

CHAPTER 11

The Role of Local NGOs in Promoting Participation in CBR

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SUMMARY

This chapter considers the three different types of NGOs working with people with disabilities (PWDs), namely, organisations of people with disabilities, associations of parents of children with disabilities and organisations for PWDs. The chapter highlights the role that NGOs have played in pioneering the development of CBR services and their potential capacity, to facilitate partnerships between the stakeholder groups. It gives specific examples of NGO activities in Ethiopia, Uganda and Zimbabwe, noting the relationship between their successes, the type of NGO and the necessity for complementary participation of all stakeholders. It suggests that NGOs' strengths lie in their potential capacity to be flexible and to participate and respond to the peoples' real needs, particularly vulnerable groups in remote locations. NGOs have skills in the development of a people centred agenda and have accumulated experiences in lobbying, sensitisation, information dissemination and advocacy. Challenges faced by NGOs are also examined, with a view to improving their capacity to form partnerships that will maximise the effectiveness of CBR programmes.

INTRODUCTION

It is recognised that NGOs have played a significant role in the development of rehabilitation services for persons with disabilities worldwide. This has been done regularly in the absence of Government involvement and initially took an institutional, charity-based approach. Present day developments, however, favour a participatory, community-based approach, complementing and liaising with Government plans and services, and working with all the stakeholders' groups. NGOs and Governments vary in their capacity to change their working practices to achieve these aims.

One factor which influences the capacity of disability related NGOs to make the necessary changes, appears to relate to their different forms, which range from small community based to national or international organisations (Lang, 2000). Local NGOs can be considered as indigenous humanitarian organisations and associations established by local community members, local professionals or a combination of both categories.

In the area of disability, the challenge is whether local NGOs have the qualities that can effectively influence power and move resources in favour of PWDs and CBR services.

TYPES OF LOCAL NGOS WORKING IN THE AREA OF DISABILITY

The types of local NGOs can broadly be divided into three and categorised by the nature of the initiators who established them. They are listed below, in the order of their historical development. These organisations, even the small and locally based ones, usually get most of their financial support from international organisations. The international NGOs range from multilateral, to bilateral funding agencies such as OXFAM and World Vision (Lang, 2000), and usually have an international influence.

1. Organisations for persons with disabilities

Organisations for persons with disabilities have been on the scene for the longest period of time, and were generally set up by philanthropists. They tended to be focused on specific impairment groups and were charity or medically based. Their membership often has a common denominator such as:

- Local community members living in the same geographical areas such as traditional organisations.
- Religious organisations/associations.
- Professional membership.

2. Organisations of people with disabilities (PWDs)

Organisations of people with disabilities were also established on the premise of uni-disability, for example, organisations dealing with the blind, the deaf. In the countries where the authors have had experience, these different organisations of persons with disabilities, joined to form a national umbrella organisation such as National Union of Disabled Persons of Uganda (NUDIPU), Ethiopian Federation of Persons with Disability (EFPD) and National Council of Disabled People of Zimbabwe (NCDPZ). The emergence of organisations of persons with disabilities, is a relatively new development that is timely and in line with a slogan of, *“nothing about us without us”*.

3. Associations of the parents of children with disabilities

The organisations/associations of the parents of children with disabilities have emerged largely as a consequence of CBR. They are recognised as pivotal organisations looking into issues affecting children with disabilities. These organisations were formed as a felt need, because parents of children with disabilities organisations, neither fitted into organisations of PWDs, or those for persons with disabilities.

The wide range of interests and perceptions reflected in the membership of these three types of disability related NGOs, is apparent from the

different activities in which they are engaged. These vary from institutional care, to educational projects, to financial support. Recent developments, have embraced a more socially orientated focus on participation, advocacy and rights.

ROLE OF DISABILITY NGOS IN PROMOTING PARTICIPATION AND CBR PROGRAMMES

Many people argue and debate as to what is the best role for NGOs in providing services and support for disabled people and their families. Has their role been effective so far? Should it remain the same? Should it change now, is this the right time? Is their role one of promoting participation, of assisting disabled people to be heard by planners and politicians? Or, is it providing services that the Government cannot or does not provide?

