

CHAPTER 3

What is Participation?

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SUMMARY

This chapter presents arguments as to why participation is important for improving life situations, particularly for the poor and disadvantaged, including people with disabilities and their families. It begins by noting that the contribution of participation to health development is not easily agreed upon. It then, outlines the reasons for participation in health development and how this has affected the development of community based rehabilitation programmes. Ways of defining and assessing community participation are discussed. The penultimate section identifies critical issues that must be addressed in considering participation as a basis for CBR programme planning, giving examples from the Ugandan context. The conclusion points to the complexity and challenges that participation presents, for planners and managers of community based health and disability programmes.

INTRODUCTION

There is no agreement among planners and professionals about the contribution of community participation to improving the lives of people, particularly the poor and disadvantaged. Some completely dismiss its value altogether, while others believe that it is the ‘magic bullet’, that will ensure improvements especially in the context of poverty alleviation. Despite this lack of agreement, community participation has continued

to be promoted as a key to development. Although advocacy for participation waxes and wanes, today, it is once again seen by many governments, the United Nations agencies and non-governmental organisations (NGOs), as critical to programme planning and poverty alleviation (World Bank, 1996).

Planners and managers cannot agree upon the contribution of community participation to health improvements.

REASONS FOR COMMUNITY PARTICIPATION

Community participation has been a constant theme in development dialogues for the past 50 years. In the 1960s and 1970s, it became central to development projects as a means to seek sustainability and equity, particularly for the poor.

It became a central plank for health policy promoted by the World Health Organisation, in its conference in Alma Ata in 1978 (WHO/ UNICEF, 1978). In accepting Primary Health Care as government policy, all members of WHO recognised the importance of involving intended beneficiaries of services and programmes, in their design and implementation. The following reasons for this acceptance were put forward.

1. The health services argument: the services provided are under utilised and misused, because the people for whom they are designed are not involved in their development.
2. The economic argument: there exists in all communities, financial, material and human resources that could and should be mobilised to improve local health and environmental conditions.
3. The health promotion argument: the greatest improvement in peoples' health is a result of what they do to and for themselves. It is not the result of medical interventions.
4. The social justice argument: all people, especially the poor and disadvantaged, have both the right and duty to be involved in decisions that affect their daily lives (Rifkin, 1990).

The process of service development for people with disabilities, in developing countries namely, Community Based Rehabilitation (CBR), arose out of the philosophies of Primary Health Care (PHC). It was recognised that institutional rehabilitation was not meeting the needs of persons with disabilities in the world, and in the Alma Ata declaration (WHO, 1978), rehabilitation was added as the fourth component of PHC, together with promotion, prevention and curative services.

O'Toole (1996, pp13) points out that the *“emergence of the PHC concept entailed acceptance of two principles... that it is more important to bring about small improvements among the entire populations than to provide highest standard of care for a few privileged”* and that... *“non professionals with limited training could provide crucial services”*.

As a result, the World Health Organisation (WHO), who were the architects of CBR, built it on the premise that there would be a transfer of information and rehabilitation skills to people with disabilities and their families. Members of the local community would also be involved in the planning and decision making of these programmes (Helander et al, 1989).

Through the 1990s, additional emphasis has been placed on community involvement in planning, decision-making and evaluation (Mitchell 1999, Sharma and Deepak, 2001). It has also been recognised that CBR partnerships can utilise resources in the community to reach larger numbers of persons with disabilities (Lang, 2000).

Twenty-five years of experience in development work, both in health and disability, finds these arguments still relevant. In the present political and economic climate, organisations such as the World Bank have modified these reasons to pursue the objectives of both, equity and sustainability. These modifications reflect the experiences of particularly the international development agencies. They also reflect the influence of strong advocacy for participation from people like Robert Chambers and other promoters of PRA/PLA (Participatory Rural/Rapid Appraisal; Participatory Learning Approaches) (Chambers, 1994).

The World Bank's reasons for community participation are:

1. Local people have a great amount of experience and insight into what works, what does not work and why.
2. Involving local people in planning projects can increase their commitment to the project.
3. Involving local people can help them to develop technical and managerial skills and thereby increase their opportunities for employment.
4. Involving local people helps to increase the resources available for the programme.
5. Involving local people is a way to bring about 'social learning' for both planners and beneficiaries. 'Social learning' means the development of partnerships between professionals and local people, in which, each group learns from the other (World Bank, 1966).

Some arguments for including participation in health and disability programmes are:

- 1. People know what works for them and professionals need to learn from people.**
- 2. People make contributions of resources (money, materials, labour) for these programmes.**
- 3. People become committed to activities that they have helped develop.**
- 4. People can develop skills, knowledge and experience that will aid them in their future work.**

DEFINITIONS OF COMMUNITY PARTICIPATION

Although many people agree that community participation is critical in development programmes, very few agree on its definition. The various definitions are:

WHAT IS PARTICIPATION?

- Voluntary contribution to public programmes but people do not play a role in shaping the programmes.
- Involvement in shaping, implementing and evaluating programmes and sharing the benefits.
- An active process where intended beneficiaries influence programme outcomes and gain personal growth (Oakley, 1989).

