such as poverty. Most evaluations of health development programs assign minor importance to community participation, or simply count the number of community members who are involved in program activities (41). In explaining problems in community participation in health promotion projects, analysts have tended to criticise the motivations of individual community members, or the negotiation process between different interests, as being deficient rather than examining the basic organisation and structures which inhibit or support the process.

Farrant (42) points out that participation is supposed to be a key strategy in health development but there is little resource support for it in practice. Health and rehabilitation development projects are often understaffed and limited in their funding which preclude public involvement in needs identification, skill development, and ongoing participatory activities.

Community members are supposed to be central in participatory strategies, but competition between more powerful professional and bureaucratic interests often marginalises the community in health development (43). Similarly, community experience is claimed to be the primary basis for planning projects, but scientifically based knowledge is often given more credibility by funders (44).

On a state level, Navarro (45) notes that there is a contradiction in the state’s advocacy of local autonomy through community development while maintaining centralised, bureaucratic planning of health and rehabilitation programs. At the local level, there is a parallel contradiction in the use of the rhetoric of empowerment without an understanding of power relations in the community (42).

Overall, the geographical and relational dimensions of community, coupled with its positive interpretation, renders the term extremely useful to a multitude of interest groups. Co-optation of the term ‘community’ happens at national and international levels and implicates academic, service, and advocacy organisations. This practice frequently leads to these bureaucracies defining what constitutes a community, how it should act, and ultimately allocating resources based on these definitions. This tendency to bureaucratise community development is fundamentally opposed to the need for individuals to define themselves voluntarily in terms of shared location or interests. Furthermore, the strong emotional connotations of community may pull local people into alliances they might not otherwise support.

If the meaning of the term can be so manipulated, how are we to recognise genuine community participation? When is the language of community used to mask deep divisions between groups? When is community simply used as a rhetorical device to promote the status quo? These are some of the questions which can be answered through close scrutiny of the successes and failures of international CBR programmes. We now turn to the basic social issues which community participation in CBR must address.

COMMUNITY DIVERSITY

An uncritical embrace of community rhetoric assumes that ‘natural communities’ exist and consist of harmonious collections of individuals, mutually supportive of one another, and committed
to communal responsibility (46). The international community development experience, however, has clearly demonstrated that communities are very diverse and often tumultuous places (47, 22). There are frequently vast differences within and between communities with respect to ethnicity, age, gender, and socio-economic status which then create problems in the co-ordination of services (48, 49). Vested interests in communities and power structures that permit access to communal goods for some people, while systematically denying such benefits to others, also threaten community development success (50, 51). Additionally, because of a variety of political and developmental trends (changes in land tenure and usage, migrant labour, urbanisation, wars and conflicts leading to large-scale refugee and displaced populations), the cohesive ‘traditional’ community, may be fast disappearing (52).

Recent analysis of the international disability context suggests that the positive language of community obscures the diversity that is inherent in disability settings (53). Investigating community diversity is imperative for CBR, otherwise neglect of its disparate factions and their contentious needs may derail attempts to mobilise community action around disability. Furthermore, ignoring community diversity risks overburdening particular segments of the population active in CBR, and risks misjudging levels of commitment to a CBR approach.

The first lesson which one can take from the international experience is the need to carefully assess the capacity of community groups to become involved in CBR implementation. When initiatives focus on the poor, the disabled, or other disadvantaged populations, utmost care must be taken so that the burden of organising change is not placed solely on disadvantaged groups. There are important costs involved in participatory activities, including personal time and out-of-pocket expenditures for travel. This has real and profound implications for participation, particularly for women who are the traditional caregivers of disabled people (54). Unless participation is carefully crafted and monitored to take these issues into account, few may be willing to be actively involved in CBR.

The second lesson to be learned about community diversity relates to the matter of disparate interests. The international experience has shown that a powerful vested interest can control the local health agenda and “usurp the resources of development in its own interests, rather than sharing the fruits of development with the deprived and neglected sector of local communities” (55). In such cases, the centralised control of medical professionals and governments is simply replaced by the localised control of powerful community interests (56, 48). If one of the aims of CBR is to address the disability needs of individuals who are not reached by institutional rehabilitation in urban centres, then it is imperative that CBR proponents recognise the diversity of these communities and find ways of including their most marginalised and disenfranchised segments (57). Once the fundamental diversity of communities is recognised, steps to determine the disability-related needs of communities can proceed with assurance that the breadth of community concerns are represented fairly.

