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Community-Based Rehabilitation (CBR)
as a Participatory Strategy in Africa

Editorial

INTRODUCTION

This publication is based on ideas shared at a conference held in Uganda, in September 2001. The conference was hosted by the Uganda National Institute of Special Education (UNISE) in Kampala and its theme was ‘Community-based Rehabilitation (CBR) as a participatory strategy in Africa.’ The steering committee for the conference had representatives from all interested stakeholder groups in Uganda, including the involvement of disabled people themselves, multiple donors, relevant ministries and local non-government organisations (NGOs). A full list of members of the Steering Committee can be found in the Acknowledgement. People with impairments participated in all stages, from the planning process, to delivering presentations, chairing sessions, giving feedback and participating in discussions. The occasion provided a unique opportunity for synergy of ideas with 140 delegates including anthropological researchers, teachers, nurses, university lecturers, disabled people, people with impaired vision or hearing, physical impairments, parents of children with disabilities, government officials and community workers. They came from 14 different countries: Denmark, Ethiopia, India, Kenya, Liberia, Namibia, Senegal, Sierra Leone, South Africa, Tanzania/Zanzibar, Uganda, the United Kingdom, Zambia and Zimbabwe.

The main aim of the conference was to bring together key stakeholders and provide the opportunity for them to share their experiences of CBR as a participatory strategy. It also aimed to lay the foundations for future co-operation and networking between groups and individuals and provide an opportunity to identify a way forward, in the form of a plan of action. As part of the process, it was agreed that the activities would be recorded and edited in the form of a book, which would be distributed as widely as possible. The management and organisation of the conference also aimed to provide a living example of a participatory approach. Feedback

from the participants indicated a very positive response to this process.

‘The most impressive thing about this conference was the way in which people with disabilities contributed so much to the proceedings, I couldn’t believe what they could do!’

‘The conference didn’t just talk about participation, it did it! I shall never forget it.’

‘We can go home and do things differently now and know that it can work.’

So for those who attended the conference, there was a very strong message of the ‘power of participation’, not as something idealistic, but as an achievable practical option. This publication aims to reflect this positive message and provide information on various experiences of a participatory approach, problems encountered and people who have worked with these problems to produce positive outcomes.

This publication reflects the rich experience of this meeting and builds on this through reflection. The publication is motivated by the need for practitioners to share their experiences and perspectives and then to evaluate and learn from them in order to improve practice. The chapters are based on presentations by the lead speakers, their designated respondents and the questions and discussion, which followed. The text is therefore, a product of all the participants and a full list of the participants can be found in the Appendix No. 3 The power of participation is particularly well illustrated by the presentations made by disabled people, parents of disabled children and in the discussion on the role of CBR in HIV prevention. The chapters of this book provide evidence of a great deal of effort and good practice developing in CBR in Africa and serve to challenge any perception that a ‘new’ approach is needed, but rather, emphasise the need for more effective sharing of information within the continent and also internationally.

The conference began by reviewing the development of CBR and examining the key definitions (Chapters 1, 2 and 3). Chapter 1 raises key controversial questions concerning the development of CBR

programmes and suggests that such questions need to be addressed in future research. Chapter 2 builds on this foundation, describing more specifically, the development of CBR in the African context and emphasising the importance of an inclusive approach, both, through including disabled people in all stages of the CBR process and also in negotiating for such programmes to be part of community development. Chapter 3 reviews participation and its role in health programmes generally, alerting the reader to the complexities of the processes involved and the need to identify and perhaps measure the key elements required for an effective programme. Chapter 4 examines the development of CBR training in Uganda, acknowledging the role of academic support from other countries and alerting us to the importance of developing training in a more practical way, rather than placing exclusive emphasis on academic training. Some real problems are highlighted, such as release from work and contextual relevance, which need addressing if training is to develop effectively.

The rest of the conference examined the roles of various stakeholders in the development and execution of CBR. This included professionals, persons with disabilities, parents and communities, local NGOs, donor agencies and governments (Chapters 5, 6, 7, 8, 9, 10, 11 and 12). There were two sessions relating to the potential influence CBR programmes could have in promoting better statistical data collection, and prevention strategies for HIV (Chapters 13 and 14). The final session looked at a way forward for CBR programmes in Africa (Chapter 15). There were presentations, responses, discussions and video and poster sessions. They are all reflected in this publication.

WHAT THIS BOOK OFFERS

This book strives to produce a reflective piece of work that can be used as a basis for future action throughout the African continent. Although it is primarily a record of a conference, the contents not only provide an overview of the information generated from the global knowledge base of CBR, participation, CBR training, etc, but more importantly show how this information has been interpreted and

implemented in the African context. The writers are predominantly of African origin and they ably provide a clear view of the ‘state of the art’ of CBR in many parts of their continent. They provide examples of their own CBR experiences and case studies of their programmes, the problems they faced and how they were overcome. The final chapter examines the way forward, which includes the participants’ consensus of the key ingredients of CBR, as seen from an African perspective, and not the perspective of the international communities, as is so commonly recorded in the literature. This is therefore a unique publication in the field of CBR and a positive step in the journey of African people sharing their own experiences and developing solutions to their own problems, within the context of their own cultural perspectives.

The book offers a range of views useful for stimulating debate by practitioners. It offers living examples of different levels of participation and evidence of how this has affected the programmes described. Within the publication, there are a number of lists that can be used for evaluation purposes. For example, Benon in Chapter 8, lists six action points that can be used to assess progress in terms of the participation of disabled people in CBR programmes, whilst Kisubi in Chapter 12, formulates key issues relating to improving the process of participation of funders. The final list of key ingredients of CBR can also be used for evaluative purposes to answer questions such as, to what extent does a particular programme aspire to these ‘key ingredients’? Or, in what way has the programme improved over a period of time? Or, where should we put our energy to strengthen our programme in the coming year?

The book also offers an appendix with discussion questions that could be used for conferences or workshops, or as a basis for discussions in training programmes. Finally, it provides a source of references, not only to academic literature but also to useful web sites, which can be used by practitioners all over Africa to access more information about services for people with disabilities.

WHAT THIS BOOK CANNOT OFFER

This book is not a manual about CBR and cannot therefore be used in this way. Neither does it present the ‘right’ way to develop CBR programmes, but describes what different people have done in different countries to overcome the barriers presented to them. It examines what appears to have worked and why, and what has not worked and why, in a variety of locations. While many chapters are in academic style and of an academic standard, other equally valuable chapters, are descriptive by nature and differ in style and presentation. The book’s overall focus is on CBR and participation, so it does not explore in any detail other important issues such as CBR and poverty, or CBR monitoring and evaluation.

WHO SHOULD READ THIS BOOK?

The groups of people who will find the content of these pages, useful are those who are interested and involved in the development of an environment that enables disabled people and their families to maximise their own potential, to improve their quality of life and have the same opportunities as people who do not have impairments. Such people may belong to an established professional group, or a profession that is just emerging. These professional groups may be medically, socially or technically based; at an individual level they may be able bodied or have a bodily impairment, they might be parents of children who have an impairment, or be a member of a disabled peoples’ organisation; or they may be politicians or personnel from funding agencies. They may be academics, trainers or programme managers.

WHAT ARE THE KEY MESSAGES OF THIS BOOK?

Although the authors of this book come from 14 different countries, there are several key themes or messages, which re-occur through many of the chapters. These messages are considered below.

1. Definition dilemmas

Most authors highlight the problems of defining the key terms and acknowledge the need to pursue more clarity of definition, as a step in the process of developing services that have the capacity to meet the needs of the people concerned. It is obvious from the comments made, that the international agencies WHO, ILO, UNESCO and UN, have played a valuable role in facilitating the development of these definitions. However, it seems that answering the question ‘What is CBR?’ and ‘What is participation?’ still presents a challenge to all concerned.

The definition of CBR in the WHO/UNESCO/ILO (1994) joint position statement, is used by many of the contributors to this volume. The indications are that this statement has been a useful tool in developing an understanding of how CBR can be interpreted. The statement’s holistic and flexible nature has, in fact, facilitated different interpretations and enabled pragmatic and culturally appropriate services to develop. It is interesting to reflect that at the time of its publication, a less broad and more stringent definition might well have served to provide an impossible goal and resulted in the demise of CBR. However, as CBR has developed, there has become an increasing need for clearer definitions for the purposes of monitoring and evaluation. The lack of rigorous monitoring and evaluation in CBR, has affected the credibility of CBR programmes and served to confuse both the service providers and the users. This has led some to question whether CBR has moved too far away from its original purpose and is no longer meeting the rehabilitation needs of the people. The discussion in Chapters 1 and 2 examine this issue. They also indicate that a kind of CBR existed in Africa before the formal introduction of the ‘WHO model’, and that the more holistic approach advocated in the joint position statement, is slowly being adopted. The authors argue that increased participation of disabled people will take time, commitment, resources and knowledge, nevertheless, the rhetoric about CBR not working (Vanneste, 2000, Turmunsani et al, 2002) should be challenged. The consensus from the conference participants suggests that this can be done by developing a stronger culture of sharing information about good and bad practice and by

providing evidence about coverage, quality of service, sustainability, comparability and cost effectiveness.

This publication makes its own contribution towards a clearer definition of CBR in the African context. The 10 key ingredients of CBR, as seen by the participants of the conference can be found in Chapter 15, page 199. This provides a useful baseline for discussion, evaluation and research.

The various definitions of participation are discussed in Chapter 3, concluding with the view that participation is a process rather than just an outcome, and as such, cannot be easily measured. Nevertheless, there is general agreement from the contributors that this process is potentially positive. Three critical issues are highlighted and discussed in Chapter 3: namely, the lack of a universally accepted conceptual framework; unrealistic assumptions about the potential impact of participation; and issues around the power and control of programmes. These issues are then discussed from a number of different perspectives. For example, the role of professionals in the development of CBR programmes, (Chapter 5), and the role that disabled people themselves can play (Chapter 8). Most contributors recognise that there is a need to find out more about the participatory process and to establish what aspects of it are necessary for the development of effective programmes.

Only the authors of Chapter 13 use the concepts from the new WHO International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) as a basis for action, in this case, collecting data on the prevalence of disability. Despite the very high level of participation used to develop these classifications over a period of 10 years, it is interesting to note that the implications and potential of the new classifications have yet to impact on the thinking and actions of the majority of stakeholders. The classifications are published and are now available on the Internet (<http://www3.who.int/icf/icftemplate.cfm>) for people to access them and utilise their concepts to evaluate their thinking and practice.

It is worth noting that these classifications also include participation as a dimension of disability. This would imply that programmes where

participation is weak, are in danger of ‘disabling’ the process, i.e. making the process incomplete and, as such, disadvantaged. This raises the question as to whether it is in fact not only inefficient, but also unethical for CBR programmes not to include disabled people in their planning and implementation. This issue is discussed in more detail by Turmusani et al (2002), who reach the same conclusion as authors of this volume, namely, that CBR programmes should work for the greatest participation of disabled people in all spheres of life, thus encouraging and supporting them to have a maximum amount of control, while at the same time recognising that the role of other stakeholders, which of course includes professionals, is one of facilitation. How this facilitation can be achieved in the African context, forms the backbone of this publication. The parents in Chapter 9, for example, provide evidence that it was their feelings of isolation and loneliness, together with the negative attitudes of professionals, that motivated their own initiatives.

2. The power of participation

As previously stated, the pages of this book reveal a strong belief in the benefits of the participation of all stakeholders in all the stages of service development. They also identify the very real barriers that exist, if the goal of maximum participation is to be realised, and suggest some ways in which these might be overcome. There is a very strong message from disabled people themselves and their parents, in Chapters 8, 9 and 10, about the importance of including disabled people at all stages of programme development. These contributions are inspirational for those taking their first steps towards the involvement of people with disabilities (PWDs) and disabled peoples’ organisations (DPOs) in community involvement. There are also many examples of the extraordinary barriers that PWDs have to face everyday, their courage and perseverance, and their ability to overcome these, against all odds.

Benon says that: ‘Any programme that does not involve PWDs at all levels and in all stages, is considered as irrelevant and may not have any significant impact on the community’ ...and that we should ‘encourage all service providers to open up and collaborate with DPOs’.

What he modestly does not say is that the improvement seen in Uganda is substantially due to the sterling efforts of people like himself, NUDIPU's officials and members and other PWDs throughout the country.

Anecdotal evidence that high levels of participation are beneficial, is not enough however, for the scientific world, and more research is needed into the participatory process and what aspects contribute to effective services. The process of including and handing over control to disabled people also requires a paradigm shift on the part of the professionals. The breadth and depth of the change required, is highlighted in many chapters, but particularly Chapter 5.

3. CBR as part of community participation

Many contributors to this publication felt strongly that CBR should be part of community development, and that to encourage the development of CBR programmes as separate entities, was at odds with a participatory approach and did not conform to the ideology of inclusion. Rather, it served to further separate people with disabilities from the mainstream services available. It is obvious that more work needs to be done on establishing the practicalities of such an approach and the expected outcomes. If it were to be shown to be the best way forward, then people also need information on how this can be facilitated and what structures need to be put in place, in order to achieve this. For example, services for PWDs relating to HIV in Chapter 14, and to accessing community services in Chapter 2, illustrate the importance of developing CBR as part of community development.

4. 'Start where you are'!

This message came from a number of contributors, but particularly Kisubi in Chapter 12. He challenges people to ask the questions: To what extent does your CBR programme respond to the identified needs of the people whom it is set up to serve? Have you asked disabled people what they want from your programme? Have you altered the service you provide according to this information? There is a Chinese proverb that says

‘begin with what they have, build on what they know’, which serves to re-enforce this message.

For people involved in the development of services in communities outside their own culture and experience, there is a real danger of facilitating action that is not based on what exists, but on unrelated idealism or on what exists in some other community or culture. For example, a rights based approach pioneering equal opportunities, may be an unrealistic and unhelpful approach in a community where few people have rights.

5. Paradoxes and tensions

It is important to recognise the various tensions between the players involved in CBR and to appreciate the positive aspects of these tensions. There are tensions between professionals and DPOs, funders and governments, between different CBR programmes, between the bio-medical and the social approaches. It is important to understand that these tensions provide the necessary environment in which creative solutions can be formulated and that they provide the ‘the chaotic edge’, which is a well known phenomenon and necessary for development (Stacey, 1992). The tensions are there. We must learn how to use them positively and to the advantage of people with disabilities and their families.

There are particular tensions between the medical and social science approaches, and it appears that more funding is presently available for medical based research, than for examining the social aspects of disability. One consequence of this is that more research is being published about ‘impairments’ than about ‘participation’. With the thrust for evidence-based practice, inevitably service development is then biased towards the medical perspective. In addition, the power of the Euro-centric view within the world, which sees the whole in the separateness of its parts, is juxtaposed with the African worldview which is manifested by an holistic and integrated view of looking at the family and the universe. The new International Classifications of Functioning

for Disability and Health (ICF DH), take a small step towards a more holistic view, but still maintain a strong concept of the ‘separateness of the parts’. They can, however, provide a useful framework for further studies, and workers in CBR and disability would do well to grasp this tool and use it to explore their field.

THE WAY FORWARD

The final session of the conference is represented in Chapter 15 and relates to the decisions taken by the participants on the way forward. This session generated the 10 key ingredients of CBR in Africa and plans for a way forward (see Chapter 15).

Individuals were identified to take these ideas into action. The points of action included facilitating associations of CBR workers; reviewing the CBR training offered in Uganda and suggesting a way in which it could be streamlined; organising another conference, and providing opportunities for CBR workers to improve their writing skills and information sharing. Developments since the conference, have seen the birth of a new organisation, ‘The CBR Africa Network’ (CAN), whose aim is to facilitate the sharing of information about CBR in Africa. Funding has been secured from the CP Charitable Trust to establish this network, which will initially be located at COMBRA, in Uganda. A coordinator has been appointed and readers of this publication are encouraged to contact the coordinator and become part of this network (c/o CAN Coordinator at combra@utlonline.co.ug). The network will provide the opportunity for sharing experiences and searching for new ideas and initiatives. CAN is one of the many positive outcomes of this conference and this book is another.

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CHAPTER 1

Some Controversies in Community Based Rehabilitation

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SUMMARY

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

INTRODUCTION

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

remain unmet (Thomas and Thomas, 1998). However, with the shift from a medical model to the social model, the emphasis today is on integrating disability into development processes. According to votaries of this model, it is more cost-effective, and promotes better social integration, by ensuring that people with disabilities have access to the same benefits and services as others in the community, unlike a 'specialised' CBR programme that concentrates on people with disabilities and may actually isolate them from the mainstream (Scott, 1994). Community participation is likely to be greater in a programme that benefits the majority, rather than a minority group. At the same time, people fear that unplanned integration of disability into other development programmes can ignore 'real rehabilitation' needs, such as mobility, special education, vocational rehabilitation and so on. In turn, this can contribute to increased marginalisation of people with disabilities, rather than their integration into the mainstream (Jones, 1999).

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

Integration of disability issues into development programmes implies a high degree of co-ordination and collaboration between different sectors such as health, education, employment and so on. Often, such co-

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

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

IS CBR INEXPENSIVE? IF SO, FOR WHOM?

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

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

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

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

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

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

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

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

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

CAN VOLUNTEERS IN CBR 'AFFORD' TO VOLUNTEER?

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

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

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

identities and roles that do not conform to the definition of the term (24). Thus, there may be persons who have the time to dedicate to their chosen task, or may have some time in specific periods of the month or year, or may be available only for a limited period of time. In the last decade, with a move to market economies in many developing countries, most people need paid employment to survive and are therefore less able or willing to volunteer. Those who do volunteer, often use their training and experience as a stepping-stone to paid employment. Under these circumstances, expectations of free work over a long period of time from volunteers, in the same way as paid CBR workers, may not be realistic or sustainable.

CONCLUSION

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

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CHAPTER 2

What is CBR in the African Context?

Shaya Asindua.

SUMMARY

This chapter examines the changing concept of CBR since its introduction in the early 1980s. It recognises that initially, it was a top-down alternative to centrally provided specialist rehabilitation services. It follows its journey through to a community-based, community-led initiative, involving disabled people at all stages of the process. It suggests that the different kinds of CBR programmes in Africa today, represent the various stages of this process. The challenges faced during the development of CBR programmes in Kenya, are considered and used, to illustrate the learning opportunities offered by this dynamic process of change. In conclusion, it is suggested that all participants of the CBR development process should remain open-minded as they endeavour to seek solutions for the challenges that emerge. This is particularly essential for the professionals, who find it hard to recognise and respect the potential contribution of disabled people and their families and to give up their positions of power.

INTRODUCTION

I have been involved in CBR myself, since the early eighties, so I speak about CBR from many years of practice. My understanding and beliefs about CBR have changed considerably over the years. I remember the early days when little was known about CBR. What did it mean? Who

should be involved? How costly would it be? Would it provide a viable and quality alternative to the institutional approach? Or, was it another way of governments abdicating their responsibilities? How were predominantly illiterate communities going to carry out tasks that had taken many of us, three to four years to learn? What about our professions and professional authorities? The concerns and anxieties were numerous and perhaps some of these are still of concern to some people today.

Trends in other development programmes at this time were no different either, with increased awareness and concentration on the rural poor, as the focal point of rural development. Governments and non-governmental organisations embarked on providing social service programmes in the name of development programmes. However, these were mainly planned and implemented through a top-down approach with superficial, or no participation of the communities concerned. This practice was perhaps more pronounced in the disability field, which has been strongly influenced by the belief, that disabled people need to be cared and provided for. Within the development discourse, the change in thought and action came towards the late eighties and early nineties, with the realisation that if the subjects of development did not participate actively in the processes, change would not be realised. Sporadic voices of disabled people also started to be heard around this time, about the inappropriateness of some of the very good intentions, which failed to involve disabled people in the decision making, in areas that concerned them. In 1991, at a global meeting of disabled people, the Disabled Peoples International (DPI) was formed. The World Congress of Rehabilitation International taking place for the first time in Africa, in 1992, in Nairobi, began to strengthen the voices of disabled people in Africa.

So, for over two decades now, the trend in rehabilitation has moved from institutional management of disability to services that place greater reliance on family and community resources. The need for an approach that would be more effective, and more accessible to the majority of people with disabilities, was reinforced by the fact, that in many of our African countries, the majority of people with disabilities (about 85%)

live in rural areas or marginal urban communities. Many of them are marginalised and do not have access to any services, so any effective rehabilitation approach must include advocacy and lobbying for policy and legislation change and public education, to ensure that people with disabilities get the same opportunities, as the rest of the community members.

