

PARTICIPATION IN COMMUNITY BASED REHABILITATION PROGRAMMES IN ZIMBABWE: WHERE ARE WE?

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ABSTRACT

Primary health care and community-based rehabilitation emphasise community participation. Many health care and community programmes attempt to develop participation. However, insufficient analysis of the processes of participation has taken place. This paper presents preliminary observations of participation in Community Based Rehabilitation (CBR). Based on the experiences of the two authors in implementing over 20 CBR programmes in Zimbabwe, the paper identifies the type and development of participation within CBR. It is hoped that lessons can be drawn from the experiences of the CBR process in Zimbabwe and further questions can be asked, to help develop a conceptual approach for planners and implementers working with communities.

INTRODUCTION

Community based rehabilitation is a process of empowering persons with disability (PWD) and their families, to take care of their needs in every sphere of their lives (1). This implies that PWDs and their families have a key role, which will require participation to a greater extent, in various processes of CBR.

A whole range of interpretations of participation has been reviewed. It has been proposed that participation exists at a series of levels ranging from information giving to initiating action - true empowerment (2, 3, 4). A review of the literature reveals interchangeable use of the terms "community involvement" and "community participation." While community participation was the term used in the original Alma-Ata document of 1978, community involvement is now the preferred term because, "to participate may be simply a passive response" (5).

Compliance, contribution and collaboration are other descriptors used, to outline the linear process of community participation/involvement from a one-way process of receiving information, or nothing at all, to control and collaboration with other key players, for all decisions (6).

Nevertheless, the essence of community participation has been described as highlighting principles of inclusion and “starting where the people are”, in terms of their perceived needs, rather than with the needs and goals of the change agency (7). Genuine involvement in the social change process is important, because participants become empowered by their ownership of the programme. Several authors view community involvement as a means of empowering communities (5, 8, 9, 10).

Implementers in CBR, recognise that community participation is in a dynamic rather than static state. After reviewing a number of programmes, it was concluded that people in the same programme over a period of time and with increasing experience, might not hold the same definition today, as they did five years ago (11).

In implementing CBR in Zimbabwe, there has been no attempt to define community participation, but rather, efforts to identify the fundamental principles that would underlie community participation and ensure that the programme embraced them. These included not just a commitment of professionalism and expertise, but a move back, to fundamental principles such as:

- An effort to remove the blinkers that professionalism has imposed upon individuals.
- A dismantling of the structure whereby others within the community have come to have more power over the PWDs, than they have over themselves. For example, in the past, the PWDs were often dependent on visits to the institution-based service for treatment and the professional determined the progress.
- A practice of CBR wherein a concerted effort is made towards empowering the client, the family and community, in dealing with the problems of disability.
- The efforts in shifting the power base to community level and trying to make the system and structures support these efforts. Examples include the legal, para-legal and social systems.
- The financial base in CBR remains largely at district and provincial level and therefore, innovative ideas on how to effectively shift some resources to the community level, are still needed.

THE CBR PROCESS

The process of community based rehabilitation emphasises integration and provides an opportunity for people with disability to have full participation and equalisation of opportunity within their society (1). During this process, the people with disability are exposed to day-to-day risks. This equips them with confidence and teaches them skills to negotiate and overcome problems and achieve their own rehabilitation through self-help.

The major steps followed in the implementation of CBR in Zimbabwe were:

1. Social mobilisation and awareness raising

The process of social mobilisation began by informing the community on the use of existing community channels and structures. This often involved meetings between rehabilitation staff and chiefs, councillors or other political leaders, and attending various development meetings, where the required special arrangements were made. For example, the sensitisation of PWDs', their families and other community support systems, schools, and community workers commenced at individual treatment contacts and in the home. Following this, needs could be identified and training programmes planned.

2. Education and training

The need-based training of community based workers such as village community workers (VCW), community health workers, family members, the person with disability, community members and community leaders was carried out. The areas of concern most often were education on the types and causes of disability, and training in the processes and interventions involved in rehabilitation. A key component in the training methodology was to inspire positive attitudes toward PWDs.