COMMUNITY NEEDS

One of the issues to be examined in the area of needs identification is the community’s understanding of disability. International experience has shown that determining who is, and who is not, disabled is not at all straightforward. Ingstad and Whyte (58) have described a tremendous
variation between countries and communities as to what constitutes ‘disability’. For example, Lysack
(59) reports how mental impairments such as mild learning disabilities are simply not recognised as
problems by local people, including rehabilitation workers, in many parts of rural Indonesia. The
same is true for physical impairments like limb deformities. The label ‘disabled’ in Javanese society
is attached only when people are unable to perform the social tasks common in their communities.
Thus, what is considered ‘normal’ with regard to individual functioning depends, for example, on
age and gender but is also highly dependent upon the society in which these norms are generated.
The lesson for proponents of CBR is that they must carefully dissect local social and cultural
understandings of disability. For CBR to have its intended impact, local meanings of disability
causes, the nature of appropriate therapies, and local attitudes toward people with disabilities also
need to be examined.

The second major challenge related to identifying community disability needs in developing
countries has been the relatively low priority of disability. A recent meeting of international CBR
experts confirmed that, in many developing countries, disability issues are ranked well after food
security, shelter, education, and income-generation as priority personal and community needs (60).
This low priority is reflected at the funding level as well. For example, the recent Canadian
International Development Agency ‘Strategy for Health’ discussion paper (61), fails to mention
disability at all.

The low priority of disability matters in communities is a complex phenomenon and is intricately
linked to several other issues. The low priority of disability issues is also related to the small numbers
of disabled people in any locality. Disabled persons are a minority, and unlike other minorities such
as ethnic groups, are often geographically dispersed. This demographic fact results in the lack of a
‘critical mass’ of disablement necessary for effective programming and lobbying, especially
considering disabled persons’ mobility limitations. To some extent, low priority is also accounted
for by the stigma attached to disability. Negative attitudes, lack of education, and other historical
biases within dominant societies prevent people with disabilities from holding substantial personal
or political power (62). Finally, the low priority of disability may be due to the notion that disablement
is a natural outcome of the ageing process in all persons, and therefore not a problem that requires
active intervention. Interestingly, in areas of armed conflict, disability achieves a much higher
priority in communities because of both the cause, overt hostilities, and the geographic intensity of
the problem (63, 64).

People with disabilities are typically isolated from mainstream political and social life in the
community, including the organisational structures of the health system. Hence, they may be unaware
of opportunities for participation. Even when relatively powerless groups such as disabled people
do find ways to participate, there may be real problems in gaining access to necessary information
in understandable forms for policy development, planning, and program implementation. Finally,
poor and disadvantaged people, including people with disabilities themselves, may discount the
participatory process, preferring instead to rely on professional and governmental management of
community health problems (21). Paradoxically, there are anecdotal reports of CBR projects
implemented via such top down administrative approaches which would have failed with less
authoritarian structures (65). This state of affairs may be particularly common in countries with
long colonial histories, like India, where local people had not previously been encouraged to take
social development initiatives independently. CBR advocates must remember that people do not automatically know how to participate, and many have never engaged in co-operative community initiatives.

A third lesson that can be extracted from the international CBR experience is that the nature of community need will undoubtedly be contested. For example, CBR experts often believe that disability prevention programmes will improve community conditions. Prevention programmes may be rejected by communities, however, if community members defend the adequacy of indigenous culturally-bound methods for coping with disability (66, 22). A related difficulty is that CBR initiatives emphasising prevention do not possess the immediate impact of quick and visible ‘curative’ interventions. Providing dramatic proof of the benefits of a community referral system in CBR may be one way to secure community interest. For example, publication of the effects of surgical correction of club foot deformities is one way in which CBR can promote itself (60).

International CBR has shown that disabled people themselves are often interested in fragmented pieces of an entire CBR programme. One popular interest is in receiving adaptive equipment that provides immediate and tangible improvements in daily life (67). However, ‘cure’ and technical devices are not the principal focus of a community development style of CBR. Thus, sustaining long term commitment to CBR as a community development practice in developing countries has been difficult to achieve (3, 68).

Finally, in the determination of community needs which are critical to CBR development, there are profound difficulties in reconciling individual and community interests. Who speaks for the community and how are personal interests protected? Again, the CBR experience in Indonesia has been instructive. In Central Java, where the wives of prominent local government officials often serve as CBR workers, real conflicts have arisen between the local agenda of disabled people and the policies of government (59).

The lesson for CBR advocates is that community interest must be generated through real consultations with local people and material improvements in their lives. Evaluations of international CBR suggest that the greatest success has been enjoyed when disability is incorporated into broader community development strategies (67, 60, 69). A community development approach integrates a disability perspective into every facet of community activity, from childhood education to nutrition, from agriculture to sanitation, and from family planning to income-generating enterprises. A preliminary step in this direction may be to append CBR activities to already established health and education initiatives. Rather than adding a new layer of paraprofessionals, such as physical therapy assistants and occupational therapy assistants with their accompanying bureaucracies, existing community health workers, public health nurses, and special education teachers could receive additional CBR education and training. In this way, preexisting infrastructures can be utilised efficiently, to maximise the gains for people with disabilities, while searching for better opportunities and more creative solutions over the longer term.