THE CONCEPT AND APPROACHES TO THE IMPLEMENTATION OF CBR

Over the years, a growing body of theoretical ideas has been published on CBR and practical experiences have accumulated. Some of these ideas are progressive, while others come short of viewing CBR within a true development concept. It is said, that CBR has been contextually defined throughout the world and this explains the different models and interpretations, certainly within the African region, where there are various schools of thought as to what CBR means.

Some people argue that CBR has always existed within the African context even before the ‘officialisation’ of the concept. That the families and communities, in the absence of any other services have always been the source of care and training for disabled persons. While some of the traditional practices can be termed negative, there were and still are, many traditional systems of care and management of disability and related issues, that are positive.

Another school of thought, is that CBR is the de-professionalisation of rehabilitation (technology transfer). Basing it on the model of community based health care programme (primary health care), rehabilitation is simplified to allow even the ‘non-literate’ community members to carry out therapeutic training exercises and to produce and use simple aids and devices. This model often uses, or has co-opted the ideas represented in the WHO training manual.

Some conceive CBR as an outreach or extension service, with the objective of bringing professional rehabilitation services to a large number of people with disabilities, particularly in the rural areas, and to

refer those people, in need of more sophisticated services to institutions outside the community. In this model, regular and programmed visits are made to the community sometimes by a multi-sectoral team. The involvement of the community is often restricted to their participation in the outreach activities (clinics).

A fourth school of thought combines elements of institutional rehabilitation and community oriented health services. This model still lays emphasis on rehabilitation service provision, but forms a link with other services such as inclusive education, grass roots organisations of disabled people and income generation activities among others.

A fifth school of thought perceives CBR as an autonomous, empowering and inclusive process, which must be rights and development based and enable access to equal opportunities for persons with disabilities and their families. This model strives to enable people with disabilities to gain ownership of the programme and feel that they have control over their lives, as they individually and collectively with their communities, identify their needs and find solutions. This school of thought, which is more comprehensive, does not denigrate the importance, or the vital role, played by 'institutional' services.

However, even programmes that promote this more progressive idea, are often just confined to the level of the family and do not integrate or involve the wider community, though a key component of CBR has been that **the community** can be mobilised for support. In reality, many parents and families still feel isolated and are not getting enough support through care, education and training for their disabled persons. Persons with disabilities are still sidelined in mainstream decision making in most societies. There are many interpretations, as to what constitutes a community. Who plans and provides the service and what is the nature in which the service is provided?

As well as being located in the community and initiated by the community, CBR also encompasses all the exciting issues, which are being addressed in the field of disability. These include inclusive education, self advocacy, community participation, empowerment,

people centered development, humanism, access and social change. This shows the vast potential that CBR has, in addressing these issues and above all, ensuring equalisation of opportunities for disabled people and protection of their rights.

As an empowering and political process, CBR can be viewed as a threat to the status quo, as, it is about the struggle to change power relationships (Those who hold power usually feel threatened by the idea of others becoming critically aware, if it means that these others slip out of their control or worse, challenge their own comfortable position). This can mean that the more powerful players may be resistant to embracing these emancipated approaches and may hang onto power and a top-down approach. Evaluation of CBR programmes is urgently needed, to provide the evidence to identify the most effective CBR approach.

EMERGING CHALLENGES AND LESSONS LEARNT

There are definitely many challenges and lessons accrued over the years. Some of these challenges may be unique to our own experiences in AMREF and in Kenya, but they are also likely to represent challenges to other CBR programmes within the region. They are considered below:

- **Infrastructure**

To develop a separate infrastructure only for CBR, is too costly and it would take too long for it to take off. The challenge in implementing a new resource into the community, is co-ordinating and incorporating it into the existing community infrastructure and hence the inclusion of CBR into existing development structures.

- **Adequate and appropriate training of personnel**

Inadequate training of personnel in CBR provides the biggest challenge in providing family/community-oriented services. CBR content and methodology need to be strengthened in the education of all disciplines of extension workers. There is need for intensive advocacy and influencing of curricula development at the central levels and provision of training opportunities, for those working at the community levels.

- **High level of illiteracy**

Illiteracy is common among people with disabilities. This affects members' ability to conceptualise their own issues and leads to a feeling of worthlessness.

- **Working with community based organisations (CBOs)**

Many programmes now recognise the importance of CBOs in respect to ownership and sustainability of CBR programmes. Capacity building of organisations of disabled people and parents means working with them to enhance their resource mobilisation and management capacities to prioritise, plan, implement and finance their activities. It also involves working to achieve unity of purpose within their membership, setting targets and objectives with specific timeliness. These are strategic issues that require long-term development support, as these organisations are usually fragile with low self-esteem and lack the wider community recognition and support.

- **Equity**

This still remains an elusive goal for many CBR programmes, which are usually on a small scale and without wider government and political support. Influencing local and national policies should form a major priority for CBR programmes.

- **Disability issues**

These are ranked low, not only by the communities, but also by the Governments and even NGOs, who purport to work with the 'poorest of the poor.' In many cases, when one sits down with the communities to discuss their needs and priorities, one finds that they are usually concerned with issues such as supply of water, the disease that is killing their cattle etc, instead of the concerns of disabled people. The challenge is in finding ways to embed the process of rehabilitation of persons with disability, in the every day life of the family and community.

- **Equal opportunities**

Although we desire equal opportunities for people with disabilities, we are working in an environment where there is extreme poverty. Opportunities are scarce for everyone just as they are, for people with disabilities. Even opportunities for income generating activities are remote. What this implies is that poverty reduction remains part and parcel of any credible CBR programme.

- **Dependency**

Due to the fact that disability has traditionally been seen in line with charity and welfare, a large part of the communities and even people with disabilities themselves have continued to exhibit a high sense of dependency. This in itself has been the greatest hindrance to community participation and sustainability of CBR. The issue and challenge lie with perceiving CBR as a development issue. Enhancing self-esteem for self-reliance through education and economic empowerment has been instrumental in changing these attitudes. Use of role models is a key strategy.

- **People with mental illness**

In many CBR programmes, the issue of people with mental illness is not adequately addressed. Communities seem unsure about their role in rehabilitating someone with a mental illness. Most people with mental illness are usually identified at very late stages and as a result, the only intervention at that time is usually institutionally based. Stigma and attitudes prevent the establishment of community based post institutional care. This requires intensive and long term community education and mobilisation.

- **Women with disabilities**

Another challenge is the issue of women with disabilities. They are still under-represented even within the disability groups. Women in our societies have low status and if one is a woman and at the same time has a disability, the situation is even worse. Women with disabilities often miss out on basic rights, such as, to choose marriage and bring up children.

- **Collaboration and networking**

As the CBR movement within Africa expands, the need for collaboration, sharing and networking emerges and must be emphasised. Emerging projects will require support in terms of staff capacity building and development of project designs.

- **Sustainability**

This remains a challenge for CBR, as for many community based programmes. Many of us see the responsibility for sustainability of CBR, as lying with the institutions of disabled peoples' organisations (DPOs). However, these organisations are fragile with low self-esteem and lack the wider community support. We need to emphasise capacity building of these organisations through training in leadership, small enterprise development, organisation and management, communication and advocacy skills and linkage with other established organisations.

- **Sexual issues**

Another challenge is that of how CBR programmes respond to sexual issues, what access do disabled women have to antenatal care and information? To what extent are they included in HIV programmes? How best, can they be included?

In conclusion, the challenges outlined above, are still part of an evolving process. CBR is not static and as we endeavour to seek solutions to these challenges, open-mindedness is essential.

Equally important, is the analysis of the community structures within which CBR is embedded. The existence of a power structure: the difference between disabled and non-disabled, men and women, disabled men and disabled women, are glaring realities. The recognition of these differences is crucial for CBR, as for any community-oriented programme.

For any CBR programme to be autonomous, the involvement of people with disabilities should be central. The *empowerment* of women with

disabilities and other vulnerable groups, such as people with intellectual handicaps should form priority agendas of CBR programmes. An autonomous CBR programme does not exclude professionals. However, the professionals' role should not only be seen as that of 'transferring technology', but should begin with the recognition and acknowledgement of the rights, power and ability of the people. This basically means that people with disabilities, parents and the community, have knowledge and skills too, to share with professionals.

I would like to end this chapter by saying that the overwhelming strength of CBR is that it provides a vehicle for embarking on the four guiding principles for developing services, as documented in the World Programme of Action Concerning Disabled Persons.

- a) Disabled persons should remain within their own communities and share ordinary lifestyles, with necessary support;
- b) Disabled persons should take part in decision-making at all levels, both in general community affairs and in matters that particularly concern them as people with disabilities;
- c) Disabled persons should receive the assistance they need within the ordinary structures of education, health, social services etc.;
- d) Disabled persons should take an active part in the general social and economic development of society, and their needs should be included in national planning. Disabled persons should have adequate opportunity to contribute to national development.

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CHAPTER 3

What is Participation?

Susan B. Rifkin, Maria Kangere.

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 services provided are under utilised and misused, because the people for whom they are designed are not involved in their development (The health services argument).
2. There exists in all communities, financial, material and human resources that could and should be mobilised to improve local health and environmental conditions (The economic argument).
3. 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 (The health promotion argument).
4. All people, especially the poor and disadvantaged, have both the right and duty to be involved in decisions that affect their daily lives (The social justice argument) (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:

- 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.

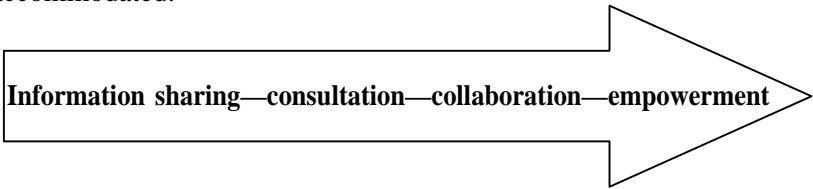
The third approach, is that of community development where health is defined as a human condition and community participation as active involvement in decision making and accountability for programmes.

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.

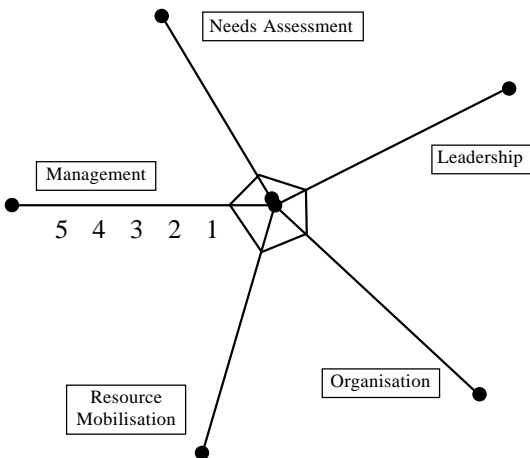
WHAT IS PARTICIPATION?

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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CHAPTER 4

Community Based Rehabilitation Training in Uganda: an Overview

Vincent Paul Ojwang , Sally Hartley.

SUMMARY

This chapter presents an overview of the development of CBR training in Uganda and highlights the achievements over the past decade. It examines some of the problems encountered and describes how these have been overcome. It also looks at some of the difficulties that still have to be faced and suggests possible ways forward.

Uganda has a wide range of CBR training programmes, which are offered by a variety of establishments. They demand variable time commitments, are aimed at different academic levels and achieve varying degrees of practical competency. Although the courses are run independently, many of the 'key players' contribute to more than one course, so there is some cross-fertilisation of knowledge and ideas between the courses. In addition, all bodies running CBR training courses have some representation on the National CBR Steering Committee. Although the formalised courses focus predominantly on training service providers, a number of less formal, innovative courses have developed, which

address the learning needs of other community group members, such as parents and CBR committee members.

INTRODUCTION

Following the disintegration of rehabilitation services in Uganda, efforts to establish Community Based Rehabilitation (CBR) training, were made by the Government of Uganda, with the support of Uganda Society for Disabled Children (USDC) and the Norwegian Association for the Disabled (NAD). The main objectives were to develop comprehensive and sustainable rehabilitation services within local communities and include as many Persons with Disabilities (PWDs), as possible.

A number of agreements of co-operation were signed between NAD, USDC and the Ugandan Government, in order to formalise CBR activities. Rehabilitation of existing physical structures and Centres had to be done before CBR training could start. New ones were also put in place.

After over a decade, CBR training in Uganda has spread widely and includes formal training at the Uganda National Institute of Special Education (UNISE), Makerere University and Community Based Rehabilitation Alliance (COMBRA), resulting in nationally recognised degrees, diplomas and certificates. Less formal training takes place in Ministries of Gender Labour and Social Development, Health and Education, and in a number of NGOs, such as Action on Disability and Development (ADD), National Union of Disabled Persons of Uganda (NUDIPU), and 'OURS', for persons with disabilities. The less formal training focuses more on improving people's practical skills.

The duration of the different training courses varies from a few days in some cases, to two years in the case of UNISE and Makerere. This variation implies that the curriculum and methods of delivery are different in each of the situations. The final awards range from Masters' degrees, to certificates of attendance.

FUNDAMENTAL CONSIDERATIONS

Some of the fundamental considerations underlying the development of CBR training courses include the fact that PWDs had no service of their own and yet their needs were many. These needs were not being met by the existing health and education services.

Institutionalised services were seen as out-dated, narrow, unsustainable and addressing only a limited number of PWDs. International experts were putting emphasis on a community approach to provision of health and related services (WHO, 1989). Training and simplification of knowledge and skills was seen as a way of achieving wide coverage.

Any form of social and economic growth, especially for developing countries, needed to address the majority of people who required such services and therefore, the issue of community participation and involvement in planning was raised. In view of this realisation, a community approach became inevitable in trying to solve problems relating to health and disability. Developing countries, including many African countries, were seen as the focus for such pertinent issues.

THE ROLE OF UNITED NATIONS AGENCIES

In many respects, the World Health Organisation (WHO) appears to have taken over the responsibility for this development, as health and disability were seen as mutually related to the well-being of the individual. This can be seen in a number of instances including the promotion of the CBR concept by WHO and specifically through the publication of the CBR training manual in 1989.

Around the same time, UNESCO and UNICEF adopted other approaches which could be considered as closely related, although with emphasis on education and preventive health respectively. In a guide intended for teachers, parents and community workers on knowledge, approaches and methods of the CBR approach, O'Toole (1991), lays emphasis on the fact that CBR has received considerable attention during the decade of disabled persons. He points out that UNESCO, in consultation with Special Education Experts, recognised integrated/inclusive education

and CBR as two complimentary approaches in providing cost- effective and meaningful education and training to disabled persons.

UNESCO (1994), in theme 3, says that special education does not exist in isolation. It can only be developed and understood in the context of the community, which includes parents and the school neighbourhood. It is further stated, that CBR and ‘education for all’ have common roots. Both are based on commitment to the empowerment of local people to work together, to gain access to basic human rights whether in education or health.

UNICEF (1995), laid emphasis on low cost approaches and community participation in the provision of health services as part of the Bamako Initiative. The use of community health workers to manage simple health complaints is also highlighted. These approaches ensure sustainability and form pillars of CBR programmes.

PIONEER COURSE IN LONDON

This international approach resulted in the development of a post-graduate CBR course at the Institute of Child Health, London University, which ran effectively for over twelve years with hardly any ‘third world’ problems to hinder its progress! The irony was that the majority of students were from developing countries; training far away from the scene of the disability and poverty problems, but nevertheless feedback from the students over the years helped the Institute of Child Health to develop courses that responded to the relevant issues.

The course developed an excellent academic profile, but it lacked relevant practical experience. It was also very expensive and only sustainable through external sponsorship. The number of students qualifying per year were few and their impact in less developed countries was likely to be small. Something had to be done, and transferring the course to the scene of the disability problem became the obvious solution. London University took the initiative to support the development of CBR training courses outside the UK, in such countries as Uganda and India, where the training can develop in a more meaningful and

contextually relevant way, and with the opportunity of real field-work experience.

JUSTIFICATION FOR CBR TRAINING IN UGANDA

Uganda was chosen from among other developing countries, partly because it was emerging from its turbulent and nightmare history of the 1970s and 1980s, and had prevalence of ill health, disability and poverty in all corners. At the same time, Uganda had international goodwill on its side and many organisations were keen to offer support.

By that time, many Ugandans had completed the London course and were readily available. At the same time, a number of CBR programmes were at their formative stages. The African condition was seen as relevant for proper training and the government was willing to accept the training. The need to establish the training of CBR workers was accepted and Makerere University, with its well established structure and hierarchy of courses, was the first obvious choice. However, negotiations with Makerere to establish the CBR training programme, proved problematic and the course was eventually located at UNISE, whose expertise in disability and strong connections with disabled people themselves, made it an ideal location. UNISE gladly accepted the challenge of pioneering the course under its banner, with the support of funds from NAD. Consultations were made between stakeholders, the two relevant Ministries of Education and Sports, and that of Local Government, Department of Community Development, NAD and DANIDA (the primary funder for other UNISE programmes).

NAD's plans and budget were now seen as aiming at the same thing, a CBR training course in Uganda. Together with the University of London, a joint curriculum committee was set up. The task was to develop a curriculum for the Postgraduate course in CBR and by 1996, the curriculum was in place, having been approved by the Institute of Teacher Education, Kyambogo (ITEK) Academic Board.

CBR COURSES AT UNISE

There are now two CBR courses at UNISE: the Postgraduate Diploma (PGD CBR) and the Undergraduate Diploma (D CBR). The PGD CBR course started effectively in January 1996. Graduates of Social Sciences and Education, with a background or interest in disability, are recruited and trained for two Semesters of 17 weeks, so as to prepare them to be community workers, trainers, administrators and planners in this area, to work in the districts and local NGOs.

Highlights of the curriculum include:

- Causes of impairments and disabilities;
- Prevention of impairments and disabilities;
- Identification of impairments;
- Assessment and management of disability;
- Teaching and training methods for the community;
- Management of CBR projects;
- Writing Action Plans;
- Production of assistive devices.

Fifty-four graduates, one from Kenya, two from Zimbabwe, one from India and the rest from Uganda, have so far, gone through the course. Care was taken in the selection process of the Ugandans to identify students from a wide range of districts, as seen in Figure 1. However, a similar map of the location of the students, once they had completed the course (Figure 2), shows that employment opportunities tend to center around the capital and many areas do not have any CBR workforce as a result of our training programme. These can be compared with Figure 3, which shows the existing CBR programmes in Uganda.

By 1998, the Curriculum for the D CBR course had been approved by ITEK, and the course started in 1999. It is meant to be skills based, to meet the needs of PWDs within the community. The duration of this

course is four semesters of 17 weeks each. It is open to certificate holders in health, community work and teaching.

It was also hoped that it would serve as an upgrading course for Community Development Assistants, currently working without sufficient training in disability, but a good number of whom are holding certificates in community service.

Certificate holders from COMBRA, would also use this avenue to upgrade their qualifications in CBR. Overall, the COMBRA course seeks to improve the skills of the grass root workers expected to work at village and sub county levels, and also give them recognised qualifications.

THE MOBILITY REHABILITATION COURSE

The Certificate course in Mobility and Rehabilitation (MBR) at UNISE began during the 1996/97 Academic Year for a duration of one year. This course sought to focus on services and support for people with visual impairments, in response to evidence that this group of disabled people was not being catered for adequately, at the community level. Obviously, it has a large CBR component. The MBR course has since been upgraded from certificate to diploma level, and the first lot of Diploma MBR i.e. 11 Ugandan and two students from the African region have completed the course.

CBR COURSES IN SPECIAL NEEDS EDUCATION

In addition to the courses in the CBR Department at UNISE, Special Needs Education (SNE) students are also introduced to basic topics in CBR, incorporated in the Diploma and B. Ed. courses. This gives the SNE students an overview of the CBR activities and at the same time, facilitates a link between special education and CBR, which is hoped will continue when the students return to the field.

WORK IN THE COMMUNITY

Students in the CBR course are linked to the community in many ways including field visits, situational analysis, community practice and fieldwork project work.

Field visits are done by both groups of CBR students, while the situational analysis is done by PGD CBR students in the break between the first and second semesters.

In this period, they collect data in their local sub-counties. The data is related to the general socio-economic condition in the sub-county, vis-a-vis the situation of PWDs.

Methods used to collect the data include documentary searches in the sub-county headquarters, interviews with PWDs and their families, observation and focus group discussions. These data are analysed and later used to develop Action Plans, to be implemented by the student graduate in the area, when they return after graduation. The plan aims to involve and benefit PWDs and their families.