NGOs have grown in numbers over the past years and also widened their scope of work in all aspects of human need. This has influenced the status quo in favour of a people centred approach to development (Bennett, 1997). In turn, this has encouraged greater participation of PWDs and their families, which has led to an increased understanding of the ways in which disabled people are excluded and segregated from mainstream society. As a direct result, more 'rights' and 'advocacy based' activities have developed. The issue now, therefore, is how best can local NGOs promote positive attitudes and foster positive attitudinal change? It is this change of attitude that will liberate PWDs and enable them to actively participate and indeed, 'own' CBR.

NGOs have a propensity to work in small locations, achieving impact on the ground, as compared to the Government services that usually address the needs of a majority with little attention given to members of the civil society, who have no voice.

Vulnerable groups such as women, children and people with disabilities, have always needed support from the voluntary sector to articulate issues.

Clark (1991) highlights the role that the voluntary sector plays in mainstream development, as follows:

- Encouraging official aid and government ministries to adopt successful approaches to development.
- Educating and sensitising the public, as to their rights and entitlements.
- Attuning official programmes to public needs, through acting as a conduit for public opinions and local experience.
- Influencing local development policies of national and international institutions.
- Provider of alternative services and development projects.

Local NGOs have endeavoured to fill up gaps left by Governments in promoting participation of the identified stakeholders; to redress issues of access to community based rehabilitation services for people with disabilities, through various strategies that may include:

- Resource mobilisation;
- Community mobilisation and sensitisation;
- Community education and training;
- Attitude and behaviour change;
- Capacity building;
- Mechanisms for social economic empowerment;
- Research and information dissemination;
- Networking, lobbying and advocacy.

By participating in these various ways, local NGOs have played a linking role between the grassroots and international organisations, which have fostered the development of CBR in Africa.

VALUE OF FACILITATING PARTNERSHIP BETWEEN STAKEHOLDERS

In Africa, families, charities, non-Government organisations, community-based organisations and the government, have made a significant

contribution in the rehabilitation of people with disabilities, in the community. CBR, which started as a concept twenty years ago, is now looked at as a strategy that promotes partnership and collaboration between various groups (Boyce & Johnston, 1998; WHO/UNESCO/ILO, 1994). But, what does this mean within the context of CBR in Africa? In what ways would local NGOs participate? Which NGOs would want to participate? How would they participate and how could one quantify participation of NGOs, parents, and persons with disabilities, communities and government?

In the promotion of participation, participants were stimulated to analyse why there was a need to first find out, what participation as a concept meant in the context of CBR in Africa. In what ways would local NGOs' participation take place? Which NGOs would want to participate? In what ways would one quantify participation of NGOs, parents, and persons with disabilities, communities and government? Participation is not a new phenomenon, so why has it become important of late?

Traditionally, social problems even more complex than disability, have always found solutions from within the communities. Given the strong cause-effect relationship between disability and poverty, there is a need for local NGOs to address this issue. Can NGOs do more to enable PWDs attain economic empowerment? Are the local NGOs in a position to elevate PWDs from poverty? If so, how? The role of local NGOs in promoting Income Generating Activities (IGAs) in CBR can thus be categorised as intermediary, training and supervision, financing, and marketing products. Then, there is the issue of which of these roles the different local NGOs may play and what impact it has on promoting participation. The trend is that local NGOs may not go out to directly finance income generating activities, but rather, enable PWDs to acquire skills of accessing credit to start their own IGAs.

Experience shows that NGOs have made a great contribution in poverty alleviation, redressing gender balance, combating environmental degradation and involving the poor, in participatory development (Save The Children Fund, 1997). NGOs have also developed a reputation for

their ability to elicit participation from the communities they serve (Carroll, 1992).

Local NGOs have the potential to be an important instrument and catalyst for social change. For this to happen, there must be a quantum shift in how CBR is perceived, and crucially, in the roles of all professionals, disabled activists and the community members involved. Rehabilitation of PWDs needs a holistic approach to effectively address their felt needs and address the problems and challenges, that they and their families have to face. CBR recognises four broad categories of rehabilitation, (Lang, 1999), namely, economic, social, educational and medical.