3. Survey and needs analysis

After training the key players, a rapid assessment of the status of disability and the situation of disabled persons was conducted. This survey was carried out by community workers selected by the community. They used screening tools that were developed and refined jointly with the professional rehabilitation staff.

4. Implementation

Examples of some activities to meet the identified needs include:

- Client, local facilitator, therapist and technician training sessions.
- Income generating facilitation either directly through community based health workers, such as environmental health technicians and extension workers from other ministries or departments.
- Home visits and outreach consultations to take care of individual needs and reassessments of chronic and new referrals.
- Regular attendance of inter-sectoral and development meetings by clients, VCWs and periodically, technical rehabilitation staff, to allow facilitation of developmental issues for PWDs.

- Referral of clients in need of services not available in the community, such as audiology services and orthotic and prosthetic fittings.

PARTICIPATION IN CBR

The process of rehabilitation includes prevention, identification and referral, treatment, resettlement and integration, vocational training and the provision of aids and appliances. Planning of implementation and evaluation must be synchronised at individual and community level, for a successful rehabilitation outcome.

One of three types of participation could be chosen during the different stages of CBR namely, compliance, contribution and collaboration. While collaboration was the desired type of participation, it became evident that communities found the contribution type more tangible and hence, more meaningful type of participation. Often, this was in the form of labour contribution, and on occasion, took the form of material resources.

Participation in identification and referral

In the past, one of the problems for rehabilitation and dealing with disability, was the lack of knowledge on the part of the community, more specifically, the community health workers. The emphasis on prevention of disability, early identification and intervention in primary health care (PHC), will not only reduce the incidence of disability, but will also reduce the prevalence and intensity of disabling and handicapping factors. Early intervention also encourages an early integration process, which helps to reach the ultimate goal of the rehabilitation process (12). After the intensive education and awareness programme, these same community members continue to play a vital role in the identification and referral of PWDs. Forty-one percent (n=100) of clients presenting themselves to rehabilitation departments in the Mashonaland Central province of Zimbabwe, were found to have been referred by the community health worker (10).

Participation in CBR programme planning

A CBR programme gives the community an opportunity to develop an awareness on:

- Development needs of disabled people.
- Skills PWDs need to acquire, in order to cope with their physical, psychological and environmental problems.
- Knowledge regarding the methods, process and advantages of integration. This continuous realisation by the community and family is paramount to the success of CBR, because disability is not a static situation. "...Disabled children become disabled adults with great vulnerabilities and needs... CBR can evolve and adapt to such fluid situations,

while the rehabilitation centres will often only be able to “take a photo” i.e. deal with one set of problems at one point in the life of a disabled person” (13). However, our experience in implementing over twenty CBR programmes shows that once they were aware, the community participated actively in planning, by defining the parameters, both geographical and at times, programme design. The community would through discussion, identify implementers, participants and priority areas. The community leaders would participate in awareness raising and community mobilisation, before the community and facilitators could start active implementation of the programme.

Participation in programme implementation

In CBR, the person with disability and his family, are expected to take the leading role in determining the key objectives of their rehabilitation process. For example, in identifying the problems faced by the PWD, the professionals’ role would be one of guiding the process and teaching the family and client, simple and appropriate technologies for coping with disability. The areas of guidance expressed by the community in the national evaluation in Zimbabwe, were:

- Materials and financial support.
- Assisting in running income generating projects.
- Identifying and referring PWDs.
- Moral support.
- Motivation of the community by local leaders.
- Setting up of community centres for self help activities (14).

Thereafter, the family and client determine where and when, to get subsequent assistance. The focus is being, to minimise the dependency on the professional, allow active participation of the PWD and family, and through these activities facilitate ongoing and sustainable rehabilitation.

Participation in programme evaluation

The direction of CBR is determined by the ongoing evaluation carried out by the family, client and community. In CBR, it is hoped that participation will be enhanced if the clients and community see that the progress and direction of the programme is determined primarily by their inputs. In the process of CBR, focus group discussions are held regularly with community workers, family members and with clients themselves, to gain an insight and to provide inputs on what they perceive as key problem areas. In this process, some of the obstacles to CBR become apparent.