Both, the PGD and the Diploma Students do community practice. PGD students do their community practice in two separate blocks of three weeks each, within the second semester, first at the beginning, then towards the end of the semester. Diploma students do their community practice for six weeks at the end of the second semester in the first year, and then for another six weeks in the first semester of the second year.

We consider it very important to work towards developing students' skills as well as their knowledge. The skill of being able to use some sign language or Braille, as opposed to just knowing about it and the skills of using observation and problem solving processes to give useful advice and support, to families with disabled children. Even the skill of riding a bicycle might be an essential component for a community worker in a rural location! We say 'work towards' because we recognise that although the students have a generous amount of exposure to work in the community, we still have to put in place more rigorous methods of supervising and assessing their practical skills. We also need to do more work on identifying the core competencies that CBR workers require and how these can be taught and assessed. Once these are established, we will then have to persuade the authorities to recognise them as an essential part of the curriculum.

For community practice, both groups of students are placed in the local sub-counties under local supervision of the District Rehabilitation Officers and Field Co-ordinators, as in the case of USDC programmes. They work with the Community Development Assistants and Physiotherapists in the community. They also interact with local leaders and groups of PWDs, their parents and the local community. They visit families, identify and assess PWDs and try to meet their needs in various ways including counselling, referrals to schools, hospitals and various community programmes meant to improve their welfare within the locality. Students also discuss and give advice on income generating activities.

As part of their practical assignment, students identify and select clients who need assistive devices. They are required to make them locally, by themselves, as part of practice, while meeting the immediate requirement of the person using local materials. When they are back in UNISE, they make an assistive device to address the needs of a particular person with disability earlier identified and worked with, in the community. This device is assessed as part of their examination process. During the practical examination, students are expected to show this device, describe its practical use and some of its advantages to the client.

LINKAGES

As has been mentioned, University of London has been in the background to the development of the course, in many ways. It has supported the course, by providing staff capacity development, in terms of courses run both here and in London, in the form of visits and attachments. It has been instrumental in the development of the curriculum and the Disability Resource Centre at UNISE. It has also promoted research activities.

Apart from NAD and University of London, the CBR Department at UNISE has linkages with Makerere University and NGOs including USDC, NUDIPU, and COMBRA. They all have contributed in various ways to the courses offered through lectures, curriculum development, examination control and field work supervision.

NAD, in conjunction with UNISE, put up a building to house the CBR course and that included office blocks for lecturers. NAD sponsored seven students per year, as well as community supervision, through lectures. They also provided equipment necessary for preparation and teaching of various lectures.

CBR COURSES AT MAKERERE

Although the initial plans for a CBR course sponsored by NAD at Makerere did not materialise, the process of negotiation stimulated interest and enthusiasm amongst staff there, and in 1996, a Masters degree and Postgraduate Diploma in CBR were introduced in the Department of Social Work and Social Administration, at Makerere University. The Masters degree is intended to train rehabilitation personnel engaged in the planning of research and training, of middle and lower level rehabilitation workers employed by both government and NGOs.

The Postgraduate Diploma in CBR aims at preparing potential rehabilitation workers, administrators, and managers of CBR programmes, at both, national and district levels.

Minimum requirements for admission for the Master of Arts in CBR is a Second Class Honours, in Social Sciences, Arts and related fields like education and health services. For the PGD CBR, the candidate must possess a degree in Social Sciences or a related discipline from a recognised institute of higher learning, including previous working experience with PWDs.

In addition to the above courses, in 1998, the University introduced a course in CBR for undergraduate students pursuing first degree at the University. Since inception, the average number of undergraduate students taking CBR as a selective course is 400, every academic year. These developments have made use of the original idea of running the course at Makerere.

COMBRA CBR COURSE

Within the period in question, COMBRA, a Ugandan NGO started an advanced certificate course in CBR, which has been very useful in turning out large numbers of badly needed CBR workers, after six months training. The course is more skills based than the UNISE courses. It has been useful both nationally and in the East African region, for increasing the numbers of trained CBR workers.

In 1993, COMBRA received financial support from African Development Fund, that enabled the organisation to construct a CBR training centre for community workers. The construction of the centre has enabled sustainability of the training programme. The programme targets development workers involved in the rehabilitation of persons with disabilities. The programme started in 1994, with 12 students and has grown ever since. To date, COMBRA has completed 14 courses and 203 field workers from Uganda, Botswana, Eritrea, Ethiopia, Kenya, Liberia, Namibia, Tanzania and Zambia, have participated in the courses. They are trained to play a key role in identification, assessment and rehabilitation of PWDS at community level. Initially, COMBRA ran two, sixteen-week courses a year, but has since diversified to meet the needs of other partners.

USDC (UGANDA SOCIETY FOR DISABLED CHILDREN) TRAINING

The focus of USDC work, is to improve the quality of life of the individual child living at home. This is done through imparting of rehabilitation skills and knowledge on disability, at community level.

Training has been a key activity targeting many different groups, including facilitators who work on a voluntary basis and act as local village disability consultants. Others trained, also include medical personnel, artisans, primary school teachers, community development and health assistants (Uganda Society for Disabled Children Annual review 1997- 98).

USDC also supports district organisations of people with disabilities (DPOs), in terms of training aimed at educating the public about disability issues, so that they can continuously advocate for their rights. The methods include seminars and workshops. In the last few weeks, USDC has started sharing information concerning issues on disability, with the public and a quarterly pull-out entitled, 'Ability' to be published as an additional piece in one of the daily newspapers. The aim of this approach is to address issues on disability in the media, so as to increase capacity for interventions. Community education and awareness raising is also carried out by USDC. At the moment, emphasis is being laid on training and counselling of parents.

MINISTRY OF EDUCATION – SNE/EARS TRAINING

Special Needs Education/Educational Assessment and Resource Services (SNE /EARS) in the Ministry of Education, using the educational model of CBR, has been working hard to assist the government to realise the goal of equal opportunity for education. This has been done through workshops and seminars. Knowledge and skills are imparted to teachers, school administrators, community leaders and parents on various topics, including prevention of disabilities, early identification, inclusion of children into regular schools, and effective co-ordination of services.

A cadre of teachers referred to as SNECOs (Special Needs Coordinators), have been trained. These move from school- to- school, advising fellow teachers on effective inclusion of children with disabilities in the regular classroom. This has helped to transfer knowledge and skills to school teachers and administrators about the education of disabled children in main stream schools. The success of the government policy of inclusive education has to a large extent, depended on the SNE/EARS training programmes.

MINISTRY OF HEALTH TRAINING

The Ministry of Health has been engaged in CBR training for a number of years, using the headquarters staff who move to districts on an outreach basis. The training is focused on serving health workers.

The Public Nurses College, which trains health visitors, also has a course unit on CBR.

The objectives of this course are to enable health visitors in training to get knowledge and skills, in the identification of clients who need rehabilitation services. They are also trained to counsel and refer clients and to support and collaborate with community based rehabilitation services. The training methods used include discussions, field visits and practical placement in CBR programmes. They carry out some of the work in combination with their home-visiting programmes.

TRAINING BY MINISTRY OF GENDER, LABOUR AND SOCIAL DEVELOPMENT

From 1995 till recently, the disability section of Ministry of Gender, Labour and Social Development has been running two sets of courses, one for field extension workers and the other for PWDs, their parents and CBR committees at community level. The general objectives of this training, were to achieve integration of PWDs into all aspects of society and local community (Ministry of Gender and Community Development 1995).

Practical methods of training were used, including facilitators and resource persons from Health, Education, Agriculture and Community Development, operating at the district level. The topics covered included prevention and management of disability, at the community level.

In the training of parents and PWDs, Community Development Assistants are the chief trainers, together with the help of extension workers at sub county levels (Ministry of Gender, Labour and Social Development 1998).

NUDIPU TRAINING

The main mission of NUDIPU is equalisation of opportunities and participation of disabled people within mainstream society. It has been able to do this through many training activities, workshops and seminars. This has been done by NUDIPU at the centre, or by many of its affiliated organisations.

Areas of training according to National Union of Disabled Persons of Uganda (1999) include:

- leadership skills;
- awareness raising in conjunction with Ministry of Health;
- logical framework.

Training of District Union Leaders and women councillors in leadership skills, has also been carried out. Change agent training and induction seminars were run by Kabarole District Disabled Union (Kwagala, 1999). In July 1999, a workshop on women with disabilities on local governance was held in Kabarole, Guzu (1999).

PROBLEMS ENCOUNTERED

The problems of setting up training for people involved in CBR are many, as noted by Thorburn (2000), but they largely relate to three main areas, namely,

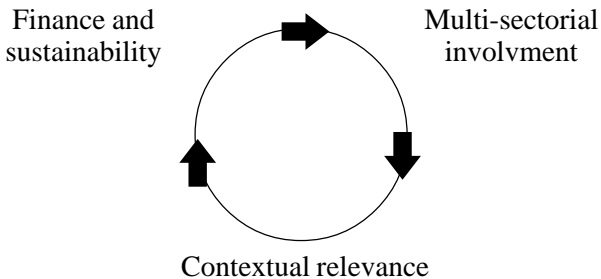
1. financial security and sustainability,
2. coping with the necessity for multi-sectorial participation including their different political agendas,
3. developing holistic, contextually specific programmes, which equip people to work effectively within the CBR framework.

We see these three factors as essential ingredients, which interact in an iterative way as illustrated in diagram 1. Training programme development normally engages in this process at the financial point, then moves on to multi-sectorial involvement and eventually, examines the contextual relevance of the courses they are developing. The extent to which these stages have been successfully handled, influences the continued finance and sustainability of the courses and the process goes round again. Realisation of the connection between these stages is an essential ingredient of successful programme development.

Some examples of the problems encountered in Uganda concerning sustainability and possible solutions available through activity in the

multi-sectorial and contextual dimensions, are discussed here and may be helpful to others wishing to set up and/or sustain CBR training, in other African countries.

Diagram 1:



1. Finance and sustainability

In an era of structural adjustment, education in Uganda has been commercialised. This is a big challenge for CBR training, as few students are able or willing to pay for privatised courses, especially when employment prospects are not forthcoming, as in CBR. There is limited sponsorship by employers and district authorities, for students who are keen to do the course and the lack of a clear employment policy and structure for graduates, once qualified. This means that students find it hard to get employment. For example, NGOs still continue to employ people without the CBR course background, despite their awareness that UNISE is turning out graduates with appropriate knowledge and skills, and so a significant number of the Ugandan graduates have been forced to take up other jobs, not related to disability. Some Ugandan students who register for the CBR courses are not released by their employers and have to opt out of the courses to retain their jobs. There have also been fewer than expected, foreign students. These factors affect the student’s motivation for doing the course and have had a serious impact on the numbers of students recruited and the sustainability of the training programmes.

Additionally, community development assistants are at the moment, heavily engaged in multiple development issues at the sub-county level. There is a danger that even after training in CBR, they would find themselves over involved in other activities and projects, which are often more financially rewarding than CBR. Thus, the development of services for disabled people loses out again.

Establishing an effective recruitment practice can also seriously affect the sustainability of these training programmes. If people with practical skills, commitment and experience are turned away in favour of degree holders who have no interest, experience or aptitude for working with PWDs, the resulting graduates are more likely to leave the CBR workforce. If male students predominate, when it is known from observation of CBR activities, that it is the women who respond more easily and effectively to the problems faced by PWDs, then, this natural inclination and strength will be wasted.

2. Multi-sectorial participation

Increased multi-sectorial participation (which includes community members and families of disabled people as well as professional and more formal organisations), will help to address some of the issues outlined above. For instance:

1. If Government and non-government personnel are increasingly involved in the CBR training and its management, and are continually included and kept informed of the process and content of the course development, then they are more likely to sponsor future students, allocate budget lines, and employ graduates.
2. Sectors are more likely to offer support, if on-going modification of the curriculum and evidence of clear learning structures and targets are made apparent. For example, we need to know what are the core competencies of a CBR worker and how does the course teach and examine these competencies?
3. If representation from different stakeholder groups is utilised to make student selection, then it is more likely that bias will be

minimised. On the other hand, if courses remain isolated and separated from other sectors and fail to engage with other stakeholder groups, then these other parties will become sceptical and critical and a climate of mistrust develops.

4. Training institutions could take further initiatives to publicise their courses through all the stakeholder groups and make sure that the communication structures are in place, to facilitate the students attending the courses.
5. An international CBR training group could gather information concerning the different courses and make this information available to the various players as a first step, in streamlining the training offered and the contents of the courses.

The degree to which participation can be achieved, appears to positively affect the outcome of these training programmes and awareness of the essential nature of multi-sectorial involvement and determination is required, if effective and sustainable CBR training programmes are to be developed and sustained.

**WORKING TOGETHER TO IDENTIFY THE DESIRABLE
COMMON DENOMINATORS WILL HELP TO SHOW US
THE WAY FORWARD.**

3. Contextual relevance

Likewise, attention to the contextual relevance of the training programmes will influence their sustainability. This is the issue that had to be faced when the post-graduate programme in London was moved to Uganda and to India. It was essential that training took place in a more contextually appropriate setting, so that the practical rehabilitation and management skills gained, were relevant to that specific setting. Likewise, what is effective in Uganda may not be the answer in Kenya, what might be the best solution in Zimbabwe, might not be the best thing for South Africa. However, this does not mean that the 'Uganda experience' and the 'London experience' cannot be useful to other

countries at a conceptual level, or for performing specific roles, such as (in the case of London) the development of a body of competent researchers, who will be able to return to their countries and have the skills to ask and answer relevant research questions relating to disability. It is by sharing experiences and perceptions across countries and continents, that new initiatives are born.

The need for relevance is not confined to country specific elements, but also applies to the different groups of people who require training. As you have seen, the CBR courses in Uganda are many and they serve different population groups. Some train volunteers, some train community workers, some train disabled people, some train districts and some train professionals. In order to cover the training needs of these different groups, different training is needed, at different times, in different places, for different lengths of time about different things. Yet, ALL these versions of training are needed, if the CBR vision of equalisation of opportunities and social integration are to be realised. My point is, that we must not be misguided into thinking that there is ONE RIGHT WAY of conducting CBR training. The manner, structure and content of such training depends on:

- who you are training,
- why are you training them,
- where will they be working after the training,
- what will they be expected to do and FINALLY and most importantly,
- how this relates to the structure of the environment in which they are living and working.

THERE IS STRENGTH IN DIVERSITY. THERE IS NO NEED FOR US ALL TO BE THE SAME...WE ARE ALL NEEDED AND ALL IMPORTANT.

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Figure 2

Uganda Districts



Key:

- Government CBR Programs
- ⊕ Comprehensive CBR
- Sight Savers CBR Program
- USDC CBR Program
- ⊕ COMBAs
- × "DURS" CBR Program

Courtesy: Moses Ddamulira, UNISE.

CHAPTER 5

Professionals’ Participation in CBR Programmes

Sally Hartley, Alice Nganwa, Joseph Kisanji.

SUMMARY

This chapter examines the role of professionals in the development and sustainability of CBR programmes in Africa. It considers what is meant by ‘a professional’ and whether CBR workers should be, or would want to be, considered a separate profession. It looks at how some professional groups have participated in the development of CBR programmes and considers what lessons can be learned from these experiences. It uses research concerning the relationship between parents and professionals and considers these frameworks as a way of clarifying the relationships between the stakeholders of CBR programmes. In conclusion, it suggests that if positive contributions are to be made by professionals to the lives of disabled people, there is a need for a ‘new professionalism’. This new professionalism will require courage and determination on behalf of existing professionals and it will need to be embraced at a contextual and local level, if it is to be meaningfully interpreted in the Ugandan context.

INTRODUCTION

What is the definition of ‘a professional’?

Perhaps, as you read this, you would like to reflect on what you consider are the essential ingredients of a professional, and whether you consider

yourself to be one, or not? What are the good things about professionals? What things are not so good? To what extent do you fulfill these criteria? To what extent do you not fill these criteria? Which of the people you work with, are professional and what makes them different from the others? What do you have in common with these different groups? Could you aspire to change yourself and your activities, to match those of the people you admire the most? Do you want to be considered a professional at all? If so, why? If not, why not?

The responses to the above questions reflect the definition adopted for a professional, which according to the Oxford English Dictionary, is a person who follows an occupation or 'calling', together with other people who have the same 'calling'. It assumes a similar educational experience with jointly maintained standards and involves using this knowledge and skills to earn a living.

Using these criteria to examine the professional status of CBR workers, I think we would all agree that they have a common occupation or calling, and most use their knowledge and skills to earn their living, some of course, are volunteers. But do CBR workers have a similar educational experience with jointly maintained standards? Perhaps the more important question we need to ask here is, is it desirable for CBR workers to have a similar educational experience with jointly maintained standards, or is their diversity and flexibility their strongest ingredient?

Another question we might like to consider is: **if CBR became a profession in its own right who would benefit most? the CBR professional or the people with disabilities?** For most of the present century it has been considered 'honorable' to be a professional. Traditionally, professionals work hard, serve other people, can be depended upon for their good judgment and can be turned to, for help, in times of trouble. Many CBR programmes were and still are, started by established professional groups such as therapists, doctors, and teachers. Many CBR programmes are run by professionals and controlled by professionals. **BUT IS THIS A GOOD THING?**

As we all know, it creates many problems. Professionals are often ‘placed on pedestals’ and this has fostered a kind of elitism, which has created a barrier for them in terms of participation with other groups. Professionals are inclined to take over, talk too much, listen too little, and know best. Traditionally, professionals work hard, serve other people, can be depended upon for their good judgment and can be turned to, for help in times of trouble.

Chambers (1997) helps us examine the relative status of the different professions. Many insights can be gained from reading his work. I am going to draw upon from two of his books, both, with a clear message in their titles. One is called ‘Challenging the professionals’ (Chambers 1993) and the other, ‘Whose reality counts?’ (Chambers 1997). These books make very stimulating reading and are strongly recommended by the authors. Both publications examine the activities of professionals and their relative status.

Chambers (1997) argues that professionals need to be challenged, particularly ‘high status professionals’, who tend to be concerned with ‘things’, or with ‘people as things’. These professionals specialise, they rely on precise measurements and their groups are dominated by men. They like things to be ‘standardised’, ‘controlled’ and ‘predictable’. For example, a consultant specialist may know everything about a certain part of the body; lets say ‘the eye’. This part of the body is looked at as a ‘thing’ not a person or part of a person, and operations, research and treatment are often carried out in isolation from the thoughts and feelings of the person who owns the eye. The daily problems and realities that a malfunction of this organ might cause, are often ignored. Chambers (a man himself) says this professional is most likely to be a man and he is most likely, to be a powerful man.

On the other hand, ‘low status professionals’ are usually concerned with ‘people as people’. They tend to work in environments, which are diverse, complex, dynamic and uncontrollable. They are generalists, they look at things holistically, they include nurses, teachers and therapists. Chamber’s (1997) says they are more likely to be a woman.

Given these different ranks of professionals, let us examine whom they participate with and how they participate.

Professionals all have their own organisations and can be seen to fraternise with their own groups, creating their own culture, education, society and rules. But one of the biggest barriers to their participation with other groups is, that KNOWLEDGE IS POWER. For example, if I know how to make canes for blind people, and you know about how to teach braille, as long as we don't teach each other to do the thing we know how to do, we will both keep our jobs. Thus, multi-sectorial teams are created with teachers, technicians and medical doctors etc. as essential members. However, it is important to realise that teams are competitive; the members seek to identify their differences to keep their status and often their jobs (e.g. 'you know how to make canes, I know how to read braille, our jobs are clearly defined, we are both needed').

Most certainly, 'Knowledge is power' and this reality CAN have a destructive impact. However, a more positive and constructive vision can be reflected if the phrase is completed as follows: KNOWLEDGE IS POWER BUT SHARING KNOWLEDGE IS PROGRESS TO A MORE EQUITABLE AND SUSTAINABLE WORLD. Rifkin and Pridmore (2001) in their publication on 'Parteners in Planning' illustrate the possibilities which open up by taking this more positive approach.