The role of the local NGO is to support the development of all three areas, but the implementation of these forms of rehabilitation, calls for the involvement of different organisations concerned with:

- Advocacy
- Access to information
- Attitudes and attitude change

Such involvement enables CBR to bring about change for disabled people, their families and the people in the community. The CBR philosophy focuses on the fact, that most people in the community do not understand disability and do not accept disabled people as equals. To improve the lives of disabled people, a CBR programme must also, therefore, try to change community attitudes and behaviour. Small, local disability focused NGOs are in a unique position to facilitate this development.

EXAMPLES OF CBR PROGRAMMES INITIATED BY NGOS IN AFRICA

Ethiopia

In Ethiopia, Save the Children UK supports local NGOs involved in disability programmes. Collaboration with the communities to carry out activities is described below.

CBR promoters work directly with persons with disability in what is known as, 'cross disability groups'(CDAGs). These are groups formed by 10-15 PWDs with single and/or multiple disabilities of different types. They are organised to work together for their rights at all levels, moving beyond sustaining basic necessities. In doing so, the five Uni-Disability associations assist and collaborate with their activities, and the umbrella organisation at the higher level also assists them. At present, there are 11 CDAGs in Addis Ababa City and 22 in the rural part (South Wollo). The aim is that these CDAGs will be organised into forums.

The present functions of these groups is three fold, working for the schooling of their children (parents are members), promotion of income generation activities and working for skills training workshops in their vicinities.

Save the Children - UK is also directly involved, through its 10 development workers, one assistant project officer in South Wollo, and the coordinator in Addis Ababa.

Their functions are:

- Assessing, sensitising and lobbying with the local district leaders (Kebeles of urban associations and peasant associations), as well as other traditional leaders.
- Organising PWDs into CDAGs with discussions and consensus.
- Home visits, physiotherapy, case study and activating playgroups in the neighbourhood (child- to- child).
- Income generation promotion for the adults by training and organising the members into cooperatives.
- Facilitating inclusive and integrated education through conduct of summer training courses for the regular teachers, sensitising and lobbying with experts and officials in the educational structures, sensitising school communities including children, coordinating for the 1 year special education course for teachers from the target community areas.

- Facilitating upgrading of courses for the members of the partner associations of persons with disabilities and the development workers.
- Strengthening the capacity of the umbrella association (EFPD).
- Conducting planned research.

The financial resources for these activities are not significant in comparison with the collaborative work. The ‘miracle outcome’, is due to the conviction and input of the PWDs and the surrounding community members through the CDAGs. This is a convincing example of the power and impact of a participatory approach.

Uganda

There are many non-governmental organisations for, and, of people with disabilities involved in delivering services to people with disabilities. The major ones are, National Union of Disabled Persons of Uganda (NUDIPU), Uganda Society for Disabled Children (USDC), Action on Disability and Development (ADD), Norwegian Association of the Disabled (NAD), COMBRA and many others. USDC, COMBRA and NAD are leading supporters of CBR programmes. So, how do local NGOs like USDC and COMBRA promote participation of PWDs in CBR?

Uganda Society for Disabled Children (USDC) was founded in 1985, with a mission to provide resources and opportunities for children with disabilities, to help them realise their potential and lead fulfilling lives. It was founded because the needs of children with disabilities were not well represented by the DPOs as neither CWDs, nor through their member parents/ carers. Through the CBR programme, USDC has been in touch and worked with individual CWDs, their families, communities, and government structures, to address the problems and concerns of children with disabilities, in the 12 districts of Uganda. It is now a leading disability focused NGO in the country.

USDC takes a multi-sectoral approach, and recognises that disability is a cross-cutting issue, that a single department or sector cannot handle.

Instead, it is viewed as more of a social than a medical problem. A large component of USDC's work therefore, lies in the area of social rehabilitation. However, because the target group is children with disabilities, medical interventions have remained a significant part of the programme package (Lang, 1999). The programme has had a number of positive effects on CWDs, families, and the communities at large. This is because USDC has deliberately promoted participation, which is a cardinal principle in the planning and implementation of the CBR programme, as exemplified in the following examples and practices.