OBSTACLES TO PARTICIPATION IN CBR

In the process of CBR implementation, it was anticipated that collaborative participation would occur. However, some issues, which hindered participation, became apparent in the process.

The poor knowledge of CBR: The historical background and orientation of most communities with regard to disability was that of disabled people being objects of charity, looked after in institutions, away from the community and in many cases, hidden away from the public eye. This discouraged the concept of empowerment and self-help, of both the community and individual, and discouraged participation of community members in their programmes.

The cultural orientation with regard to disability: The cultural beliefs with regard to disability did not encourage a positive outlook towards people with disability. The person with disability has always been considered as an outcast as evidenced by the episodes of the hidden child or member of the family, and the attitude of, "not worth investing in". The parents in most rural areas of Zimbabwe and elsewhere in Africa, will educate their child with the expectation of gain, once this child is gainfully employed in adulthood.

Expectations of the community: Most communities still had expectations based on previous beliefs, experience and exposure. Disability has always been an area well endowed with charity and handouts. This has generally efficiently killed any element of self-help reliance and involvement in programmes by the person with disability and their family. It was extremely difficult to convince the people with disability and their family to participate in CBR, in areas where organisations with a charity orientation had previously operated, as they openly expressed the preference for the "easier route" i.e. "handouts". Other authors have also alluded to this culture of dependency, where communities expect charity, rather than empowerment (8).

The poverty within communities: For most rural people, survival is their greatest challenge (2). This was found to consume most of their energies, leaving precious little time to participate in community development programmes.

The social environment: Health and social problems such as communicable diseases, HIV, poor sanitation and hygiene proved to be obstacles for participation in community development issues, including disability issues. Most key people, with influence in the direction of community participation, would invest energy dealing with one or other of these overwhelming problems. From personal experience, where community workers or parents and family, would, in the past, spend some time participating in CBR, their time was now occupied, in some cases, with social obligations such as attending funerals and in a drought situation, looking for alternative sources of food.

Health workers' attitudes: Health workers, by virtue of their training orientation and the paradigm within which they work, often wittingly or unwittingly find themselves assuming a position of authority. It has also been observed, that some health professionals find developments in promoting participation threatening, while others find them irrelevant and a matter for scorn (15). In CBR, education for the professional in order to overcome some of these attitudes, which hinder progress, have been integral parts of the programme.

The health organisation orientation: Until recently, the health departments' organisation was largely centralised and only now, with the advent of decentralisation in Zimbabwe, does the organisational structure go some way towards supporting participation.

In spite of all these obstacles, seen as a real hindrance to community participation, successes have been observed. However, in these circumstances, issues that emerged impacted negatively on the CBR process itself.

EMERGING ISSUES AGAINST PARTICIPATION IN CBR

The authors' experience has shown:

- The risk of providing substandard service due to the decreased use of professionally trained workers, exists. As illustrated by one VCW “ *You cannot expect us to be precise on things we learnt without background training...*”.
- A dilution of quality and poor rehabilitation outcomes may result. The stated objectives in CBR need to be closely monitored and more so, the systems put in place, to fulfill these objectives. Community members were in most cases, perhaps ill equipped to cope with this aspect, which requires both skill and experience. In the management of CBR, this was true for trained personnel and therefore, to a greater extent, the community members.
- A dilution of the benefits and advances in technology occurred in the course of translating the technology into simple technical terms, to be implemented by families and grassroots level workers.
- The existing infrastructure in the various implementing agencies such as health and social welfare, in some cases, have not been ready to integrate CBR. This has affected the participation of clients and key facilitators such as community leaders as well as the health workers themselves. Furthermore, multi-sectoral decentralisation was inadequate at the grassroots level and this seemed to hinder participation in a broader sense.

ARGUMENTS FOR PARTICIPATION

The broader arguments for participation have been grouped under the following:

- Efficiency,
- Effectiveness,
- Self- reliance,
- Coverage,
- Sustainability (2).

The authors have looked at each of these arguments for participation and attempt to describe the extent to which they have been fulfilled, in CBR.