The illustration from 'Helping health workers learn', (Werner and Bower 1982), gives us a visualisation of the barriers between the different professional groups. I think we would all agree that these barriers exist but need to be broken down. Are we still in separate boxes? UNISE boxes, USDC boxes, ADD boxes, CICH boxes? Education boxes? Health boxes, Physiotherapy boxes? Doctor's boxes? UK boxes? Uganda boxes? Do we want to break down the barriers between our professional boxes? Or, do we want to create more professional boxes? If we do want to break down these boxes, what do we have to do? How can it be done? How can we break down the barriers that exist between us and get to know each other, work together? Perhaps, CBR programmes offer a unique opportunity to do just that? Most disciplines become more

successful the more they specialise; however, in the development of effective CBR, EVERYONE is needed for a programme to be effective. No, one agency or profession can succeed alone, it is essential that ways be found to break down the barriers. We must find a way!

So far, I have only been talking about the barriers between the different professions and the organisations that those professionals create, but I am not forgetting the other important stakeholders in the CBR vision; the people with disabilities themselves, their parents, families and communities in which they live.

Goulet (1997), says that partnerships, whether with other professionals or with other stakeholders, are created when two or more people or organisations plan and implement projects and activities together, with the intentions of achieving agreed outputs. Implicit in this definition is, ‘a sharing of power, resources and information in the context of cooperation based on common goals and values’. Since it is known that achievements through partnerships are greater than the sum of the parts working alone, a partnership is of mutual benefit.

As the Masai proverb puts it, ‘One head cannot contain all wisdom’.

In CBR work, a very important partnership is often formed between the professional and the parent of a disabled child. Let us look at the research relating to this relationship and see if any lessons can be learnt from this.

Community work often relies heavily on training parents, and it is salutary to remember that when professionals ask parents to carry out certain tasks, parents are not paid, but professionals are, parents are on duty 24 hours a day, professionals have more reasonable working hours. Parents are often isolated, professionals have a network of colleagues, parents look at the whole child and professionals tend to look at one aspect. These different ground rules make partnerships difficult. There is an assumption that parents will be able and responsible, but in practice this is determined by time, energy, resources and attitude (Coleridge 1993) (O’Toole 1991).

The literature indicates that there are different partnership models and I will examine them very briefly.

The **Expert model** as described by Cunningham and Davis (1985) is often associated with rehabilitation in institutional settings and has the following dimensions:

- Professionals are experts, have knowledge and skills;
- Professionals aim to promote a child's functional status;
- Perceptions of users largely rejected;
- Users mainly passive recipients;
- Comply with treatment and advice;
- De-skills parents and disabled people;
- Creates dependency;
- Reduces personal efficacy;
- Creates feelings of inadequacy;
- Unique knowledge and skills of parents and disabled people ignored.

The **Transplant model** described by Mittler and McConachie (1986), has the following dimensions:

- Trains parents to promote functional status.
- Users of service are regarded as a resource for expanding the coverage.
- Parents are co-educators, co-therapists.
- Professional is the instructor.
- Transplant technical knowledge to parents.
- Ensures consistency of approach.
- Sustainable, after parent leaves.

- Two-way dialogue.
- Assumes all parents are willing and able.
- Ignores differences between families.
- Lack of recognition for parents' existing strengths.
- Professionals still in control.
- Parents can become dependent.

The **partnership/negotiating model** described by Cunningham and Davis (1985) has the following dimensions:

- Recognises parents' expertise and ultimate knowledge
- Recognises diverse needs of different families
- Active participation in decision making
- Professional supports the parents and family
- Professional enhances the use of existing recourses and coping strategies
- Assumes parents and professional will reach agreement

The **Eclectic model** described by Dale (1996), is perhaps the most desirable solution where the 3 models are used at different times, in response to need. i.e. sometimes parents need the expert model.

Interestingly, these structures have many similarities with the structures used to describe levels of participation (Werner and Bower 1982).

1. Expert prescription dis-empowerment
2. Expert recommendation 'opinion asked'
3. Expert suggestions 'participation'
4. Consultant support 'involvement'
5. Enabling support 'empowerment'

These models can be applied to the different possibilities open to professionals, who wish to participate in the development of CBR programmes. For example, professionals have the choice of starting CBR programmes, of teaching CBR students, of conducting research, using any, or even all of these models. What they have to decide is, which one should they use and how much of each?

Examining key aspects of the legislative service system can also serve to give us guidance about how services should develop and subsequently, what role professionals should/could play in this. The UN Standard Rules (UN 1994), give a clear mandate for professionals to participate with all stakeholders, not just parents. They say, 'every individual has a right to participate' but, how often does this happen? Are professionals trained in how to do this? Is participation an objective of programmes from the very beginning? Or, even at the end? How many professionals working with people with disabilities are aware of the UN rules? How seriously do they take them on board and apply them to their practice in training, in research, in curriculum development? What changes have been made to the training of professionals, so that they have the necessary attitudes and skills to participate with other stakeholders? Indeed, have the skills they require, been identified at all?

The UN rules also say that persons with disabilities have a right to remain within their local communities and should receive the support they need, within existing local structures. This is of course the philosophy underpinning the development of CBR services, but is providing professional services at community level something that professionals strive for enough? Do they set up their services in remote rural communities? Or, do they tend to prefer the city life? Do they spend enough of their time, sharing their knowledge and skills with community workers, to enable them to function more effectively at community level? If the answer to these questions is no, then we need to ask, WHY NOT?

Helander (1993), says that it is hard to think of a better way of blocking the development of services for disabled people in developing countries, or of a more effective instrument to make governments delay in the

setting up of services, than insisting that there should be no change in duration of professional training and no change in the curricula. Adoption of unnecessarily high standards of training and narrowness of specialisation considerably increases the price of providing training and subsequent rehabilitation.

O'Toole and McConkey (1995), attribute the lack of progress to adopting professional roles which are inappropriate for that society (i.e. imported from other cultures). 'Modernisation image' fosters the illusion that western skills, knowledge and attitudes should be diffused to developing countries. I think we probably all agree with Coleridge (1993) who says, 'professionals need to change... but this does not mean that they should become passive and de-skilled. Quite the contrary: acting, as a resource actually requires a higher degree of skill than treating someone who is merely an object in the process. But it does require a different attitude and different training. The questions we must address therefore are, how are we going to change the attitude of professionals?

HOW ARE WE GOING TO CHANGE THE TRAINING?

Chambers (1997) also suggests that there is a need for a new professionalism, that professionals have to learn not to dominate, that dominant superior behaviour damages participation, that professionals need to learn to facilitate, to engage in participatory rather than didactic teaching, to function effectively in communities rather than institutions, to teach through experience, to 'learn by doing', to develop participatory action orientated research, to stop rushing about and take time to listen.

So how can we carry forward these ideas in CBR practice? Some suggestions might include:

1. Engage with CBR programmes so that services develop in communities.
2. Establish what community services providers; disabled people and their families need to know.
3. Give up exclusive rights to their knowledge about impairments.

4. Share the knowledge and information they have, with all participants.
5. Act as facilitator.
6. Act as re-enforcer.

Finally, and perhaps most important of all, professionals need to change their attitudes, they need something I am going to call 'HUMRESH'.

1. **Humility**, to be humble about their so called achievements.
2. **Respect** and learn from others.
3. **Sharing** their knowledge and skills willingly.

In the Ugandan context, the attributes described can be highlighted by three Ugandan terms, which seem to summarise what is required of a professional in CBR. The first is *Mwalimu*, the second is *okuyiyayiya* and the third is *Muntu mulamu*.

Mwalimu means teacher, leader, and the one who shows the way. One such teacher was Mwalimu Julius Nyere, the former president of Tanzania. Professionals in CBR need to show the way, to be facilitators, to share knowledge and help others discover things for themselves.

Muntu Mulamu. Translates literally into 'person alive', but its meaning relates to one who does not cheat, is not proud, not quarrelsome, shares and is down-to-earth and helpful. This is what the new professional should be. They should be 'persons alive'.

The third term *Okuyiyayiya* is very interesting. This term became popular when Amin was President of Uganda. Essential commodities were scarce, so one had to be creative in order to survive. This creativeness required using what one had at hand to replace or get a commodity, like using honey in porridge; washing clothes with pawpaw leaves. The new CBR professional needs to have this skill of *okuyiyayiya*, to be creative, to be innovative, to persevere in solving problems.

We need to consider nurturing the skills we wish to find in professionals during their training. We need to ask, do our training schools give

physiotherapists, doctors, teachers and economists, the skills to be creative, adaptable and work with the community? Do we train them to be facilitators or bosses?

A few weeks ago, we were reviewing curricula for nurses, clinical officers, midwives and health assistants with the view of including CBR. The curricula we use are very much facility-based and community health and practice is often cosmetic. One issue of concern of people with disabilities and parents of children with disabilities was the rude, uncaring and crude manner in which people with disabilities (PWDs) were treated by health workers. In a recent meeting with District Directors of Health Services, it was noted that rude health workers reduced accessibility to services.

The challenge however, is how do you ‘train’ a person to be a *muntu mulamu*- a living person? Where does it fit in the curriculum? Should it be placed under ethics? Can it be learnt from his mentor? Does a large salary buy politeness and empathy? Or does it have the opposite effect?

On the issue of diluting the profession, are we watering down our noble professions when we train a community worker to teach a mother how to care for her baby? Or are we effectively providing information to those who need it? Professionals, especially rehabilitation professionals, are very few and the need is so big. We need to consider if there is a way that CBR can utilise more professionals, such as nurses, health assistants or community health workers and how can they be taught to identify people who require direct intervention from the more specialist rehabilitation worker. We also need to consider the role, which could be played by the indigenous professionals. Can CBR programmes capitalise on their existence? How can they do this? Do the local communities recognise their usefulness? How can they participate and make their contribution towards better lives for disabled people and their families?

Then, there are the power struggles. Are CBR professionals willing to leave decision making to the community? Are they prepared to involve and work with the indigenous professionals? Where will their next meal come from, when they are no longer needed? My experience is that the

service users continue to be 'them' and service providers 'us', or vice versa. How can this wall between the groups really break? Who will break down these walls when the professionals have fought so hard to build up their credibility, their standards and their professional status? Perhaps one possible solution lies with the inclusion of PWDs within the professionals' ranks; perhaps it is only PWDs who can lead the way towards breaking down these walls and bridging the gap.

CBR professionals with formal training in CBR also need to be creative-*okuyiyayiya*. When reporting back to their station after training, many wish to deliver the complete package of CBR exactly as they were taught. This is often not possible because CBR is contextually defined and activities may need to be fed into the existing programmes or job descriptions, at the same time as networks are built with communities, professionals and organisations to fill the gaps.

A Parting Thought

‘There is very little difference in people. But that little difference makes a big difference. The little difference is attitude. The big difference is whether it is positive or negative’

W. Clemens Stone

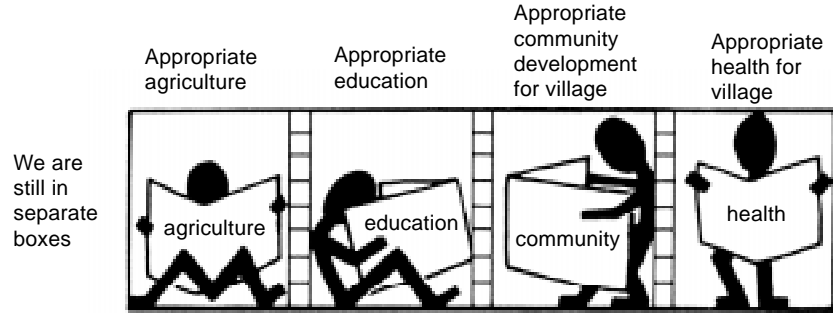
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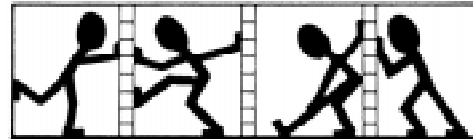
Illustration 1

THE DISCIPLINES THAT NEED TO WORK TOGETHER FOR HEALTH

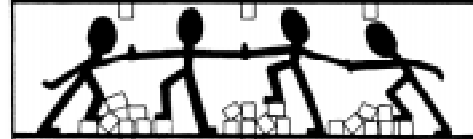


Where do we go from here?

Break down the walls



Get to know each other



Work together



Courtesy: 'Helping health workers learn', Hesperian Foundation.

CHAPTER 6

Government's Role in CBR

J.S. Mpagi.

SUMMARY

Several international documents are available to help and guide Governments to set up structures that will benefit people with disabilities. It is the challenge of every government to use these documents to create legislation appropriate to their own settings according to the needs and wishes of the people concerned. In Uganda, 'The World Programme of Action Concerning Persons with Disability' (UN 1983) was found to be a very helpful guide, and in the beginning of the 1990s, it was decided to promote the development of CBR programmes as a mechanism for facilitating a holistic approach to disability. The Government of Uganda has undertaken support of marginalised groups, including persons with disabilities, by formulating supportive policies within the constitution and in Local Governments' Acts. As a result, there is now representation by people with disabilities at every level of Government. This creates the structure and a level of participation that enables disabled people to develop their own solutions within the framework of the existing system. Other strategies include the introduction of Universal Primary Education (UPE), which encourage parents to send their disabled children to school, facilitating a move towards inclusive education. Mobilisation of resources, new administrative structures, de-centralisation, appropriate referral systems, training programmes and evaluation procedures, all contribute to ongoing activities relating to persons with disability, in Uganda.

INTRODUCTION

The extent of the need for rehabilitation services in Africa has so far not been reliably established. In 1992, a figure of 185 million people with moderate or severe disability in developing countries was estimated, as most of these people were thought to be without any rehabilitation services. In the 1980s, the World Health Organisation estimated that the prevalence of disability in developing countries was 10%, which was later revised by Helander (UNDP 1994) to 5%. However, according to the Uganda Bureau of Statistics, it is estimated that there are about 2.1 million PWDs who need rehabilitation, which is more than 10%. It is argued by some, that this figure could even be higher, given the political turmoil that this country has passed through.

Over the years, there has been some progress in the development of traditional vocational rehabilitation services, set up in 1965, to assist disabled youth and adults to learn vocational skills and become productively employed. This traditional approach, where services were provided in institutions by multi-disciplinary teams with specialised equipment, had limited capacity, high maintenance costs and promoted social segregation by removing PWDs from their environment.

In view of these shortcomings, coupled with the rising population of PWDs, the UN World Programme of Action concerning the PWDs (UN 1983), presented a document to guide the individuals, governments and non-governmental organisations (NGOs) in the promotion of programmes for PWDs.

In addition, the document provided for effective measures for prevention of disability, rehabilitation and the realisation of the goals of full participation of the disabled persons in social life, development and equality. This document has been used by the Ugandan Government to guide us in setting up the structures, that promote a conducive environment for full participation of PWDs in all spheres of life.

DEFINITION OF CONCEPTS

Presently, the Government uses the following operational definitions of the central concepts relating to people with disabilities. I, however, take

cognisance of the different definitions by different authors and development strategists, which have developed since the 1980s and recognise a need for our Government to re-consider our policies in the light of more recent perceptions.

Disability refers to any form of restriction or lack of ability to perform an activity in the manner, or, within the range that is considered normal for a human being. A person with disability is an individual who is officially recognised by society as such, because of differences in appearance, behaviour, communication and functional limitations (WHO, 1980)¹. Disability may be temporary or permanent and reversible or irreversible and may be described as progressive or regressive.

Rehabilitation includes all measures aimed at reducing the *impact* of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation. It includes not only training of persons with disability, but also interventions in the general systems of society, adoptions of the environment and protection of human rights.

Community is defined as a group of individuals living together, with similar interests and having the same ideological, religious, cultural and economic aims.

Community Based Rehabilitation involves measures taken at the community level to use and build on the resources of the community, their families and the community as a whole. This means that CBR programmes should be planned and implemented with the participation of PWDs. This is different from the so-called community programmes, where the core phases and plans are done away from the actual community, often in the city.

Participation refers to the involvement of the beneficiaries in the programmes being initiated/implemented in the community, in order to ensure ownership and sustainability of such programmes. This is based on the assumption that it is the beneficiaries who know their own problems the best.

Decentralisation means delegation of responsibility, or functions of an organisation, along with authority for carrying out these functions, to those at the periphery of the organisation, i.e. the local governments and other implementers e.g. NGOs.

COMPONENTS AND PRINCIPLES OF CBR

As mentioned earlier, the World Programme of Action (UN 1983) concerning the persons with disabilities, was worked out by the United Nations in order to guide the stakeholders in the field of disability. The Community Based Rehabilitation approach is part of the recommendation of the World Programme of Action.

It is increasingly accepted, that a good CBR programme is based on a holistic approach and will include many of the following aspects (O'Toole and McConkey 1995):

- Understanding community needs;
- Identifying community perceptions and beliefs;
- Promotion of social integration;
- Transferring knowledge to communities but also learning from the communities;
- Empowering PWDs and community;
- Encouraging PWDs reach their potentials, mobility etc.;
- Removal of physical barriers, social and physiological;
- Building strategies for sustainability;
- Changing negative attitudes;
- Addressing human rights issues and information sharing, as essential components of the CBR programme.

INTRODUCTION OF CBR IN UGANDA

In Uganda, the Government started planning for a community based rehabilitation programme in 1989. In 1992, the Norwegian Association

of the Disabled (NAD) agreed to support the Government in the implementation of CBR. The programme was first piloted in the three districts of Kabale, Mbarara and Bushenyi. The CBR programme was initially started in 15 sub-counties in each district. The lessons learned from the three pilot districts were later used to extend the programme to six more districts namely; Kamuli, Iganga, Tororo, Mbale, Ntungamo, Rukungiri and Mukono.

Strategies and role of government in promoting participation in CBR

In order to improve and strengthen implementation, the Government must set up management structures to facilitate the smooth operation of CBR programmes. This includes policy-making and planning, appropriate administration structures, provision of resources, decentralisation, training personnel, onward referral systems and monitoring and evaluation.

Policy, formulation, review and promotion

Today, various governments have laid down a number of strategies to promote participation of marginalised groups. Governments have policies applicable to vulnerable groups in general, but there is a need to design policies, which adequately address issues of PWDs. This may require formulating new ones, promoting or reviewing existing ones, so that any deficiencies in particular sectors such as health services, schooling and employment opportunities that affect PWDs are corrected. By formulating detailed *policy statement*, the government points out what is to be achieved, how to implement change, who is responsible, when can change be made and a commitment to provide the resources. In Uganda, the affirmative strategy has been used to promote participation.

For example, at present, in the bid to ensure participation of PWDs in the political life of the country, the Ugandan Government included Article 32 (1995) which states:- *'Notwithstanding anything in this Constitution, the state shall take affirmative action in favour of groups who are marginalised on basis of gender, age, disability and any other reason treated by history, tradition or custom for the purpose of redressing*

imbalances which exist against them. In addition, commitment is made to addressing the needs of older people. The state shall make reasonable provision for the welfare and maintenance of the aged.'

The Local Government Act of 1997 also provides for representation of PWDs at all levels of Government. Presently, there are 47,000 councillors representing PWDs participating in decision-making processes at various levels. The Government has also appointed a Minister of State for Disability and Elderly, and created a full Department of Disability and Elderly to address needs and issues of disability. More affirmative action was done through the election of five members of Parliament to represent PWDs.

The crosscutting nature of disability calls for the development of mainstream strategies, to address all the aspects, which affect PWDs. For example, the Ministry of Education and Sports has also established a Department of Special Needs Education Guidance and Counselling, to ensure participation of children with disabilities in school activities at all levels. The Universal Primary Education (UPE) has a policy, that in families where there are children with disabilities, they must be given priority to attend schools. The Functional Adult Literacy Programme has also mainstreamed issues of PWDs in the curriculum. All these efforts by Government are to ensure full participation of PWDs in all programmes.

Putting up appropriate administrative structures

The Government has set up the necessary structures to ensure Community participation in CBR programmes. This includes the Department of Disability and Elderly in Ministry of Gender, Labour and Social Development to coordinate disability issues. This Department has also set up a National CBR steering Committee, which consists of the key stakeholders to monitor the activities of the CBR programmes. Due to decentralisation, a similar structure has been duplicated at district and lower levels. The Ministry of Health has set up a Disability desk and they are in the process of reviewing the health related curricula to include disability issues. The Ministry of Education too, has a special unit.

Mobilisation of resources

Funds, personnel, equipment, transportation, physical structures, statistical services, research and information are some of the resources that have to be mobilised.

Central and local government bodies, communities and non-Government organisations provide these resources. The government role here is to identify with the communities the available resources, and to point out to the community what it has to do, such as, provide local management and some of its resources. The government can then fill the missing components through training, technical supervision, administrative support and referrals.