The planning process must involve Government, key partners and other stakeholders in the districts, as a basis for active participation and sustainability. USDC has undertaken PNAs in Lira, Apac Hoima, and more recently in Jinja and Soroti districts using PRA methods (Reports are available from USDC on request). During this process, consultants go into the villages, and attempt to maximise the involvement of community members, using participatory appraisal methodologies and other tools. By using this approach, the programme is able to address the needs of children with disabilities, by creating an opportunity for the children, parents and other community members to express these needs.

USDC has been working consistently with Government and other stakeholders, to influence positive response and commitment. USDC works through the existing Government and community level structures. This, in essence means that USDC in the districts plays a mere facilitatory role, letting the government departments and other partners to plan and implement the activities. In the process of implementing the programme, USDC lays emphasis upon mainstreaming disability work fully into government and community systems and structures.

Parents and families play a primary role in the process of rehabilitating CWDs. As carers, they are involved at every stage of the rehabilitation process and their views and those of the children, are always sought. USDC supports home based activities aimed at family members, to participate in the planning and implementation of the rehabilitation process of their child. This takes place through home visits and follow-

ups by rehabilitation professionals, such as physiotherapists and special needs education teachers supported by the programme. While at home, the aim is to help raise the self-esteem of the child(ren), as well as to make therapy enjoyable.

It is more effective to work in partnership with other organisations and agencies. For example, USDC has successfully implemented capacity building programmes in the districts, in partnership with the key structures in the districts and central government, such as training classroom teachers in special needs education, with the Educational Assessment and Resource Services (EARS) and Uganda National Institute of Special Education (UNISE), training clinical officers in EAR care and hearing assessment with Ministry of Health and other activities. In addition, USDC has been supporting the development of rehabilitation infrastructure such as vocational training centres, educational resource units, physiotherapy units and workshops for assistive devices, in collaboration with government and communities. This has greatly improved the quality of the work and minimised unnecessary duplication.

Information sharing, with the government and partners is a powerful and effective tool in influencing decisions, policies and plans. USDC has witnessed this from the prompt and positive government response to some of the issues raised in the quarterly and annual reports of the programme. In its focus districts, therefore, USDC is looked to as a source of vital information for planning for children with disabilities (Kapiriri & Wrightson, 2001). Therefore, an effective system for community education and information on disability is necessary to create the enabling environment. People need to be offered the right information and in the right way, to be able to effectively influence attitudes and practices. USDC has found out therefore, that community led theatre (drama) is a successful mobiliser and conveyor of disability messages and information to communities, and hence, enhances community participation in CBR activities. But critical to this is the fact, that it is the community members including children themselves, who are involved in this theatre.

Another local NGO, COMBRA, was among the pioneers of community based rehabilitation in Uganda. The organisation provides services through training of grassroots CBR workers, running a slum project, information dissemination and advocacy. COMBRA centre provides information to grassroots workers, students and researchers, with hands-on training experience in the community.

COMBRA has been running a community based rehabilitation programme in partnership with the community, in Kampala, in an urban poor area, for over ten years.

The CBR programme in Bwaise focuses on early identification, assessment and appropriate intervention for children with disabilities. The organisation trains CBR volunteers who in turn, train parents/carers of children with disabilities. COMBRA has also been running a revolving credit scheme, to enable families to overcome some of their financial difficulties through petty trade and gainful economic activities.

In its early work in the slums, COMBRA consulted community members and acknowledged that the negative attitude towards people with disabilities was a result of misconceptions, cultural beliefs and lack of awareness. A strategy was devised to raise awareness about causes of impairments in the community. This was a strategy to dispel the existing negative attitudes in the community. An evaluation following this intervention revealed that persons with disabilities are now respected and treated as part of the community (Rifkin & Pridmore, 2001).

COMBRA has used successful persons with disabilities as role models, to give talks to Bwaise members and sensitise the community on disability issues. COMBRA trainees also work with families as part of their fieldwork, which has also given parents of children with disabilities continuous support and motivation. Through close contact, COMBRA has slowly gained confidence.

Through this work, COMBRA has learnt that: people in the community know their problems and if well facilitated, they are in a better position to develop appropriate interventions for their needs.

Looking back over the years, COMBRA can positively say that the strength of changing negative attitudes has been in understanding the community, appreciating their strength, their beliefs and by providing facts on disability, counselling, training and the staff identifying themselves with the members of the community. The successes in awareness raising and information dissemination has also brought new challenges, such as the high demand for services, which the organisation did not have the capacity to handle.