In the field of health and disability, perhaps a more concrete dissection shows the differences in definition and understanding of the concept. We might suggest that planners/professionals in this field have looked at community participation in three distinct ways (Rifkin, 1985).

Definitions of community participation range from people passively receiving benefits from health/disability programmes to people actively making decisions about the programme policies and activities.

The first is the medical approach whereby, health is defined as the absence of disease and community participation is seen as doing, ‘what the doctor ordered’.

The second approach is a health planning approach where health is defined in the World Health Organisation’s term of, “*not merely the absence of disease, but also the physical, social and mental well-being of the individual*”. In this context, community participation is contribution to the delivery of a health service by contributing money, materials and human resources.

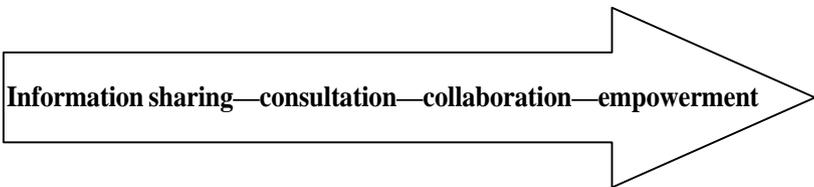
The third approach, is that of community development where health is defined as a human condition and community participation as active involvement in decision making and accountability for programmes.

These three views correspond with frameworks drawn from those involved in rural development thinking. The following table illustrates two additional aspects of defining participation—that of interaction between professionals/planners and community people and the process of developing community participation.

Practice of Community Participation

Approach	Model	Process
Medical	Compliance	Marginal Participation
Health Planning	Contribution/ Collaboration	Substantial participation
Community Development	Community Control	Structural Participation

The table above illustrates the different approaches. They should not be seen as mutually exclusive. It is perhaps better to see them on a continuum that at one end has information sharing and at the other, empowerment. While there is no one definition of the concept, the continuum presents a framework, which allows the range of views to be accommodated.



Information sharing is equated with professionals giving information to lay people. Empowerment means providing opportunities and experience, to allow community people to be actively involved in the decision making about the programme (Rifkin and Pridmore, 2001).

Community participation is best seen on a continuum, because this emphasises the importance of the participation process, rather than just the outcome.

ASSESSING PARTICIPATION

If there is no agreement about how to define participation, there is a growing understanding among professionals and planners at least, that participation is best seen as a process, rather than an outcome of an intervention. This does, however, pose questions about how to assess the process in order to assess programme achievements.

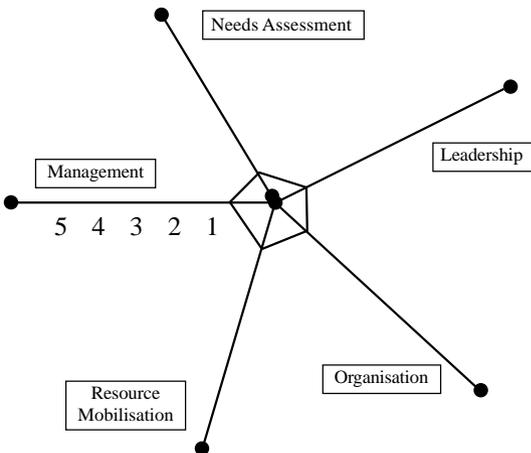
WHAT IS PARTICIPATION?

Traditionally, community participation has been assessed in quantitative, numeric forms for example, by asking how many people have come to a meeting or how many people have joined in a community activity. The dilemma however, is that presence does not indicate participation. People can come, but not have any commitment or understanding of what is going on.

Sherry Arnstein, about 25 years ago wrote about this situation. She offered an analytical visualisation called, 'ladder of participation'. The bottom step is that of informing people, while the top step is citizen control. Mid-way, where partnership begins to develop, the degree of participation moves from mere tokenism to degrees of citizen power (Arnstein, 1969).

A more recent visualisation that stresses the same points, is that of the spidergram. Here, it is possible to describe changes in the process by plotting the situation along 5 continuums. Each is a critical factor in participation and all are joined in the middle to give a holistic view of the programme. The five factors are—needs assessment, leadership, organisation, management and resource mobilisation.

Participation viewed as a spidergram (Rifkin et.al 1988)



By placing a mark corresponding with the width of participation in the programme on each continuum, over time, it is possible to record the changes in participation.

The spidergram is a tool that allows planners to see participation as a process and assess the changes and progress of a programme, over time.

CRITICAL ISSUES FOR PARTICIPATION AND PLANNING

Over the past 50 years, experiences have highlighted critical issues for planners and professionals, who promote participation in development programmes. These issues emerge from trying to seek a universal definition of community participation and shifting views from participation as a product (either an outcome of an intervention, or a means by which to implement an intervention), to viewing participation as a process. Given below, are some most important issues.