Decentralising to encourage community participation

One of the key features of CBR programme development is decentralisation. However, this in itself is not enough, as there is no guarantee that this process can lead to higher levels of participation in the community based rehabilitation programmes. Decentralisation must be followed by a change of attitudes. The implementers of decentralisation need to be disability sensitive, to ensure that issues of disability are mainstreamed in the plans at district and lower levels of local Government. In Uganda, CBR programmes are implemented by the local Government and NGOs.

Training and Sensitisation

This component is important, for building a competent workforce at all levels. In Uganda, training of CBR workers is carried out at UNISE, COMBRA and Makerere University (Makerere University 1994). Sensitisation is another key activity. All stakeholders have been involved in sensitisation of technical personnel, political and district local authorities, to increase awareness and appreciation of the issues that PWDs have to face (Jackson 1993). Training of the PWDs themselves has been done to build their confidence, capacities and capabilities to realise their potentials and actively participate and demand attention of the issues that affect them. Training of families and communities has

raised awareness on causes, management and prevention of disabilities as well as contributed towards a change in attitude and increased awareness concerning the provision of resources.

Building and maintenance referral options

Referral options are looked at as places where PWDs can be referred for treatment, education, employment and legal advice. In most cases, these cannot be handled by communities, so it is the role of the government to ensure that these services are operating efficiently. Referral options in Uganda, have included major hospitals, special schools and vocational rehabilitation institutions. The government is encouraging integration in all fields as a way of increasing participation of PWDs. As the community based programme is being implemented, any PWDs identified and referred, should receive the necessary service.

Monitoring and evaluation

The Government monitors and evaluates the progress of all the programmes relating to people with disabilities. This serves as a check and contributes to the quality of the programme's development. High levels of participation are encouraged and where this is not achieved, action is taken to increase the level of participation and the range of stakeholders involved.

CONSTRAINTS

Inadequate funding

The Government would like to extend the CBR programme to the whole country, but due to inadequate funding, CBR is still limited to 10 out of 56 districts.

Lack of statistical data

The magnitude of disability prevalence is not known due to lack of reliable data. It is hoped that the next Population and Housing Census will come up with better disability statistics for ease of planning and resource allocation.

RECOMMENDATIONS

Empowerment

Even though some measures have been undertaken by the Government to eradicate poverty among PWDs and promote access to employment, this is an area, which still needs greater focus. For example, more PWDs need accessibility to micro-finance schemes in the community. Through this, the government will have ensured that PWDs are engaged in productive ventures for an improved standard of living.

There is also a need to promote cultural values and languages, including sign language, which is used by the deaf to preserve and enhance dignity of all.

Gender balance

Emphasis should be laid on gender balance, fair representation of disadvantaged groups and a call for society to respect the rights of PWDs, particularly the girl child and women. There needs to be better educational opportunities for the girl child, whether she is able-bodied or not.

Health care system

Since the leading causes of disability are communicable and preventable diseases, an improved health care system is a pre-requisite for reducing the rate of disability. This has a corresponding positive impact on the situation of those already affected by disability, in the sense that the available limited resources would be used to cater for a large number of PWDs. This could be supported by development of support services including supply of assistive devices, such as sign language training, provision of Braille, as well as the more obvious wheelchairs etc.

Removing physical and environmental barriers

The Government should be able to be more vigilant and avoid activities that increase disability, such as wars and motor accidents. Laws should be enforced to punish careless drivers and those involved in domestic

violence. Work places should be conducive to productivity and repetitive straining influences should be avoided.

Institutional rehabilitation

Everyone is well aware that community based rehabilitation does not provide all skills to PWDs. There are those who are severely handicapped, and, who still need the services of institutions. Governments should therefore continue to fund Institutions, so that they work hand- in- hand with the CBR programmes.

Coordination

As has already been discussed, CBR is implemented by different stakeholders. In order to avoid duplication, the government should be able to coordinate the activities together with the stakeholders and monitor and evaluate them.

CONCLUSION

In Uganda, it is believed that community based rehabilitation is one of the best approaches to rehabilitation. It is cost effective and more PWDs have been reached. However, there are people with severe impairments whom the community may not be able to accommodate and assist. This is why the referral system has been integrated in the programme. Institutions like hospitals, health units and vocational rehabilitation centres will remain points of referral. The two approaches should be seen as complementary and not in competition with each other. We believe that it is through this complementary approach that the problems of PWDs will be effectively tackled.

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¹ **(Editor's note: These classifications have recently been revised through a lengthy participatory process and the new document The International classifications of Functioning (ICF) (2001) is now available. For more details of these new classifications please look at Chapter 13).**

CHAPTER 7

The Role of Legislation in Facilitating CBR in Zimbabwe

Obert P. Ndawi.

SUMMARY

This chapter examines some of the ways, in which legislation can facilitate the development of community based rehabilitation (CBR), with particular reference to the situation in Zimbabwe. CBR is seen as a programme that cuts across medical, educational, social and vocational services. Each of these areas is examined and suggestions made as to how important legislation is in facilitating the development of services in these areas.

INTRODUCTION

Community based rehabilitation (CBR), attempts to restore or maximise the full potential and functions of persons with disabilities (PWDs), in their natural environment within the family and the community. Integration into the community is concurrent with the rehabilitation process and not subsequent to it. Ong'golo (2000), supports the idea of programmes for PWDs being carried out in their immediate environment,

but questions the communities' capacity to provide the necessary resources, and calls for improvement.

Rehabilitation institutions have been criticised for isolating PWDs from their natural ecological environment and in some cases, giving them a distorted view of their niche in society. They also deprive the other units of society, such as the family, the village and the school, of the chance to make their contribution to the development of a person with a disability. While CBR is extolled for reaching more PWDs than institutional rehabilitation (Kim, 2000, Tjandrakusuma, 1989) in developing countries, the logistical problems caused by the scatter and diversity of needs of PWDs in rural areas, tends to contradict this view. Consequently, the CBR programmes usually fail to run along the structures and functional modes that have proved effective in more developed urban communities. Generally, necessities such as food production, primary health care and basic education have been given higher priority than CBR. Regrettably, political power and war have been considered ahead of the needs of people with disabilities.

It is necessary to point out in this introduction, that PWDs suffer a lot of deliberate and sometimes inadvertent discrimination from the governments and the various units of their society, such as employers, schools and even hospitals. Their plight therefore, needs to be addressed. Perhaps, this cry from a Nepalese Council for the Disabled (Gautam, Personal Communication) may help to stress this point:

‘We disabled people of Nepal are facing maximum, unexpected discrimination from the private sector, society and the government as well. We have decided to visit you in your active organisation to study, to gain the vast experience and knowledge which is necessary to establish and implement the following agenda in Nepal:

- **The formulation of an anti-discrimination policy and related legislation concerning disabled people.....**
- **To re-enforce legal measures and influence additional legislation.....’**

As there is minimal goodwill for PWDs in society, lifeline programmes such as CBR, need to be facilitated and protected by effective legislation, to ensure that the programmes can work and produce results.

THE FORMAL STRUCTURE AND REQUIREMENTS FOR CBR

Whilst home-based rehabilitation (HBR) can be carried out by one institutionally trained family member, with the assistance of the other members of the family, CBR is more complicated, with more complex structures. CBR entails a supervisory committee including health workers, welfare workers, members of the Red Cross and people with disabilities. These people determine policy and oversee the activities of the programme. Under the committee, is a trained, intermediate level supervisor in charge of the local supervisors. The intermediate supervisor instructs, organises and oversees the local supervisors. The local supervisors put in definite hours of work per week, training and supervising family trainers. Each family trainer directly trains the family member with disability (Zhou 1989). In this model, **‘Rehabilitation is no longer the task of the specialists, but a responsibility of the whole community. Instead of having one person at the community level to deal with all aspects of rehabilitation, more people are involved’ (Burk, 1998).**

For an elaborate organisation like this, to function smoothly and realise its goals, there is often need for some regulatory and facilitatory instruments, which may need the enforcement of law. This chapter will examine some of the ways in which legislation can facilitate CBR.

THE ROLE OF LEGISLATION

CBR has often been seen as cutting across four areas, namely, medical, educational, social and vocational. It is expected that when all these areas have been addressed, the negative effect of a disability on a person is minimised and that they can realise their maximum potential. Each of these four areas can be facilitated by some favourable legislation.

MEDICAL REHABILITATION

In medical CBR, the PWD may require access to expensive specialist equipment, professional expertise or drugs. These services are often too expensive for most PWDs to afford. CBR projects usually do not have adequate financial resources. If in a country, the government has legislated for free medical treatment for all its citizens, the PWDs will be able to access the expensive medical facilities. In Zimbabwe, at independence (1980), free medical attention for all, was legislated. Poor people, with, or without disability were able to access specialist medical services. However, this proved to be too expensive for the national economy and had to be modified. The current position is that certain categories of medical or physiotherapy services are available only on payment. There is no preferential treatment for PWDs and exceptions are made only for those who cannot afford to pay, based on an entirely financial assessment.

Under these circumstances, CBR projects find it difficult to access medical specialists, who often charge very highly to provide the necessary medical treatment. Politicians need to lobby for PWDs to enjoy unconditional free treatment as they used to do earlier, as a way of giving them some head start, to enable them to cope with the challenges they face in life. It may be necessary to add that, 'free' treatment' means a service provided by a government institution, but where a private institution provides the service, the government pays for the treatment, possibly through the social welfare department.

Most CBR projects in Zimbabwe rely on voluntary services of the supervisors, trainers and caregivers. With the increasing numbers of PWDs, it becomes more demanding on these voluntary workers. They have to put in more time and still have to spare some time to work in their remunerative endeavours, to sustain themselves and their dependents. In fact, in the present harsh economic conditions, some caregivers and trainers volunteer in the hope, that the free service may be turned into remunerative employment. Governments cannot continue to sit back and leave such heavy work to NGOs, like the Red Cross.

They now have to legislate and put these activities under their Ministries of Health or Social Welfare, so that these activities receive regular funding to enable them to pay for the services rendered to PWDs. Things are now changing and Governments need to be responsive.

In Zimbabwe, after the general elections of 1995, the president appointed a man with disability to represent PWDs in Parliament, occupying one of the presidentially nominated seats. The PWDs found a lot of hope in this gesture, as their problems and concerns were sure to be fully articulated by one of their number. However, five years on, this was withdrawn when political expediency demanded otherwise. One admires systems like that of Uganda, where PWDs are represented at all levels of government and examples such as theirs, has shown the fruits that such structures can bear.

EDUCATIONAL REHABILITATION

In the area of educational rehabilitation, the debate on inclusion versus segregation appears to have occupied the minds of academics more than other issues. However, legislation should be put into place to support and safeguard the rights of PWDs to access education, since free education for all, requires supporting legislation. Where there is free education, CBR can be expected to promote and facilitate its use and development, whereas, when PWDs have to pay for education, the local school may be too expensive for the person with disability, or, the school may not know how to cope with his/her educational needs, thereby forcing him/her to seek education elsewhere, outside his/her original community. In such a case, they cannot remain in their own home and community; which renders the whole concept of CBR impracticable. It could be legislated that, PWDs in the local community be given special priority for admission in any school. This requires facilitation by the government. Such a legislation would ensure that PWDs can learn in their schools, so that other aspects of CBR can be conducted while they are within their own community.

When Governments award scholarships for specialist training, a quota system could be legislated, so that a certain percentage is reserved for

people who undergo skills training associated with the needs of PWDs. CBR requires people with specific skills associated with the needs of PWDs, it also requires these people to be available within the community. When they are not available or when they are too few in number, the clients have to travel away from their communities to institutions where such skilled persons are available. This is against the recommended structure of CBR, which requires that the person be rehabilitated within his/her own community. It can therefore, be seen that there is a lot of scope for legislation to facilitate the educational aspect of CBR.

In Zimbabwe, in spite of free primary education introduced at independence in 1980, by 1997, 21% of persons with disability aged between 5 and 24 had never been to school. This could indicate that declaring free education for all is not enough. It could also be, that at that time, the institutional approach which was mainly used for the education of people with disability, was not effective in enabling them to access education. Perhaps a CBR approach could have achieved better coverage for the PWDs. This also shows that any legislation that is decreed, needs to be compulsorily enforced, to ensure that the desired effect is achieved.

SOCIAL REHABILITATION

Social rehabilitation is concerned with integrating the PWD into society with the maximum possible adjustment, to cope with the normal social demands as well as the extra demands placed on them by their disability. The ultimate goal of social rehabilitation is to allow people with disabilities to have the same sense of well being in society, as people without disabilities. If an adult man loses his arm, for example, he will first of all, need treatment to get rid of the pain and heal the wound. This is the medical rehabilitation which has to be followed by an educational rehabilitation of learning how to perform daily living operations such as dressing, eating and washing with only one hand. If an artificial arm is fitted, the PWD will also need to learn how to use it to maximum advantage. Another important aspect of his educational

rehabilitation is that he will need to learn to accept and assert himself as a normal, though one-handed, person. He will also need to learn to cope with the initial shock expressed by people on meeting him for the first time, and make the best of his new circumstances, rather than resigning himself to his new condition and waiting for social handouts. Indeed, the person will also need rehabilitation to regain much of his/her vocational abilities. However, social rehabilitation is not altogether confined to the person with disabilities, but should also address the needs of family and friends. What information do they require, to make the adjustments necessary for PWDs to continue life in an integrated and acceptable way? How can they accommodate their different needs and help to create an environment where they can be accepted, and function as independently as possible? Social rehabilitation also calls for the community to institute measures that make life easier for PWDs. Aspects such as easy access to buildings and toilets, voice aided traffic controls and removal of hazards from busy paths to protect PWDs from injury, are very important and may need enforcement by the law. Ensuring that PWDs are represented at all levels of local government, best facilitates efforts of this nature.

VOCATIONAL REHABILITATION

This requires the support of legislation, probably more than any other aspects discussed so far. According to Mapande (1986), 'vocational rehabilitation is a preparation for work and placing disabled people in suitable jobs'.

The Government and private institutions may recruit PWDs and impart vocational skills to them, but they will also need to be placed into jobs for vocational rehabilitation to be complete. The training can be conducted within the community or at external institutions. CBR programmes would however, be looking at them being employed like other people, within their local community. Very often, prospective employers are suspicious or uninformed about the capability of a person with disability, to perform productively on a job, hence, they opt to play

it safe and exclude such a person without even trying him or her. This is discriminatory and can call for legal intervention. Perhaps, the action taken in Korea and reported by Kim (2000), is appropriate in that, the law for employment and promotion of people with disabilities requires that companies with 300 or more regular workers, employ people with disabilities as at least 2% of their workforce. Employers would be required to ensure that they abide by this requirement, job placement officers would also have to ensure that such vacancies are made available, and whenever possible, fill them with PWDs. Unfortunately, such laws are often flouted. In the Korean example, in 1996, with 2227 companies subject to this law, only 23% of the required number of PWDs were employed in an integrated work environment.

The law in Korea requires national and local governments to enlighten employers on the employment of PWDs and to assist them to do so. The governments themselves are required to lead by example, in this regard. The employers are also expected to assist the PWDs in their career development and not to discriminate against them in staff development, promotions and transfers. Legal provisions such as these would enable PWDs to secure jobs, work and live normal lives within their own communities. Only then, could the PWDs be said to have been given a comprehensive CBR programme.

CONCLUSION

As discussed in this chapter, the main areas of concern in CBR have been cited, and used to explain how legislation can facilitate the smooth organisation and delivery of CBR programmes. It has also been shown, that legislation alone may not suffice, especially where the co-operation of other institutions is required. There has to be effective mechanisms to monitor and ensure that the legislation in place is adhered to. It has also been argued that further to legislation, financial and moral commitment on the part of the governments to the welfare of PWDs in general, and to CBR in particular, is important.

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CHAPTER 8

People with Disabilities ‘Owning’ CBR

Benon Ndaziboneye.

SUMMARY

This chapter seeks to share the views and wisdom of a national organisation of disabled people (National Union of Disabled Persons of Uganda (NUDIPU)), concerning the participation of people with disabilities (PWDs), in the development of CBR programmes in Uganda. It traces the historical development of CBR programmes in Uganda and relates this to the UN position on the role of people with disabilities and their organisations. It uses several examples from the CBR development initiatives in Uganda, to analyse the role of disabled people and examine the criteria necessary, to nurture the feeling of ‘ownership’. It leads the reader through the rationale for NUDIPU’s conclusion, namely, that involvement of disabled people is essential at every level, if CBR programmes are to be effective and sustainable.

INTRODUCTION

The National Union of Disabled Persons of Uganda (NUDIPU) is a non-Government umbrella organisation of persons with disabilities that brings together persons from all categories of impairments, including

those with physical, sensory and mental impairments. NUDIPU's mission is to create a unified voice of PWDs to influence the development and provision of services in favour of PWDs in the country. It does this in close co-operation with the government, NGOs and the general public, through advocacy for equalisation of opportunities, involvement and participation in policy planning, and implementation of disability programmes.

In Uganda, the Government and NGOs have been running small rehabilitation initiatives since pre-independence. This has been a big challenge. Early initiatives often centered around the charity model, which basically isolated PWDs into homes where they were protected and cared for. This did not have a positive impact on the communities from where these individuals came, and did not empower PWDs. Vocational institutions and sheltered workshops followed and at first, added some value to the few individuals involved, but did not prepare the environment for adequate integration of the beneficiaries. With time, these institutions became too costly to run and they declined in importance, as they could not meet the overwhelming demands of PWDs. Worse still, the skills they offered became less competitive in both, the formal and informal labour market.

In the last two decades, CBR has developed and become accepted as the most comprehensive strategy for rehabilitation, as it not only targets the individuals with impairments, but also aims to interact with the whole community by utilising the local resources and enlisting the involvement of most of the players. The United Nation's position concerning the role of disabled people and disabled people's organisations is made clear in the Standard Rules for the Equalisation of Opportunity for Disabled People (UN 1994). It is the intention of this chapter to examine the development of CBR programmes and uses the UN rules as a yardstick for evaluation in relation to the participation of PWDs, in these programmes. It is through this process, that NUDIPU has clarified its position and established its conclusions and recommendations.

THE UNITED NATIONS POSITION ON THE PARTICIPATION OF PWDS AND THEIR ORGANISATIONS

Four of the UN Standard Rules on the equalisation of opportunities are particularly relevant to the potential role and participation of disabled people in the development of CBR programmes.

Rule 1 Section 4. says that, ‘States should invite persons with disabilities, their families and organisations to join in public education programmes concerning disability matters.’ This awareness-raising role is a very important component of CBR, as it facilitates the community to change their negative attitudes, thus creating a friendly social environment for PWDs, and helping to minimise the possibility of segregation and exclusion.

Rule 3 recommends that PWDs and their families be actively involved in programme design for their own rehabilitation, right from the word go. Rule 18 re-emphasises this in relation to organisations of PWDs and says that they should be encouraged to participate in every initiative concerning them, by any service provider, the State or NGO. Involvement in a programme at a later stage, often means that PWDs become passive recipients and do not understand the values of the programme, let alone agree with them. This minimises the chances of them feeling a sense of ownership for the programme.

Rule 4 requires that in the provision of appropriate assistive devices, persons with disabilities be encouraged to participate in the design and production of appliances. If this does not happen, the appliances are unlikely to perform the function for which they are required and will therefore, not be used by the person concerned.

Rule 18 emphasises again that organisations of PWDs should be encouraged and supported to participate in every initiative concerning them by any service provider, the State or NGO.

THE HISTORICAL PERSPECTIVE IN UGANDA

In Uganda, active CBR was started by Mrs. Nightingale Kalinda in 1989, with an organisation called Community Based Rehabilitation National

(CBRN). She herself, was physically disabled and an occupational therapist by profession, and hence, was involved with both medical personnel and PWDs. CBRN had projects in Mityana, Katwe in Kampala and Kayunga in Mukono. They targeted mainly the physically impaired and a few children with mental/cognitive impairments. The main features of this programme were rehabilitation through physiotherapy, occupational therapy and counselling. It also stimulated the formation of self-help groups, some of whom still exist today. Although this programme had a long lasting impact on the individuals who received the services, it did not have a multiplier effect as a rehabilitation programme. The individuals were only recipients of the services and were not imparted rehabilitation skills to carry out rehabilitation for others. The groups that remain are the income generating groups. Additionally, in an evaluation by Oxfam who was one of the funders, they identified that there were no benefits for blind and deaf people, who were thus marginalised. This situation was not sustainable and there was limited involvement of other stakeholders in the programme. When CBRN could not continue in the communities, the rehabilitation process stopped until other players came in and started afresh.