Efficiency

Participation implies a greater chance that resources available to any development project will be used more efficiently (2). In the authors' experience, the participation of one group in CBR has often saved the staff from explaining or lobbying for a programme in an area of need. This is because the communities often see the area where the programme has been implemented as a paradigm. Community members already involved, often act as educators for new areas and hence catalyse the process.

The participation of the client, family and community in the programme, allows them to take responsibility for the programme and the needs of PWDs. This, therefore, allows the professional staff more time to deal with other areas of need. The trade-off however, is that the government may then start to allocate less resources and time, to community based development work because of the perceived saving. This places the burden of the CBR programme costs, squarely on the local community and in particular, on the family and PWD and thus endangering sustainability.

Effectiveness

Many evaluations have shown that CBR has been instrumental in dealing with a large number of the problems faced by PWDs (10, 14). After implementation of CBR, PWDs have perceived a more positive attitude towards them by the community, and have reported physical and functional improvement and the ability to sustain this improvement, in the home or community. Also of interest, is the progress in the objectives which involve the larger community, such as accessibility to schools and other community amenities.

Self Reliance

Self-reliance has been described as referring to the positive effects of participation in development projects, on rural people (2, 11, 16, 17). Participation helps to break the mentality of dependence, which historically characterised much development work. It also promotes awareness and self-confidence and encourages rural people to examine their problems and to think positively about solutions (18). Participation is therefore, concerned with human development and increases peoples' sense of control over issues, which affect their lives. This helps them to plan and implement programmes and prepares them for participation even at national and regional levels.

In the CBR programmes that were evaluated, many people with disability reported a sense of control that they did not have before. Even where the disability was severe and irreversible, the client and his/her family expressed a sense of control and self-sufficiency, where the necessary support for them was available, when sought.

Coverage

There is no doubt that the process of CBR has increased coverage and more people have access to services, that were previously available only to those residing in the cities and urban areas. This is evidenced by the growth of rehabilitation services from nine departments in the cities in 1980, to sixty in the year 2000. Forty-five to sixty percent of all geographical wards in the sixty districts in Zimbabwe, have been covered by CBR (14).

Sustainability

Experience suggests, that externally motivated development projects frequently fail to sustain themselves, once the initial level of project support or inputs diminish, or, are withdrawn. Participation is seen as being able to counter this (2). In CBR, sustainability is seen through the ability of the community and family to maintain the delivery systems and to maintain the status of community awareness and involvement in disability issues, with little, or no external support. Currently, the CBR programme is over thirteen years old in Zimbabwe. Its continued existence and activity is still very dependent on external inputs, albeit, with a different focus to the original role played. The question asked in CBR is: Are community programmes sustainable, if left entirely alone? Or, is the input of external catalysts necessary, provided their role does not remain static, but changes to suit the stage of development of the community?

CONCLUSION

Sustainability and community participation are linked strongly by the literature. The arguments that link sustainability with participation are largely economic i.e. "the maintenance of an acceptable flow of benefits from the project's investments after its completion" (2). Some include project ownership, political support, and/ or the maintenance of delivery systems. In

CBR, all these things are crucial to meeting the multifaceted needs of the person with disability. The flow of benefits can be both material, but other qualitative benefits are of significant importance for the sustainability of the programme (10, 14). One notable benefit that has been observed, is the sustenance of good and positive community attitudes in promoting community participation and sustaining CBR.

In conclusion, there are two points made by the authors. Firstly, that although some authors believe that it is difficult to tell whether genuine community participation has been initiated (19), it has been found that the communities' participation in CBR is clear, as far as the family and the community workers are concerned. The difficulty arises from the many grey areas in translating this participation to the entire health system and the total CBR programme.

Secondly, do community leaders and the systems of community development including health, really embrace participation into the mainstream development? The understanding of the types and process of community participation will be enhanced by an in depth analysis of specific systems within the CBR process.

Finally, the authors propose that planners and implementers of CBR need to develop a comprehensive model of enhancing community participation around three sets of fundamentals described in this paper. These are:

- The obstacles to participation,
- The emerging issues against participation,
- The arguments for participation.

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