COMMUNITY MOBILISATION

Since the essence of CBR is community participation, it is important to understand how communities have become mobilised in CBR in the international context. First, some communities
view rehabilitation as a government, not a community responsibility, and do not become involved at all (70). Second, some communities, even though they accept that they have a responsibility for rehabilitation, have rejected CBR because they perceive it as a second-rate service in comparison to institutional care (71, 72). These villagers have feared that CBR means replacement of limited professional services with services delivered by unpaid volunteers who have inadequate knowledge and skills. The accelerating pace of modern communication has meant that many communities in developing countries have become aware of what they do not have, and are unwilling to settle for something they perceive to be secondbest.

Third, there is evidence that community mobilisation has many purposes and intentions: from ‘efficiency’ in gaining community members’ contributions of time and money; to ‘involvement’ of disadvantaged persons in socially supportive activities; to ‘equity’ in decision making with professionals (32). In its idealised form, CBR is highly reliant on the concept of equity. But, the entire idea of equity may be alien to people who are not used to being asked for opinions that will shape the delivery of rehabilitation services. It is has been very difficult to convince people in developing countries who are suspicious of past community development failures that CBR will be any different (73).

Thus, lack of interest, inexperience, and distrust in community mobilisation efforts characterise a number of international CBR experiences. One can ask why the public should be attracted to CBR services. One potentially powerful motivator, the devolution of central control to local levels, appears to be undertaken primarily for economic reasons. Governments provide the monies for services and leave their configuration and delivery to local groups, thus saving the central planning costs. A growing concern with this approach, which is increasingly voiced in the international context, is that local control may not guarantee financial savings. Especially during periods of economic decline, rural communities are wary of programs which call upon local participation to supply scarce resources. They may also be sceptical of CBR if it does not address issues such as poverty and discrimination that so profoundly affect the experience of disability. Furthermore, local control of disability programs may not eliminate the negative aspects of centralised models. It may just reproduce them on a smaller scale with elite community members at the helm.

Finally, international CBR foreshadows increasing tensions between people with disabilities and able-bodied persons. For example, in many countries of south east Asia where economic competition is fierce, efforts to improve efficiency and enhance market shares mean that commercial enterprises focus their energies on recruitment of fast-working, able-bodied employees. As global modernisation forces national governments to shift resources away from social programs toward economic stabilisation goals, communities may view job accommodation or services for disabled people to be luxuries that they can ill afford. If this occurs, it is possible that disability services, talked about today in the language of independence and empowerment, will revert tomorrow to more traditional models of care.

Charitable organisations, religious groups, and volunteer agencies are still responsible for the care and rehabilitation of great numbers of disabled people in developing countries. Although it is unlikely that this will return as a major trend in the industrialised world, we have already seen in the West significantly increased demands on voluntary agencies and families as government financial
support for community disability programmes are decreased. How will people with disabilities react to losing these hardwon rights and services?

CONCLUSIONS

The overall goal of this paper has been to assist in identifying the opportunities and constraints which CBR faces with respect to community participation. The critical lessons from abroad can be summarised as follows: Community diversity reminds us of the disparate interests of communities and that expectations of participation can overburden specific segments of the community, especially women. Examination of the process of eliciting community needs highlights several other problems around the determination of the meaning of disability and what counts as needs. We have learned that the definition of disability is culturally constructed, as are its causes and proposed remediation. We also know that disability may not be a community priority, and what is in the best interests of individual disabled persons may not be in the best interests of the community as a whole. Finally, critical examination of community mobilisation strategies reveals that projects grounded in local participation can still be rejected. Rehabilitation may be believed to be a government responsibility, or CBR may be seen as a second-rate service in comparison to professional and institutional services.

Suspicion of community based projects in a time of shrinking global economies and diminishing resources for health should not come as a surprise. The off-loading of traditional government responsibilities in areas of health and social services to the private sector is a growing feature of the political landscape. If CBR is to escape this dilemma, it seems imperative that those who are interested in developing a community approach take note of others’ experiences. Critical analysis is clearly the starting point for understanding the history and lessons of international CBR. The next step, and undeniably the more difficult, is understanding and applying these lessons at home.

We have shown that community diversity, needs identification, and mobilisation strategies have represented considerable challenges to the development of community participation in CBR. Those interested in CBR should take note of these experiences and adapt their plans accordingly. We assert that knowing the communities in which we live and work is crucial to this task (17).

Community is a term with powerful positive characteristics, but also with the potential to divert attention from significant problems in society. Its idealist basis is easily coopted without regard for its true characteristics and values. We need to be aware of this danger and critically examine claims to community for the legitimate signs of ‘communitas’ and ‘biocenosis’ - common concern, integration, and interdependency. The challenge of CBR is in finding ways of integrating persons with disabilities in such communities.

(* Sections of this chapter have been adapted from an article previously published in the Canadian Journal of Rehabilitation (Boyce, W., and Lysack, C. (1997). Understanding the Community in Canadian CBR: Critical lessons from abroad. Canadian Journal of Rehabilitation, 10(4), 261-271).

REFERENCES