Another experience was that of the Uganda Society of Disabled Children (USDC). USDC introduced their programmes in a number of selected districts and enlisted the participation of PWDs in community work, especially in awareness campaigns. Some of them were trained as volunteer rehabilitation workers in the community. They also supported the local DPOs, through various training programmes and funding for their capacity building. This approach enabled PWDs and their organisations to own the CBR programmes and participate actively. They were also involved in monitoring and evaluation of the programmes at the local level. However, one shortcoming of the USDC programme was that it lacked inputs from national organisations of disabled people. In fact, for a long time, the national DPOs saw USDC as an organisation that did not involve disabled people, because PWDs were not involved in the programme design. In reality, USDC had a comprehensive outlook. They had services for most impairment groups such as infants, school

going children, for the blind, for the deaf and for mentally and physically handicapped people. USDC also supported hospitals to strengthen referrals.

Another important player in the field of CBR is the Government of Uganda, who entered the scene in 1992. They started programmes in Mbarara, Bushenyi and Kabale districts. At the National level, only NUDIPU was involved in drawing up the guidelines for their CBR activities. Uni-disciplinary organisations were not involved and they felt left out and un-appreciated. Also, at the implementation level in the districts, the local organisations were not actively involved in the management of CBR programmes. This led to serious resistance by some prominent DPOs, whose representatives in the Southwest saw CBR as a foreign concept and one that did not meet their needs. They did not see CBR workers as partners.

While the Government trained some disabled people as CBR workers, they were not facilitated to participate actively in the programme. In contrast, community development assistants, as government employees, were facilitated and paid some top-up allowances. This led to a perception that the involvement of people with disabilities was just a form of 'window dressing', which caused a lot of resentment, and as a result, CBR did not have an impact on the organisations of PWDs at the community and district levels. Although a few individuals were being used as resource persons at different levels, leaders of the organisations did not recognise this as an involvement of their organisations. The DPO stalwarts were constant critics of the programme and for a long time, government supported CBR was not accepted by most of the adult PWDs, who had already organised themselves in associations.

Secondly, the Government programme targeted physically impaired people. For instance, it had no services for blind people until specialised services came later as separate programmes. This was seen as marginalisation by the groups concerned and for a long time even the Uganda National Association of the Blind (UNAB), did not see CBR as their programme. It was also discovered, that the majority of the

beneficiaries had been children, although there were many adults who could have also benefited.

One of the latest players in CBR programmes in Uganda, is Action on Disability and Development (ADD). This programme is unique in that, it has been implemented by DPOs and has PWDs as CBR workers. This has been greatly welcomed by these organisations and by the PWDs in the communities where they are active. Unfortunately, many of the national DPOs were not involved in the initial planning and although the local organisations feel an ownership, the activities miss out on the influence that could have been offered by the national DPOs at the national level.

Another player in the development of CBR in Uganda, is the Cheshire Homes. One of the ways in which they involve PWDs is through the formal employment of qualified PWDs. They also give further training to build their professional capacity to do their work. However, again at the national and local level, DPOs are not involved. Although the efforts and work of the Cheshire Homes is appreciated, in the opinion of NUDIPU, establishing relationships with DPOs would enhance their work.

Community Based Alliance (COMBRA), is another player whose major activity is the training of CBR workers. Right from the beginning, they have involved PWDs in leadership, in the design of the curriculum and in actual training, which has made the training relevant and useful to all the participants. Although their relationship with many PWDs in their individual capacities is strong, their relationship with DPOs has yet to be explored and utilised to the fullest.

THE CURRENT SITUATION

In the last four years, the trend has been changing for the better. Most of the prominent players in CBR, are open to recognising the need to involve the beneficiaries in the development and delivery of rehabilitation services themselves. One prominent development is the new approach to the involvement of PWDs and their organisations. The government

programme has opened up and now involves most of the major stakeholders in the planning and development of programmes at the different levels. The national organisations are represented on the steering committees, with each organisation having a large role to play, supported by appropriate resources. Their organisation has been decentralised to the district levels and lower levels. Even at the district level, PWDs are involved in the planning, which was not the case earlier. The government CBR programme has also addressed the problem of marginalisation of the different impairment categories of PWDs and has different services for the different groups. It is envisaged, that the government CBR programmes will register more successes than ever, if this kind of arrangement is enabled to function. USDC is also beginning to involve National organisations on different committees, at the national level. For example, their committees on advocacy.

With these few examples, it is clear that although initiators of CBR projects may recognise the desirability of participation of PWDs at all levels of a programme, the reality is different, due to many barriers which have to be identified and overcome.

THE POSSIBLE BARRIERS

Unfortunately, the attitude of most rehabilitation providers towards participation of PWDs is still negative. Many still believe that PWDs can only be recipients of the services and not participants, in the whole process. Most of the initiators have a professional bias, they do not believe that their skills can be transferred to beneficiaries who are not professionals, and so they tend to reserve provision of services to traditional professionals, who are in most cases medical people or social workers. As a result, most persons with disabilities do not have the requisite skills to provide the specialised services. The professionals also fear, that giving up their knowledge will put their job and position in jeopardy. Some players see DPOs as competitors, therefore, they tend to protect their territory.

NUDIPU'S POSITION IN RELATION TO THE ROLE OF PWDS AND DPOS

In the view of NUDIPU's mission, we strongly advocate that every rehabilitation programme provides for involvement of PWDs in the programme design, implementation, monitoring and evaluation. It is strongly advocated that the position adopted should be that, there is 'nothing about us without us'. In this context, any rehabilitation programme that does not involve PWDs and their families in the identification of needs and appropriate interventions, is considered irrelevant and will not have a significant and sustainable impact on the community. As a voice for PWDs, NUDIPU encourages all the service providers to open up and collaborate with DPOs.

We acknowledge the efforts of the Rehabilitation section in the Ministry of Health in Uganda, which has never started any disability programmes without involving DPOs right from the national level to the remote district levels, where they are working.

We do believe that when programmes are designed for PWDs without them being involved, there are a lot of missing ingredients, which can only be articulated by the prospective beneficiaries. Their involvement in the implementation plan is paramount, if they are to receive the maximum benefit.

NUDIPU believes that communities easily appreciate the service when the target population is actively involved with the other members of the community, in the programme. The other recipients of the services easily accept them, especially when the programme is still new in the community. The programme will have a multiplier effect, i.e. the DPOs and the community will sustain the CBR activities long after the external provider (facilitator) has left the community, because the skills, philosophy and the attitudes of the people remain in the community.

It is the view of NUDIPU, that CBR projects that do not involve beneficiaries right from the beginning, are seen as belonging to the external provider or the local initiator and not belonging to the people. As a result, the PWDs and the community tend to take a dependency

role and when the CBR initiator goes away, the activities collapse. From NUDIPUs experience, if PWDs are involved, they become the chief advocates and jealously protect the programme with a strong belief, that it is theirs.

RECOMMENDATIONS

NUDIPU recommends six strategies to strengthen participation of PWDs into CBR:

1. At the beginning of a new programme, the CBR service provider should identify all the stakeholders and clearly define the framework for involvement of both, organisations and individuals. This ensures that no important stakeholder is left out.
2. To enable persons with disabilities to ‘own’ the programme, the CBR service provider should systematically introduce the concept to PWDs, the expected benefits, the resources involved and what would be their role, until they have understood the concept. Transparency, here is very crucial. NUDIPU’s experience here is that most players are not transparent about the resources involved. When people with disabilities have understood the basic concepts, then one can begin to involve them in the subsequent stages, such as needs assessment and the planning processes.
3. The programme should also strengthen the capacity of both DPOs and key individuals to participate meaningfully. This can be done through training of individuals, not only in the basics of CBR, but also with professional training in the relevant areas such as medical, social work, community development and education etc.
4. The CBR programme should be flexible enough to be able to build on already existing initiatives of the DPOs in the community. When the existing initiatives are ignored by CBR, it is seen as a parallel programme, which threatens their initiative and they can become protective about their programme and hence un-cooperative.
5. PWDs should be appointed on different technical committees of the programme.

6. PWDs who have relevant qualifications should be employed to implement the programme. This is not advocating for simply humanitarian employment. We need to give preference to competent PWDs in the labour market. There are several advantages to this, which include the following:
 - Disabled people employed in this way can act as role models. It provides an opportunity to test their commitment and challenges them to venture where others would fear to tread.
 - Disabled people employed in a CBR programme will feel a great sense of ownership, they have great opportunities to become innovative, given their personal experience of being disabled persons and they work with maximum enthusiasm and volunteerism, when the need arises.

CONCLUSION

For a CBR programme to be successful, it needs to be built on the following:

1. Appreciation and understanding by all stakeholders, from the national to the district levels, which include the community, important personalities and the ultimate beneficiaries.
2. The needs addressed by the programme should be the needs agreed upon, between the local participants, the PWDs and their families, the organisation and the provider. Similarly, the intervention must be based on what has been agreed upon as appropriate, by all parties.
3. The provider should ensure that constant dialogue takes place so that important issues are not ignored.
4. If the CBR programme claims to serve all categories of PWDs, then it has got to ensure that all categories have specified benefits. This can only be done when deliberate efforts are made to consult all stakeholders.

In conclusion, therefore, DPOs should have a stake in the development, implementation, monitoring and evaluation of all CBR programmes at all levels. It is the belief of NUDIPU, that this will serve to maximise the effectiveness and sustainability of CBR programmes.

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CHAPTER 9

Parents' Role in CBR

Olive Bwana, Olive Kyohere.

SUMMARY

This chapter describes our activities and perceptions as parents of children with disabilities. It presents case studies of the organisations with which we are involved and relates the lessons learnt from these experiences, to the development of CBR programmes. Our organisations perceive CBR as the de-centralisation of responsibility and resources to community level. The key focus in this process is working, living and sharing with persons with disabilities. This serves to enhance participation and consequently, promotes CBR as a participatory strategy in community development initiatives. Parents realise that a collaborative approach by all stakeholders is the best.

INTRODUCTION

The experience of having a child with a disability has stimulated us to establish and become part of parental organisations. These organisations aim to provide support for groups of parents who have children with impaired functioning. Both these organisations relate to specific impairment groups, namely children with hydrocephalus and children who are deaf/blind. Both organisations address the needs of our own children, together with others. The first hand experience we have gained, has put us in a unique position of knowing about the problems of establishing and running such organisations, about how parents feel when

they have a child who is disabled, about the sort of barriers and problems they are likely to have to face, and about the strategies that are effective in combating these realities.

CASE STUDIES

1. The Association for Spina Bifida and Hydrocephalus, Uganda (ASBAHU)

ASBAHU was started in 1995, by parents of children with one, or both conditions. It was the brainchild of Mr. and Mrs. Sekatawa who had two consecutive daughters with hydrocephalus. Mr. Sekatawa is the Director of ASBAHU, while his wife serves as co-ordinator for the association. The association was born as a means to counteract the then prevailing negative attitudes exhibited by some medical personnel, educationists and society at large, towards children with Spina Bifida and/or Hydrocephalus. The affected individuals and their families experienced a lot of stigma, loneliness and isolation, often being treated as 'outcasts' in their own communities. Even the traditional cultural support system of the extended family seemed unsupportive. Since unity is strength, parents of ASBAHU came together under the old African Philosophy of, **'I am, because we are'**. They chose interdependence over independence. ASBAHU is a registered charity and membership is open to all well-wishers on payment of a membership fee.

The activities of the organisation centre around the following areas:

- Awareness creation using the media (radio newspapers, video recording etc).
- Identification and mobilisation of new parents with affected children, followed by treatment at Mulago Hospital or CURE Christian Hospital in Mbale. Initially, Mulago was the only option and due to pressure and bureaucracy, some parents were overcome by frustration, which led them to abandon their children. Now the situation has improved with the addition of the second hospital facility.

- Counselling of new members by the experienced members about on-going projects, treatment, care, etc.
- Providing moral support and encouragement to parents, urging them to maintain contact with ASBAHU's social workers.
- Keeping constant contact with similar and other interested associations/organisations at local, national and international levels.
- Researching and training in the management and support of affected children/adults.
- Creating advocacy and lobbying, by holding regular conferences, seminars, workshops and meetings with opinion leaders and policy makers.

Achievements

The achievements over the last 6 years have included the improvement of medical services for this group of children through improved acquisition of shunts and better access to surgical interventions. It has also involved increased dissemination of knowledge and information, through sensitisation of community members, policy makers and opinion leaders. It has organised meetings using role models (adults with the conditions, who have attended school and are now leading independent lives), and the publication and circulation of regular newsletters.

Future Prospects

Possible future activities of the organisation include:

- Opening an ASBAHU centre at Kabowa, to provide a venue for keeping children in constant contact with social and medical personnel, who will make regular visits to the centre. The centre will also be used as a collection point for children, before they are taken for surgical intervention and as a convalescent centre for children after surgery.
- Participation in the 13th International Conference for Spina Bifida and Hydrocephalus in Dar-es-Salaam, Tanzania.

- Organising a two-week study tour to Britain and USA for 8 ASBAHU social workers.
- Opening up a school with the assistance and advice from sister organisations like the Uganda Parents of Children with Learning Disabilities (UPACLED), to provide services that can address the special needs of these children.

2. Uganda Deaf/Blind Parents Association (UDBPA)

UDBPA was started by five parents of deaf/blind children in 1998, and registered as an NGO in March 2002. Ms Olive Bwana B.Tibekyinga is chairperson and Ms Suzan Luyiga is the treasurer. After attending a regional conference sponsored by SHIA, in Nairobi, Kenya, parents saw that there was a great need to come together, share experiences and try to find solutions to problems faced by parents and their disabled children in day-to-day life. As we were sharing experiences at the conference, we realised that each parent thought she/he was alone with such a problem. This inspired us to start the Association, so that parents can be helped in one way or another. This is based on the appreciation that if one does not become critically aware, then one cannot fight one's way out of an oppressive situation. This Association is based at Uganda School for the Deaf at Ntinda in Kampala.

Aims and objectives of UDBPA:

- To facilitate parents who have deaf/blind children, with professional assessment and appropriate therapy.
- To promote awareness among the public about deaf/blindness education and facilities given to them.
- To consider the future of deaf/blind adults.
- To plan, identify and find ways of mobilising sources of income by advising members on methods of setting up income generating projects.
- To identify more deaf/blind children and establish more units in the country.

PARENTS' ROLE IN CBR

- To train parents and guardians on how to care for the deaf/blind persons.
- To promote guidance and counselling.

Activities:

- Counselling and guiding both parents and deaf/blind persons.
- Home visits to families who cannot bring children to school due to lack of funds, distance, type of disability etc.
- Training parents to help their children live an independent life.
- Training parents to run income-generating projects.

Achievements:

UDBPA has recorded some achievements since they started.

- The Association is registered as an NGO and has grown strong.
- They have a unit at Iganga High and Ntinda School for the Deaf.
- A poultry project has been started at Iganga High.
- Parents have attended workshops in Uganda, Kenya and Tanzania.
- The chairperson (Olive B.Tibekyinga) was elected the regional parents' representative in 1999, for a two-year term.
- The chairperson attended a world deaf/blind conference in Lisbon –Portugal, July 2000.
- A vocational training unit was established. UDBPA is happy to inform that its students Emaringati and Ojok are doing very well and thank the headmaster of Ngola school, Mr Morrissy, for work well done.

Future plans:

UDBPA hopes to hold a regional conference (East Africa) in Uganda, in March 2002, with the help of SHIA, and to start an animal husbandry

project at Ntinda School for the Deaf, once funded. In this project it is intended to train parents in animal husbandry.

PARENTS' CONTRIBUTION TO CBR DEVELOPMENT

Parents' potential contribution to CBR development is enormous, but in this chapter, five possible areas will be explored, where their efforts could make a significant difference.

1. Overcoming ignorance

We all know that CBR has a major role to play in the education of the community, about disability. Ignorance is a big obstacle, many people with disabilities are in their present situation because they did not know what to do at the time when, the 'enemy' attacked them. Community members need to know how to prevent disabilities. They need to know how to care for, respect and communicate appropriately, with people with disabilities. Parents can make a major contribution towards sensitising families in these areas, by sharing their own experiences. They can encourage other parents to include their children in everyday activities, by providing a sympathetic, listening ear to the families' difficulties. They can also facilitate referrals to medical and social services. Their contribution in these areas can strengthen these aspects of a CBR programme considerably.

2. Promoting sustainability

The sustainability of an individual's independence relies heavily upon setting up the structures and support, which will enable him/her to acquire daily living skills and provide the opportunity for education and employment. Parents can facilitate this process by establishing NGOs, finding ways of sustaining individual PWDs, and making relevant connections between PWDs and prospective educational opportunities and employers. People tend to underestimate the capacity and capability of PWDs to carry out productive activities, for which they can be financially rewarded. They need the opportunity to practise any newly acquired skills and this is where parents can also be very supportive.

3. Promoting the validity and relevance of CBR activities

Essentially, PWDs and their families are the customers and consumers of CBR programmes and one of the objectives of any organisation is to satisfy its customers. In order to do this, the customers need to be involved in the identification of what is required and how it can be best achieved. In practice, this means that PWDs and their families need to be involved from the very beginning in any initiative so that their perspectives, wants, hopes, needs, fears and deep seated knowledge of the barriers, can form the design of an initiative, from the very beginning. Their participation is then required throughout the project, to keep the monitoring process relevant and to ensure that the project develops in a way, which will continue to benefit the 'customers'.

4. Parents' role in promoting education

Parents have a very powerful role to play in the promotion of the inclusion of disabled children within mainstream educational settings, as well as working towards the development of special provisions that children, both, within mainstream settings and in special settings, require. Their role is again one of raising awareness and providing the drive and inspiration needed, to initiate and sustain programmes with a lifetime of interest and commitment.

5. Raising gender awareness

Disabled girls, appear to be at a double disadvantage in many societies and Uganda is no exception. CBR programmes need to be very sensitive to the situation faced by disabled girls and women, which includes facing both physical and mental abuse, rape and exploitation. It is difficult for others to imagine what they have to learn to face, such as the problems that arise from menstruation, pregnancy and labour. Culturally, girls are expected to get married, have children and create their own homes. In Uganda, and I believe in many African societies, it is very painful (for parents and PWDs) to know that marriage is almost completely out of question. The worry is also that if you do get married, will you (or your child) be able to live up to the expectations required, and if you do not, what will happen to you?

As the parents of disabled children, we feel that the following soul searching questions are worth pondering upon.

- What are my weaknesses?
- What are my strengths?
- How do I feel or react when someone talks about disability?
- Am I able to talk or discuss disability freely?
- Do I have positive or negative attitudes to disability myself?
- How do these manifest themselves?
- How can I move the situation in a positive way?

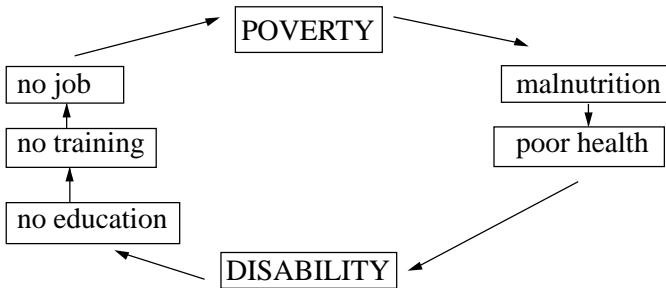
The following are real situations that parents and their disabled children have to face.

- They are disabled.
- They have no job. No one is interested in employing a disabled person.
- They feel rejected.
- They cannot do things like their brothers and sisters and friends.
- They cannot marry easily and have their own children.
- They do not go to school like other children.
- They do not know what their future holds and they are frightened
- The parents are not sure how long they can look after them, especially in being able to meet their emotional, physical and financial needs. (The world is big but to some disadvantaged people, the extent of their world is as small as just a house or a room, since their opportunity to interact with others, is so limited.)

Understanding that this is what preoccupies disabled children and their parents, goes a long way in establishing support services that are meaningful.

PARENTS' ASSOCIATIONS IN RELATION TO POVERTY

For families with disabled members, poverty is a dangerous but inevitable companion. It encroaches on their lives directly and frustrates participation and self-actualisation. Disability often affects families that are already poor, and parents in remote rural locations often feel that they are so poor that they have nothing to offer. It takes a lot of persuasion to encourage them to participate in the activities of parents' associations, since they feel trapped in the vicious cycle where, poverty is taken as a function of disability and vice versa.