The first, is the lack of a universally accepted conceptual framework. Although it is argued that participation has strong methodological roots, this view has been challenged. In a recent publication entitled '*Participation: the new tyranny?*' (Cooke and Kothari, 2001) it is argued that it is not possible to develop such a methodology, because participation comes about as a result of practice in specific situations. To view participation without the grounded experience would not be possible. People, especially those involved in the projects, view specific projects in a variety of ways. Consensus about what works and why, is not possible and is in fact, mutually exclusive from a single view about the process. This lack of a framework makes those living in a technological world, feel uneasy and view participation as a 'soft' science. That, participation cannot be measured, quantified and replicated, is a concern to those who are trying to see universal solutions to the wide-ranging problems of the modern world.

A second critical issue for programme planners/professionals concerns the assumptions about participation as a panacea to development. It is assumed that participation will lead to sustainability of programmes, to

equity and to empowerment. However, the evidence of a direct causal relationship is very scarce. Anecdotal data provides support of a linkage, but not a direct knock-on effect. While it may be fair to say participation is necessary for all these outcomes, this in itself is not sufficient. More research needs to be undertaken to examine the relationships. However, we must recognise that these relationships are most likely to be situation specific. The third and most critical issue is the way in which planners/professionals deal with power and control. By involving local people, professionals and planners are giving up complete power and control over the design and management of the programme. Many see this step as threatening and dangerous, because professionals can no longer be sure that the programmes are making good use of the resources given to them. They are afraid that they will be challenged about the power given to local people, if things go wrong. Past experiences, attitudes, beliefs and usually behaviours, re-enforce the power, high status and often the salaries of professionals. They do not want to share power with local people, if this might damage their chances of continuing to receive these rewards.

Three critical issues for the development of the future of community participation are:

1. How to deal with the fact, that there is no universally accepted conceptual framework to develop participation in health and disability programmes.
2. Unrealistic assumptions about the contribution of participation to these programmes.
3. Issues surrounding the power and control of programmes, between professionals and community members.

COMMUNITY PARTICIPATION IN CBR

The assumption that communities are homogeneous, cohesive and benevolent towards people with disabilities, is challenged by Lang (1999) and Thomas and Thomas (2001). Lang points out that, “*CBR advocates have been criticised for an apparent assumption that local communities*

are benevolent, homogeneous, willing to get involved in meeting the needs of some of the marginalised members of their community and have adequate resources to do so” (pp135). These authors further point out, that disabled people are a minority who are not usually part of the power in the communities and generally get very little attention.

In addition, given the origins of rehabilitation in the charity model, communities often feel that disabled people ‘belong to the government’ and view any expectations from the community, as an abdication of responsibility on the governments part (Thomas and Thomas 2001). The top-down approach of the medical model has also meant that professionals in CBR, continue to be the decision makers and this has supported a tendency to postpone participation as a long-term goal (Lang, 1999).

Thomas and Thomas (2001) point out that, it is difficult to share the little resources that there are in communities where poverty is rampant, where there are so many unmet needs. Nunzi (1996), notes that attempts to overcome this difficulty by the use of volunteers has made it a precarious situation.

Examples from the development of CBR programmes in Uganda, however, indicate that the process of participation appears to be a key ingredient. In Uganda, CBR was initiated by local NGOs, but in the early 1990s, the Ministry of Local Government launched 3 CBR programmes in the western region. At that time, there was a highly motivated NGO, National Union of Disabled Persons of Uganda (NUDIPU) whose support was utilised. The Uganda programme realised early itself, that using volunteers as service deliverers was not a workable solution. The programme therefore, trained community development assistants (CDAs), who were already an officially paid cadre of workers that operate at the community level. These CDAs work in different sectors of development and are in a position to coordinate different groups for community participation. The roles of the CDAs have included: identification and rehabilitation of people

with disabilities; counselling of families; community mobilisation and sensitisation; formation of groups including cultural groups; and socio-economic activities. It is generally agreed, but not formally illustrated, that their involvement and the high level of community participation that they have achieved, has been a key ingredient in the success of the programmes. In the initial period, the CBR programme was working in isolation from other programmes, but in recent years has formed CBR committees, from the national to the grassroots level, with members from all stakeholder groups. There are also increased joint planning meetings of Government Ministries, NGO and training institutions, for joint planning and training and increased sectorial collaboration. The Government is now contracting NGOs to carry out some activities at the grassroots level. One of the lessons learnt in this process, has been the important role played by the disability leaders, who have motivated disabled people to participate in CBR activities.

CONCLUSION

In conclusion, to answer the question—what is participation? We can say it is a complex and challenging approach to improving the lives of all people, but particularly the poor and disadvantaged. We can also say that viewing participation as an intervention to achieve this goal, has produced disappointing results and suggests that viewing participation as a product, raises expectations that experience shows cannot be met. For those addressing issues of disability and community-based rehabilitation, there are lessons to be learnt from the health experience, which can influence the development of service strategies for people with disabilities. It is important to critically examine these experiences and distil the important points. But it is more important to keep an open mind and be flexible. This includes examining our own assumptions about what works, and developing attitudes and behaviours that support intended beneficiaries, in their search to gain control over their own lives.

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WHAT IS PARTICIPATION?

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