At a national level, COMBRA was fortunate that it has developed during the tenure of the current government in power, which has encouraged participation of NGOs as partners in development.

As a result, COMBRA has been contracted to undertake some of the government programmes, such as training extension workers and a health programme for schools. This process has brought COMBRA in closer contact with the government programmes, creating opportunities for the sharing of skills and competencies. More important, the National Union of Disabled Persons of Uganda (NUDIPU) has worked with COMBRA, to develop a strong foundation for advocating and lobbying for the equalisation of opportunities for people with disabilities in Uganda.

Zimbabwe

Zimbabwe is a country where poverty, inequality and deprivation are the everyday experience of many disabled people. This situation is further exacerbated by the current political situation; lack of clear government policies on disability and rehabilitation; and the unfavourable IMF/World Bank policies. Children with impairments are especially disadvantaged and often left out of the national health care programmes.

There are various kinds of local NGOs in Zimbabwe, who are involved in community based rehabilitation (CBR) programmes. Some are small, while others take the national podium because of their size and coverage. Some local NGOs were established as far back as in the 1950s, such as Jairos Jiri Association and Council for the Blind. They are old and experienced. Some are newly formed to fill gaps that were left by the

former ones, such as the National Council of the Disabled People of Zimbabwe (NCDPZ), Southern Africa Federation of Organisations of Disabled People (SAFOD). The reasons for the existence of a varied number of NGOs emanate from differences and the areas of emphasis of their core business, in the field of disability.

The organisations of, or for PWDs alone, are far from enough, to meet the needs of the disabled people, and neither are the associations of the parents of disabled children on their own, adequate enough to effectively implement CBR programmes. For these reasons, there are numerous organisations implementing CBR programmes in Zimbabwe, which includes the following:

1. Jairos Jiri Association for the disabled and the blind
2. Southern Africa Federation of the Disabled
3. National Council of the Disabled People of Zimbabwe
4. Council for the Blind
5. League of the Blind
6. Deaf Society of Zimbabwe
7. Zimbabwe Parents of Disabled Children Association

All these organisations in one way or another, work in the communities both in rural and in urban settings, but have different aims and objectives. Some provide a service, such as provision of aids and appliances, or therapy or counselling, others promote advocacy, credit schemes, home-based care, educational, vocational rehabilitation and capacity building. Some services are widely duplicated in certain communities. This is because in the past, conflicting interests and the spirit of competition for scarce resources, resulted in clashes among organisations implementing CBR programmes. Notwithstanding these problems, there is a symbiotic relationship, which exists among local NGOs implementing CBR programmes in the country.

The major problem noted in CBR programmes implemented in Zimbabwe at the moment, is lack of cohesion. As mentioned already,

local NGOs seem to duplicate CBR programme activities rather than filling in important gaps left by others in a complimentary way. To some extent, local NGOs fail to realise and articulate issues affecting disabled persons. History shows that these organisations were not effective in addressing needs of their clientele in many respects such as health, income and social security, education, legal rights and social participation. These issues are poorly co-ordinated by local NGOs (Jairos Jiri Association, 1996).

CBR programmes lack funding and this is a major set back experienced by local NGOs. For example, in Zimbabwe, with the threat of SIDA funds being withdrawn, due to the expiry of their bilateral agreement with the government, the national CBR programmes are at stake. The local NGOs have no capacity to raise funds locally to implement meaningful CBR programmes. Hence, a concerted effort is required from stakeholders in the field of rehabilitation. Grants given to local NGOs by government are inadequate to meet even a tenth of their budgets and hence, this assistance is just a drop in the ocean. Local NGOs are left entirely on their own to raise most of their budget funds through income generating activities and donations in cash or in kind, from well-wishers within or outside the country. It is a mammoth task for local NGOs to meet their needs adequately, in serving their clientele.