CONCLUSION

It can be seen from the above, that PWDs and their families are a tremendous resource to any CBR programme. They really know what the effects of environmental conditions are on themselves and they almost certainly understand those same effects on their peers with disabilities. They have a better knowledge of what it means to be disabled in society, in the family and in the nation. They know the costs, both in emotional and financial terms, they know and understand the pain. This knowledge and experience is invaluable to CBR programmes and the most effective way of acquiring it, is to employ disabled people as CBR workers.

Understanding and empathy, cannot generally be taught to other people who do not have a disabled child, or a disability themselves. It is something acquired through experience. This is why PWDs and their

parents are an essential and invaluable element of any CBR programme or CBR work force. They contribute essential understanding and empathy, which cannot be obtained by any other strategy.

Additionally, their involvement also serves to improve the quality of life of PWDs and their families, as it gives them confidence and improved self-esteem. They find that they are needed, their expertise is wanted and valued. It reduces the sense of isolation and loneliness. So, by their participation in CBR programmes, they not only help others, but they also help themselves.

There are many fears and questions, unresolved issues, unpredictable situations, personal experiences and unexplained phenomena. There are natural situations, as well as man-made constraints. But, the situation of persons with disability is obviously such that it places them among the disadvantaged groups, often deprived of very basic human needs, including love and a desire for life. The greatest challenge for us all is the challenge of learning to live together and it is this challenge, that CBR programmes need to address, through promoting participation as a viable strategy in Africa.

Participation should be understood in its broadest dimension including the basic elements of making direct contributions, whether material, physical or professional knowledge, or simply in the form of organisation of a delivery system or the employment of PWDs. But the approach however, ought to be based on the principle of working with, and for, PWDs and their families. Participation is in itself, empowerment.

The parents of these organisations do not claim to have found solutions to the problems most children face, but there is a saying that if you have to wash an elephant you have to start somewhere. So they have made a start. They realise that in order for CBR to have the desired impact, there is a need for a collaborative approach. It is important for governments, local communities, NGOs, parents, teachers and other professionals, to join efforts and together participate in the rehabilitation, education, social and economic integration, of the affected individuals.

CHAPTER 10

Finding People Where They Live: The View From A Tricycle In Busia

Susan Reynolds Whyte, Herbert Muyinda.

SUMMARY

This chapter describes the situation of wheelchair users in Busia and their efforts to make a living on the Uganda-Kenya border. Using ethnographic methods of participant observation, the authors try to appreciate people on their own terms rather than from the point of view of a pre-defined programme. This contrasts with participation that is imposed on local communities by outside agencies. The story told here is one of local initiative and resourcefulness, in exploiting economic and political opportunities. The Busia tricyclists have created a community and are in a position to 'participate' equitably with NGOs, government and donor agencies, because they have developed an ability to pursue projects themselves and enter into dialogue with others.

INTRODUCTION

'Community participation' emphasises the active involvement of people in a matter of common concern. But, in practice, it often implies that

‘THEY’ should participate in ‘OUR’ projects’. The original initiative usually comes from some outside agency, which enters into dialogue with a ‘target group’. The relationship was tellingly captured by villagers who told one of our colleagues: ‘Yesterday Save [the Children] Denmark came and participated us’. They saw themselves as the objects of an NGO’s participatory exercise. In this chapter, we want to examine a different kind of community participation: local initiatives to create a community of people with disabilities organised around common interests. In this process, those concerned took the lead; although they too, interacted with representatives of government and NGOs, their own efforts were the foundation of development.

We are using ethnographic methods to document the situation of tricycle users at the Kenya-Uganda border. The basic approach of ethnography is participant observation. This means involving oneself with members of the community, observing, listening and trying to understand the world from their point of view. We want to appreciate their projects and their creative survival strategies in the face of difficulties (‘okuyiyaiya’ is the Luganda term for such enterprising efforts, as Dr. Alice Nganwa reminded us in Chapter 5). So far, we have had long discussions with key people individually, in twos and threes, and in one large meeting. Individuals have been asked to recount their life histories, in order to grasp the trajectories that have brought them where they are today. Visiting people in their homes, and seeing how they move around the town and pursue their work gives us an impression of their everyday lives. In order to put this local world into a broader perspective, we are trying to reconstruct parts of recent history, especially the political and economic developments that shaped opportunities for people in this area. Our work is on-going and we hope that it will be useful for the members of the Busia Disabled Association, in their attempts to mobilise support for their self-help initiative.

TRICYCLES AND CROSS-BORDER TRADE

The town of Busia, which straddles the Kenya-Uganda border, has long been the focus of a lively trade. At the border crossing, people stream

across in both directions, with everyone carrying something. On the Uganda side, the ‘boda boda’ bicycle taxi men, in their electric pink shirts, compete to ferry passengers and goods. (The very term boda boda - the business of transporting on the back of a bicycle - originated in Busia, where cyclists shouted ‘border! border!’ to attract customers). Prominent in all these activities are the big hand-crank tricycles loaded with goods, expertly manoeuvred by disabled people. Some speed back and forth; others wait chatting to one another, or to friends and acquaintances. The thirty or so, owners of these three-wheelers are clearly an integral part of Busia’s busy scene.

The story of the Busia tricycle transporters goes back to 1990. The cross-border trade was flourishing at that time, mainly with agricultural produce going to Kenya, and manufactured goods coming into Uganda. A few business people on the Uganda side helped individual polio survivors to purchase the relatively expensive hand-crank wheelchairs, made of bicycle parts and fitted underneath with sturdy baggage carriers. Shopkeepers entrusted the tricyclists with cash, to make purchases across the border and transport the commodities to retail outlets in Busia, Uganda.

These pioneers discovered a niche in the local economy. Others soon came, as word spread that there were opportunities in Busia. Friends and relatives told people in villages: ‘your fellow disabled are making money at the border. You better join them instead of sitting redundant in the countryside.’ People came from many parts of Uganda to try their luck. The necessary capital for participation was a tricycle, but most did not own one when they arrived in town. Some got loans, some negotiated help from relatives; many worked and saved to purchase their own three wheelers. Wandera Fred recounted how he came to Busia to work for his brother. At first, he paid a man to push him in a wheelbarrow back and forth across the border. In time, he was able to buy a tricycle. No organisations supplied these people with the means to make a living. They procured their mobility through their own resourcefulness.

The economic careers of the tricyclists have followed slightly different paths. Many started out working for customers who placed orders for

goods and advanced the money to pay for them. This arrangement requires trust on the part of the customer; the tricyclists built up a clientele of businessmen who could rely on their honesty and dependability. Simply waiting at the border can pick up some business for anyone who needs a load moved. While most continued as transporters, others went into business for themselves. They acquired enough capital to buy goods for resale; a few set up their own shops. Some went into specialised trade in certain commodities (milk, beer, cement, diesel); one set up a restaurant.

MOBILITY AND THE EXTENSION OF SOCIAL RELATIONSHIPS

The disabled tricyclists had all been handicapped by lack of mobility. Hearing their stories, it was easy to understand that physical and social immobility are closely related. The tricycles had mobilised them in more ways than one.

Many of the individuals we have spoken to, told of being ‘stuck’ in their villages. Some had been able to attend school; others either could not physically get there or had not been supported by parents who gave higher priority to children with legs, in situations of scarce resources. In people’s minds, the lack of opportunities in rural areas was associated with discrimination. There were those who blamed their families for underestimating them. But at the same time, many told of how relatives had helped to get them to Busia to start their new lives.

One of the basic dynamics of being a person is the extension of sociality: growing through the creation of new relationships that enrich the lives of individuals and families and enlarge their worlds of social interaction. This can be accomplished by going to school, by visiting relatives and friends in other places, by attending church or mosque, participating in ceremonies and gatherings, and by working with other people. In Uganda, marriage is a fundamental extension of social relations not only through a spouse and children, but also because links are created to a large network of in-laws. Because kinship and family are so central in Ugandan life,

the social growth of persons extends the sociality of families as well as individuals.

Those physically handicapped people, who went to Busia to seek their fortunes, were first of all, looking for work. They wanted to earn money so they could be self supporting. Once they were able to move around on three wheels, two things happened. They developed networks of colleagues, business contacts and friends. They also acquired resources to marry and start their own families.

All of the tricyclists we have met so far are men (though we understand there are a couple of women in the community). In Uganda, men must provide a gift or bride wealth payment to a wife's family, and husbands have the primary responsibility of earning money for the home. Without an income and without sufficient economic support from their own parents, these men had been 'stuck' in bachelorhood in their rural villages. With the opportunities that physical mobility opened, they were able to marry after a few years, in town. In our visits to their homes, we met attractive wives and children.

One of the most important extensions of sociality has been the creation of a new community of people with disabilities, who could support one another and work together for common interests. That story is tied to national policy and local politics.

ORGANISATIONS AND POLITICS

In 1992, the Uganda Revenue Authority (URA) began to crack down on cross border trade. The campaign to increase state revenue through collection of taxes and duties included tough moves against any activities defined as smuggling. Whereas, customs officials had hitherto allowed the tricyclists to ferry commodities across the border with little hindrance, they now began demanding duty and confiscating goods. No exceptions were to be made for people with disabilities. But, paying duty would have destroyed their comparative advantage in a competitive situation, where others stood ready to transport goods even more efficiently.

Two years later, in 1994, the Busia Disabled Association was established as a voluntary organisation. The subsequent accomplishments of the BDA had partly to do with the role played by certain programmes, NGOs and the Ugandan government. It is also the story of enterprising individuals, who grasped the possibilities and made something of them. One of these was Wandera Geoffrey, who had been working with a Community Based Rehabilitation project supported by the Norwegian Association of the Disabled. He was a member of the National Union of Disabled People of Uganda, which held workshops in Busia that attracted new members to BDA.

One of the most important tasks of BDA from its early days up to the present, has been to smooth relations between the tricycle transporters and the Uganda Revenue Authority. ‘Sensitisation’ was the term used by Wandera to describe the continuing efforts to persuade URA officials to respect the efforts of the tricyclists to support themselves. When new URA officials arrive, they declare that the transporters are smugglers. They must be invited to sit and talk about the limited opportunities for disabled people and the need to make room for them too. When the Revenue Protection Police arrests tricyclists, BDA requests that they be released with their goods. ‘Don’t disable our disabled people,’ is their plea. They point out with satisfaction that there are no disabled people begging on the streets of Busia, not even on Fridays when Muslims give alms.

The BDA represented its members’ interests in other ways as well. It negotiated with the Town Council, to provide an office free of charge. It targeted the police and the central government representative in the district. Through its efforts, Busia District was ranked second in the country in terms of local initiatives for disabled people; the chairman of the district council is to be sent to South Africa by the Rotary Club to visit disability projects there. In Uganda, local councils at every level must include representatives of people with disabilities. Strong representation by BDA members on the District Council and the Municipal Council has been essential. They have obtained seats in strategic committees including Finance, Planning, Works and Health and Social Services.

The organisation has facilitated advocacy for rights and promotion of common interests. In a general meeting with BDA members, they told us that the attitude of Busia town residents towards disabled people was fairly positive. Their activities in trade and municipal life had brought them trust and recognition. At the same time, the organisation had enhanced solidarity among disabled people. This was evident in the multi-ethnic composition of the group, the way they defended one another against harassment by officials, went collectively to mourn at the funerals of each other's family members, and welcomed disabled people who were new in town. In fact, one of the organisation's plans is to establish guest accommodation for newcomers.

DIFFICULTIES AND DELICATE PROBLEMS

The story told so far, has been a rosy one, but life is seldom all roses. Without going into a long catalogue of problems, we would like to mention two areas of concern: the economic activities and the balance between local initiative and outside help.

Cranking a heavily loaded tricycle on potholed roads is strenuous work. People without enough strength in their shoulders and arms, need a child to help push them. Even the muscular marathon cyclists who live outside town and commute an hour each way to get to work, know they will not be able to continue as they grow older and weaker. Moreover, competition is tough. Lots of other people in Busia are looking for ways to make money. Children carry head loads across the border and the boda boda bicycles are ubiquitous. Some avoid the customs officials by taking the back paths, the 'rat' (panya) routes to Kenya, but as one tricyclist remarked, those paths are not wheelchair accessible. Nobody gets rich doing transport alone. At best, one can hope to get enough capital to do something else.

The border work is a delicate matter that must be handled as carefully as a baby. On the one hand, there are many arguments for exempting the tricyclists from paying taxes on the goods they bring across. After all, they are importing on a very small scale in a situation where local residents do their shopping in Kenya anyhow, without paying taxes on

the household needs they carry across. The shops in Busia Uganda have difficulty competing with the lower prices of their competitors in Busia Kenya. Some of the goods brought over are not otherwise available in Busia Uganda; there is no petrol station there, for example. There are few alternative occupations for people without good legs and good capital. On the other hand, they must not abuse the sympathy and cooperation of the public by blatantly breaking the law. Disability must not be an excuse for illegal activities.

For all these reasons, diversification and new possibilities are needed. Many would rather not do border transport but lack capital and training, for an alternative source of income. In Uganda, the popular solution to problems is 'A Project'. The tricyclists of Busia have so far, not attracted donor funding for their plans for a vocational school. They have tried to establish their own projects with a little help from the Town Council, but the money is small for so many people. A modest credit scheme is far from sufficient to provide loans to those who need them to get out of the border trade. People had heard of funds provided for rehabilitation by government or donors, but they had not seen it and wondered if someone had 'eaten' it.

Community based projects tend to be imposed by outsiders on people defined by them as a community. Sometimes, the 'target group' does in fact become a community through participating in the project. In contrast, the tricyclists of Busia have created themselves as a community because they had a common interest. As a kind of 'natural community', they are not representative of people with disabilities in Busia. They are predominantly male and all have an impairment of their legs. They have a common history of enterprise and resourcefulness.

As we hope to have conveyed here, we admire the initiatives and accomplishments of these men. We think they are a superb example of the way communities can take action without 'being participated' by an outside force. Yet, it is important to bear in mind that communities exist in interaction with global and national forces. The Busia Disabled Association took advantage of the structure of political representation and they would welcome support from an NGO or donor. They are

appealing for more government assistance. It seems to us that this is exactly the sort of community that could enter into an equitable relationship with CBR programmes and organisations. The trick is for the professionals and programme administrators to, ‘find people where they live’ and respect what they are trying to do. And, for the people to learn and grow from new opportunities, without letting them undermine their solidarity and initiative.

CONCLUSION

In this chapter, we have presented the first results of an on-going study. There are four general themes guiding our work with the tricyclists, which may be of interest to others engaged with CBR.

- 1) The subjective situation of people as social actors: life stories and frank open conversations, provide an insight into values, hopes and disappointments as well as struggles and accomplishments.
- 2) The immediate social world: different social relationships form a web of possibilities, such as kinsmen and resources, family and fulfilment, business contacts and income, officials and restrictions, councilors and advocacy.
- 3) The larger context that has shaped the present situation: regional history, political economy and the local incarnation of national policies form conditions and local possibilities.
- 4) The relations between communities and outside agencies: examining reciprocal assumptions and expectations is important both for operational studies and for establishing a realistic and equitable partnership.

Our approach is ethnographic and sociological, rather than technical and rehabilitative. It cannot stand alone, but it provides a good basis for communication and cooperation.

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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 (INTRAC, 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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CHAPTER 12

Role of Donor Agencies in Promoting Participation in CBR

Mohammed Kisubi.

SUMMARY

This chapter examines the need for donors to support CBR programmes in such a way so as to maximise the participation of all stakeholders. It argues that increased participation creates a positive impact on such programmes and is an essential ingredient, if they are to be sustainable after the donor has withdrawn support. The chapter outlines numerous strategies that donors might like to consider, if they wish to improve the efficacy of their funding processes. The points raised, relate to lessons learnt in the Ugandan context, and they include a helpful summary of points for consideration.

INTRODUCTION

The Need for Donors

It is generally agreed, that there are not enough resources to address all the needs of society. Yet, there are pressures on all governments by their citizens, to provide quality goods and services. Many governments,

especially those in the developing world, do not have access to enough resources to enable them to do what is expected and required of them, by their citizens. Governments have therefore to find ways of getting additional resources, and one such way is to turn to donors.

However, the presence of many donors over many years, can serve to hinder as well as help, the development of the country concerned. In fact, some countries are sinking deeper and deeper into a 'dependency upon donors', and this dependency is difficult to break. The resources provided to programmes may not be adequate, and/or some of the resources may be misused. For example, in CBR programmes, they can be used for activities that do not bring about the empowerment and participation of disabled people in the communities, or for activities that lead to dependency. There is need to examine carefully, how donors can promote more participation in CBR activities, to ensure the development of ownership and sustainability.

Donors are in a position to support and promote participation in CBR when they extend resources and technical assistance to programmes in developing countries

For governments to provide adequate CBR services, the challenge lies in the provision of adequate funds for the relevant sectors involved. Uganda, like many developing countries, faces a major challenge of resource mobilisation. Nevertheless, it has made tremendous progress in its approach to persons with disabilities (PWDs) and is one of the few countries, if not the only one, where PWDs have a right to be represented at all political levels, right from the village to parliament. At each and every political assembly, there must be at least two representatives (one for women and another for men) for the PWDs. There is even a Minister for Disability and Elderly Affairs. PWDs have also benefited quite a lot from the Universal Primary Education (UPE) scheme in Uganda, and many have attained higher qualifications and are becoming competitive in the labour market. Nevertheless, many PWDs still live in villages with nothing to do. PWDs are often the poorest

of the poor, and have no systems to fall back on. Since most of the PWDs, like the rest of the Ugandans, (about 80%) live in rural areas, the only logical framework for ensuring their greater participation in socio-cultural, political and economic activities, has to be based in the places where the majority of them are located. Hence, the need for increased community based activities. Therefore, any donor who supports such activities should definitely promote increased participation of PWDs. Despite some critics of the CBR philosophy, in many developing countries, the activities that normally succeed and have greater impact are those that are community based.

Need for budget support rather than project support

Uganda, like many other countries has had its share of projects and programmes in CBR and other activities. The single factor that cuts across many of the projects, is that they are usually limited to a small group of people, or a given region, or a few selected districts. By doing so, the donors ensure participation of a small group of the community.

Although there are donor agencies supporting CBR activities in Uganda, they are not evenly distributed. Some are operating in a small section of a given district and although some may claim to be in several districts, they are either covering a few sub counties in those districts, or reaching out to a few people. One of the factors is that there seems to be no systematic approach and policy regarding the way donations are distributed. The Ministry of Gender will need to have donor conferences that will direct interested donors to areas that have no support and have the greatest need. For those areas with no donor support, the government should come in with equalisation grants so that support is evenly distributed. This is the only way that full participation and involvement by all communities can be assured. However little there is, it should be evenly distributed.

Yet, if one takes stock of the different donors, they would have had better impact and involved more people if they had joined hands and

pooled resources. Through the 'Poverty Alleviation Fund', Uganda is now negotiating with donors to pool their funds together 'in one basket', so that it can be shared equally among all Ugandans. In reality, when the funds are pooled together, it is possible to generate savings, for example, on management costs, which allows for more of the funds to be spent on actual CBR activities. It is in this light, that donors are being urged to pool their resources together and become partners in development.

Who is participating in donor-funded CBR programmes?

Some donors themselves are the implementers of programmes, doing things directly for the recipients. This sometimes promotes a paternalistic approach, which does not promote the participation of the PWDs and their communities. Alternatively, local implementing agencies like donors, prefer to remain relevant and in control. The best approach is one where the people who are the beneficiaries, are involved in the design, planning, implementing and monitoring of the CBR programmes. It is this kind of involvement that will bind all those involved and accountable to each other and will ensure continuity and sustainability of undertakings. The recipients must be made to feel that the programme is their own and not dictated and controlled from elsewhere.

Is there a need for a common understanding of the CBR concept?

Participation and involvement of all, in CBR activities can only be assured if all stakeholders have the same understanding and commitment to the CBR concept. Yet, as it appears now, several people have different views and understanding of CBR. There is a general feeling that CBR needs to be defined within given boundaries, so that those who come to provide assistance, do so from a point of understanding. The Ministries concerned, should, for purposes of coordinating CBR activities, have a clear definition of CBR and the institutional framework in which it is to be implemented. This publication based on the CBR conference in Uganda, has gone a long way to meeting this need, in establishing the key ingredients of CBR in the African context, which are outlined in the final chapter of this book. Based upon these outlines, programmes can be designed appropriately and the impact will be measurable.