Disabled people have no claim to rights and entitlements to enable them meet their additional needs. In other words, it is difficult to talk about these rights in a poor country with very little resources, such as Zimbabwe, where the economic situation has deteriorated to its lowest ebb. To expect organisations to be effective in implementing community programmes, is expecting too much, not unlike the miracles in the Bible. However, local NGOs are expected to work in communities and bring about a positive change towards disability, to enable this disadvantaged group to have equal access to socio-economic mainstream activities. There is a need to create awareness among the community members on matters concerning disabilities, in order to facilitate a positive change of attitudes, which at the moment, is very negative. This is a thorny

issue that has been taken up seriously by organisations of disabled persons in Zimbabwe.

As mentioned earlier, like many other countries in Africa, Zimbabwe has deep-rooted traditional/cultural beliefs. Some cultures and traditions are positive, but others are very negative about issues concerning disabilities. For example, to a large extent witchcraft is thought to be a major cause of disability, by the majority of the rural population. Most forms of disabilities are thought to have been a result of witchcraft from an enemy or a form of punishment, imposed upon the family because of their evil doings. Because of such beliefs, the general community has no sympathy towards families with a disabled child and does little, to help individuals having some form of disability, to integrate into the mainstream society. At times, families are even shy to share their problems in public, because they would have to bear the humiliation, of facing such negative attitudes from their community. This is a big problem, as the majority of Zimbabweans, including some enlightened and literate people such as community workers, broadly embrace the negative attitudes towards people with disability. This means that there is a need for a concerted effort to be made by the stakeholders to facilitate a positive change in attitudes of the community at large, towards disabled people. Awareness campaigns should be intensified and could be through drama, films, documentaries, pamphlets, printed T-shirts and other forms of printed messages. Collaboration among the stakeholders, is an important way forward, towards approaching a common goal in the implementation of CBR programmes by local NGOs, in Zimbabwe.

CHALLENGES AND LIMITATIONS OF LOCAL NGOS IN PROMOTING PARTICIPATION

The biggest ‘enemy’, for people with disabilities in the three African countries represented here, are the negative attitudes that are entrenched in their societies. Sometimes, a disabled person wants an easier life and wants to remain taking advantage of his/her disability, using underhand means. This does not create an enabling environment for CBR development. NGOs’ experience of CBR has been rather challenging,

where local NGOs are operating in communities that are already affected by ‘Acquired Relief Syndrome’ and ‘Self Reliance, Unwilling Syndrome’. This makes the existing CBR programmes in the communities precarious and unsustainable. For example, in Uganda, some of the districts are used to agencies with a heavy relief inclination such as UNHCR and WFP. This dependency culture makes it difficult to sustain CBR self-help activities.

HOW CAN NGOS’ PARTICIPATION IN CBR BE ENHANCED?

International donors and the government should build the capacity of local NGOs into their plans and programmes, so that complementary activities can take place, and the coordinated approach can thereby safeguard against wasting resources.

With the current privatisation strategies in developing countries, NGOs should build skills that enable them to compete with the private sector in contracting Government jobs, which need action at the community level. While the private sector may have better skills in bidding for government jobs, the NGOs have a wider experience in working with communities.

NGOs need to ponder and ask themselves some of the critical questions that Uphoff and Cohen (quoted in Rifkin and Pridmore 2001) have put forward, to enable them understand participation:

1. How is participation taking place?
2. Who is participating?
3. Does participation help people to participate in decision making, by building up their experience?

CONCLUSION

NGOs have played a very significant role in pioneering CBR programmes. Their ability to be accountable to donors, deliver services at community level through consulting with the beneficiaries and to be flexible, are largely responsible for the metamorphosis of CBR and

arguably, its survival as a viable strategy. Their efforts have undoubtedly increased community awareness about issues affecting disabled people. This has been done through the combined efforts of the key players by coordination, collaboration and increased information dissemination.

They have been continuously aware that rehabilitation of persons with disabilities encompasses various stakeholders, persons with disabilities, their families, local leaders, service financiers such as the government and international agencies, who all need to compliment each other, through participation in various roles.

Participation by local NGOs has so far, been very crucial in the implementation of CBR Programmes in Africa, but as Governments take on more responsibilities, the challenge for NGOs is to lead the way in sharing its expertise of how to work in a participatory way, at community level. This needs to be done in a complementary and co-ordinated way, so as not to compete in the implementation or fund raising for CBR programmes in developing countries.

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