CBR in a decentralised framework

Uganda is at an advanced stage with regard to decentralisation. The underlying assumption behind decentralisation in Uganda, namely taking services and responsibilities for those services nearer to the people, is an important step in the right direction for increasing participation. Decentralisation in Uganda provides a conducive environment for increased participation in CBR, by the communities.

Since the districts and lower local government levels are in charge of their own planning, Uganda is already on the path to full community based implementation and management of programmes. This implies that more and more people will be able to participate in CBR activities. Thus, the operational framework has been well spelt out through the decentralisation act. The only factor that will limit people's participation, and for which more donor support is needed, is the area of capacity at the local levels. Whereas responsibilities have been moved lower down in the communities, the accompanying requirements, like skilled labour, logistics and financial resources, are not readily available in such communities. One strategy to overcome this difficulty would be to provide communities with 'start-up kits', in the form of training in logistics and fund management. To be sustainable, the support should facilitate the community to generate their own financing. Unless this is done, the assistance will come and many persons will participate, but as resources dwindle, the participation will also reduce. To keep involvement and participation as high as possible, the assistance that will have the biggest impact, will be one that has elements of its own income generating activities. Indeed, donors need to consider using part of the funding, to set up alternative community financing projects.

If a donor provided two hundred thousand United States dollars, to a given community and fifty thousand went into setting up a grinding mill for that community (which may be a maize growing area); the community would be assured of revenue from those who would want their maize ground and at the same time would be able to market this value added maize. This would be an

important source of alternative funding. Such projects can also make provision to include disabled people and their families. If such projects were made part of the support structure, then sustainability and economic improvement would be assured.

The Ministry that determines what goes to the districts, usually receives donor funds. Usually, the greater part of the funding is reserved at the centre for so called ‘management, supervision and monitoring’, with little filtering down for actual implementation. No wonder participation is often very limited. The donors would achieve better participation and sustainability if they insisted that a certain larger percentage, permeates down to the communities. Instead, the donors trust that the funds will find their way down to the beneficiaries. The donors would help initiate participation and attainment of better results, if they became more interested in knowing where the funds end up in terms of service delivery and impact. Otherwise, the local communities become passive and only await instructions, rather than being the lead agents in planning and implementation. In Uganda, the Ministries are now responsible for guidance and policy formulation, and the district and lower levels are responsible for their own planning and implementation. Since this is the case, the donors need to re-align their support so that the largest percentage of funding goes to the district and lower level (as part of the condition for the donation and grants). This way, the donors will not only ensure better results, but they will have promoted full participation and involvement of the individuals and their communities, in CBR.

Donors need to decentralise

In order to manage their funds at community level, donors also need to decentralise and have many of their programmes based in the areas where they are being implemented, rather than having all their officers and staff stationed in city centres, trying to manage the CBR programmes by ‘remote control’. The advantage of locating the project management and implementation in the districts and communities, rather than in capital cities, is that the persons responsible for the programme can be in direct touch with what is happening on the ground, and be able to attend to

issues as they arise. When this is done from a distance, the reaction may be inappropriate and too late. In terms of capacity building, institutional development programme managers based in communities would help to build sustainable systems that encourage participation and also allow for dialogue and consultation. One is provided with the benefit of observing things as they unfold. The presence of such programme managers at community level also serves to limit the abuse of funds, promoting better transparency, financial and activity accountability and therefore, better value for money.

Donors and recipients as equal partners

Donor support needs to move away from an approach whereby the donor seems to be in the driving seat and the target community members are passive recipients. Many of the recipients know exactly what they want to do. In many cases, they have even more technical expertise in some of the areas, than the donors themselves. They also understand the local situations and people better. They are trying to do what they are supposed to do, in spite of many difficulties. With proper funding they would do an excellent job. Therefore, if donors become 'partners in development', then they will come to appreciate that those receiving assistance, are as good, if not better, in managing the programmes. All they need is extra funding to speed up implementation and to spread out to more areas. If there was this mutual trust, then many CBR programmes would succeed, because the stakeholders would put in their best efforts. Such a situation calls for joint planning, joint supervision and monitoring, increased openness, transparency and accountability. Each one should look at the other, as an important player in CBR undertakings.

In some instances, the donors' agenda is hidden. The donor's role should not be about doing things for the recipients, as is sometimes the case, for this kills initiative, innovativeness and lowers participation, but, rather, to support and create an enabling and supportive environment. Indeed, some donors have never informed partners about their budgets and workplans. This makes upward planning very difficult for the recipients. They are not able to mobilise local participation, for they are

unsure whether what is promised will be delivered. They do not want to raise peoples' hopes for nothing because in the end, participation gets thwarted. Donors will promote better participation and involvement of communities if they are upfront on what funds are available when, and for what activities. If this is followed then planning gets based on known criteria and communities will engage in activities up to their maximum affordability. Also, when people know how much has been invested in a given area, they are more likely to value it and jealously guard it. They will always view the project as their own, and be vigilant to ensure that no one messes it up. Similarly, if the communities are made aware about what the donors are providing and what is required of them, they are more likely to value such assistance rather than if things are done for them and they do not know the costs.

There is also a problem of whom to deal with, at each different government level. Many different people claim to be in control of whatever is happening in a given area, when actually they have no mandate to do so. Clarity in roles and responsibilities will go a long way to ensure better implementation and participation in CBR activities. Thus, many donors are often caught between trying to work through official central-local fiscal transfer mechanisms, while also gunning for expeditious execution of projects and programmes. Sometimes, the systems and institutional framework are so complicated, that they bog down implementation and cut back on participation. Donors should insist upon clarity of their relationships with the recipients, the channels of communication and responsibility. The systems and procedures should be less bureaucratic and more project oriented, if one is to see participation of as many people as possible.

IN SUMMARY :

Donors can increase participation in CBR in recipient countries by:

- Increasing their funding levels;
- Pooling resources together and promoting joint funding of CBR activities, rather than duplicating or competing with each other;
- Seconding staff (technical expertise);

- Attracting other donors to support government initiatives and programmes;
- Sharing information on good practices;
- Joint planning and implementation of activities;
- Increased openness on funds available.

Donors can increase Government's participation in CBR through:

- Ensuring that the country has a national policy on CBR;
- Setting up institutional arrangements for the management of CBR programmes;
- Setting up a national CBR steering committee
- Ensuring that each Ministry and District authority has a budget allocated for CBR activities;
- Factoring into their funding a requirement that all programmes and projects supported by their governments should have a component for disabled persons;
- Promoting international laws that promote the well-being of disabled persons.

Donors can increase participation at district level through:

- Joint and integrated planning (integrated and bottom-up);
- Joint and integrated implementation, supervision and monitoring;
- Allowing the communities and local governments to take the lead in CBR activities;
- Support to capacity building, systems and institutional development;
- Supporting community based organisations and NGOs that support and complement Government efforts in CBR undertakings.

Donors can increase individuals' participation in CBR by:

- Taking services and activities to the grassroots and forming community committees to monitor implementation;
- Ensuring that the CBR activities are community based; led by the community and implemented by the community for the community members;
- Supporting the establishment of alternative financing/income generating activities;
- Assisting to build the necessary capacity among the CBR implementers and the recipients of the goods and services.

DONORS VERSUS POLITICIANS

Donors need to be careful when it comes to demands by politicians. Only such requests should be entertained, that have clear workplans and measurable outputs, specifying how communities will be involved and the benefits they will accrue. Sometimes, donors are confronted with unrealistic expectations from the politicians. There seems to be an assumption that donors have infinite resources. The continuous dependence on donors also brings about a dependence syndrome. Some politicians, instead of facing problems, squarely shift the problems on donors. Some politicians are eager to have projects that have physical infrastructure because these make them appear 'good' among the populace. Yet, what is needed are programmes that are concerned with the well-being of PWDs; their income levels; their education etc. But, these may not be seen as the priorities. Therefore, donors will promote better participation in CBR by the communities if they take the time and trouble to undertake feasibility studies and interact with the communities to identify 'real needs'. This way, they will not be presented with a shopping list, but will get to know which activities will be of benefit to the communities. Project proposals are sometimes designed with other motives. The best proposals are those based on the identified felt needs of the people.

Nevertheless, donors need to create partnerships with the local politicians if they are to realise their objectives and assist districts to improve upon their CBR activities. Politicians are very good mobilisers and can be relied upon to promote community participation in CBR, since they were elected by the mandate of those very communities. Also, when it comes to community participation in CBR activities, other crucial community persons are the religious, clan and opinion leaders. They have an important role to play when it comes to shaping community beliefs and methods of work. So, they should also be included in some of the advocacy and mobilisation programmes to ensure better participation and results.

Field evidence shows that even without official encouragement, people tend to have a lot of expectations. Field reports indicate that people at the grassroots, seldom have a realistic understanding of the limitations of what the donors are able to achieve. The local communities have a lot to contribute in terms of local resources and their own labour, but they need to be encouraged. If there is a clear description of what needs to be done and differentiation of roles and responsibilities, then many citizens will acquire an understanding of what is possible. In this regard, donors ought to work with district and community leaders, to understand what the community can do and what support they need. The local communities can easily be mobilised and be relied upon, to participate effectively if they fully grasp what is happening and why.

DONORS AND CIVIL SOCIETY

There are many other stakeholders who must be brought on board, if the donors' assistance is to realise maximum benefits. These include local small NGOs, community based organisations, religious bodies or groups and so on. These organisations have in many cases won the 'hearts' of the local people by their contributions, however little they may be. In some cases, the only help the communities have received is from such philanthropic organisations. Donors may actually engage or sub-contract some of the work to other organisations, so as to reach the community better. Since these organisations have been accepted in the communities

and have a following, they are more likely to be successful in mobilising people than the external agencies. However, care needs to be taken especially where there are religious organisations, because the communities belong to different organisations and if a donor sides with one religious group, it may lead to loss of participation of other community members.

Donors need to interact with the civil society to conduct monitoring and ensure that programmes are properly executed and that people are benefiting. The civil society can be relied upon to bring about more transparency and accountability. The donors should work with civil society organisations as the monitors. External evaluations are good, but the best mechanism to ensure that things happen, is when the people themselves check on each other. In this vein, there should be a forum that brings together all key stakeholders where experiences are shared and strategies discussed and agreed. The donors and governments can serve the people better, if they bridge the gap between the different partners. This will result in better appreciation of each other's efforts, increased communication and information sharing, and will eliminate duplication and overlap.

There are many NGOs, both local and international, involved in CBR activities. There are also individuals, community initiatives and government programmes. This multiplicity of CBR providers and efforts implies a need for coordination and collaboration to ensure maximum participation, since they all serve the same interests and the same communities. Hence, the strategy of bringing stakeholders at a round table as advocated above, is likely to create a synergy that yields significant benefits to all involved. This also eliminates the temptation by some donors to establish 'spheres of influence', in an effort to justify their existence and a continued receipt of funding by their mother countries. The idea to create 'empires' is fruitless, as it leads to duplication of resources, unnecessary conflicts and misunderstandings. The situation is unfortunate, because it does not serve the local populace. The local people are not really concerned about where the funds are

coming from, but about whether those funds bring an improvement towards their well-being.

THE WAY FORWARD

One of the major problems that have troubled donors in developing countries is poor transparency and accountability. Some donors have suspended their assistance because of a lack of proper accountability. Indeed, many donors delay funding projects until they are sure that their assistance will be put to proper use and that there are proper accounting procedures, for they have to account for these monies to their populace, the taxpayers. This is a big challenge for the recipients, if they are to continue to receive the greatly needed extra funds. Donors can assist by initiating measures to promote transparency and accountability and encourage involvement of local communities and civil society, as monitors of donors funds.

In Uganda, the districts are facing a lot of capacity shortage, since decentralisation is still at an infancy stage. Many systems and procedures are yet to be instituted and many crucial staff, like accountants, is still hard to come by. Donors can help a great deal, if part of their assistance goes towards building the necessary capacity. Some donors complicate the situation by instituting their own accounting and reporting requirements, making it even more difficult for the already overstretched staff. This leads to a delay in accounting and hence, delays in release of funds etc. If one is talking about improving upon existing systems and procedures, then the donors should not bring in other systems and procedures outside those of the government. They can have their own external audits, but this should be funded by the donors, rather than the recipients. Donors will also promote better participation if they limit the external (expatriate) staff. The aim should be to build local capacity that will ensure continuity and sustainability. If expatriates must come, then it can be for a short spell of time and essentially to train and provide a back up for the local staff and lend their expertise.

Some donors come with a predetermined agenda. They have specific activities they are willing to fund and sometimes these are not necessarily

the priorities of the communities. If the assistance is to be useful and if full participation and involvement is to be attained, then the local communities should be given the upper hand in determining the direction and speed of the implementation programme.

Implementation should start where the community is based and move at a speed relative to the capacity and ability of that community. To do otherwise, is to overstretch and hence kill local participation and initiative.

The local communities should be allowed to form their own management teams in whom they have confidence. Donors need to let the local people appear to be in the lead and in-charge; otherwise, they become passive and do not participate fully. The communities must be made aware that the programme is their own and they are responsible for making it work. The donors should be seen as supporters who will eventually leave. The communities must always be prepared for the departure of the donors, so that efforts are not lost.

Generally, donors are well intended and they really want to help, but often, they undermine their good intentions by introducing new and untested practices instead of building on those of the communities and helping the communities to change from within. If a project or activity is truly 'community based' then it must start at where the community is, in socio-cultural, political and economic terms. Therefore, the donors would serve communities better, if they take the trouble to understand the communities they want to assist. There is also need for more transparency and openness from all sides, so that all the players know what is at stake, and the expectations from one another. There should be a clear definition of roles and responsibilities; an agreed work plan; an indicative budget with sources of funding; expected results and performance indicators. In short, all programmes should have clear work plans and a logical framework including implementation plans. This is the only way that all stakeholders will be kept on track and bring about better results, through increased participation and involvement of all concerned.

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CHAPTER 13

Collecting Disability Statistics: A Participatory Strategy?

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SUMMARY

This chapter examines the background to disability statistics and introduces the WHO definition of disablement in the form of the International Classification of Functioning, Disability and Health (ICF) (WHO 2001). It argues, that utilising this classification system as a basis for collecting survey data on disability, provides a new and exciting opportunity to gather information that will be more meaningful and useful, than one based on impairment categories. The approach includes collecting data on levels of activity and functioning, participation and contextual factors. The problems faced in structuring the survey questions, training the enumerators and motivating the service providers to collect information, are examined. Accommodating different languages and cultural norms are discussed and some ethical issues are also considered. Recommendations are made, relating to a participatory approach to collecting disability statistics.

INTRODUCTION

Collecting statistics on disability has proved problematic, mainly due to the confusion surrounding the definition and parameters of disability. This lack of clarity has served to confuse both, those collecting and those interpreting the data. Data collected in different countries and in different settings are virtually incomparable from survey- to-survey, as different categories of disability are used with different cut-off points. The impairment categories that are used are not mutually exclusive, for example, speech or communication problems can be found in most impairment groups. This makes the data almost impossible to interpret.

Until recently, methods employed to collect disability data have been based on bio-medical definitions and impairment groups. Given the higher level of morbidity together with less developed medical facilities, researchers were surprised to discover that surveys showed a lower disability prevalence level in Less Developed Countries (LDCs), than in More Developed Countries (MDCs) (UN 1990). The explanation lies, in part, in the social and contextual construction of disability. There are other real differences that explain the higher prevalence rate in MDCs. These include higher levels of road and industrial accidents, longer life expectancy and better health services, which mean people survive traumas but are left with impairments. In LDCs, different criteria are used to define disability and impairment levels that may have to be much more severe, before communities consider members disabled. For example, many people with mild to moderate intellectual impairments in a rural, pre-dominantly illiterate setting, will not be considered disabled at all. Additionally, given poorer medical facilities, it is likely that many more severely disabled children may not survive. The higher incidence of certain diseases such as measles and meningitis, which relate to subsequent impairment (e.g. hearing impairments), are known to be higher in LDCs but this is not often reflected in the data collected, coupled with the fact that these children often die and do not survive as they would in MDCs. These factors help to explain the prevalence rates in the UN Disability Statistics Compendium (UN 2001). Their website (<http://esa.un.org/unsd/disability/>), currently reports a range in the

proportion of the population from 0.2% in India and Qatar, to 33% in Norway.

The advent of the new International Classification of Functioning, Disability and Health (ICF) (2001), replacing the WHO (1980) Classification of Impairment, Disability and Handicap (ICIDH), has provided a framework that has great potential for the collection of more meaningful disability data. The framework offers the opportunity to look at all aspects of functioning and disability, regardless of the nature of the impairment, or health problem information. The additional information it can provide, is about the person's capacity to participate and how this is affected by the environmental/contextual factors.

The ICF follows a bio-psychosocial model, integrating the medical and social models of disability. It is universal, as it considers disability on a continuum and not as binary categories of 'disabled' and 'non-disabled'. It is also interactive, as it accommodates the complexity and multi-layered interactions between the person, his/her health condition and environmental factors. It is cross-culturally applicable and takes account of the parity across different aetiologies (i.e. where two very different aetiologies have the same experience of disability) and it has a full life span coverage from children to elderly people.

The new classification considers disability as the outcome of an interaction between a person's health condition and contextual factors. This outcome of disability can be described at three levels. One, is at the level of the body, as an impairment of the body function or structure, the second, is the level of the person, which looks at activity limitations and is measured as capacity. The third, is at the level of society and looks at participation restrictions measured as performance. A description of the contextual factors, both personal and environmental, completes the picture.

For example, let us consider a person with a hearing loss. The hearing loss is an impairment caused by damage to the ear (for whatever reason). This is the body function level. This impairment makes it difficult for the person to listen and communicate (e.g. understanding conversation),

both activities engaging the whole person rather than just the hearing organ. This person will therefore have an activity limitation in listening and in communication. When this person is in his/her current environment, the interaction between the hearing impairment and activity limitations and the environmental factors, determine the person's experience of disability. If the person works in a noisy environment with poor lighting, making it difficult to lip-read people speaking, they will experience a high level of disability. Whereas, if the environment is quiet and there is good lighting making it easy to lip-read people speaking, the experience of disability will be much less. In the first situation the environment is full of barriers, whereas in the second, these are facilitated.

The new classification has been extensively field trialed in a number of regions of the world, including Europe, North America, Australia, Latin America, Nigeria and India. The ICF has now been developed and endorsed. It must now be implemented in different applications, from service provision, through to national survey data collection.

Problems associated with data collection

Survey research on levels of living conditions among people with disabilities in Namibia and Zimbabwe, carried out by SINTEF and funded by the Norwegian Federation of Organisations of Disabled People (FFO), involves Government and University departments, together with NGOs and people with disabilities. The studies are attempting to establish better base-line data, in order to get a more accurate and realistic indication of the true level of disability, so that there can be a more equitable distribution of resources. Household surveys on living conditions, are used together with detailed disability questionnaires and elements of the ICF, to collect this information. They aim to find out who is disabled, by asking what the person can do, what happens when they are in their usual environment and the environmental factors that make it easy or difficult for them to undertake the different activities. It aims to find out, where a person's needs are not being met, both at the national and community levels. Pilot projects have been completed in both countries and national surveys are now underway.

Capacity building at the local level has been an important element of the research project. Participants from Government departments, NGOs and representatives from organisations for people with disabilities, have attended seminars, discussed research methodology, how the data have been collected, and how it will be used, presented and interpreted with particular reference to disability issues. Efforts have been made to bring together managers, administrators and supervisors, in order to learn how to formulate questions in the most appropriate way, and to best identify the target population, namely, people with disabilities. Time must be taken, to train the enumerators and prepare them to handle situations unique to people with disabilities.

Two major problems face those interested in studying or determining the extent of disability in a population. One, is coming up with a definition for disability. There is no standard definition, and no standard test for disability, that is constant from one population or society to another. The other major problem encountered, is the choice of 'instrument' used, to measure disability. That is: what question(s) to ask, in order to capture the proportion of disability in a population. In the past, many African countries have reported disability prevalence rates in the order of 1-5% (or 1000 to 5000 per 100 000 population). This is far below the European rates of 15-20%. That is not to suggest that African rates should be as high as, or higher than those seen in western societies – but there is a real fear of under-reporting among African countries. What is needed is a standardised approach to the disability phenomenon, so that international measurements can be compared.

A recent workshop on Disability Statistics for Africa, held in Kampala, 10th-14th September, 2001, organised by the UN Statistical Office and attended by representatives from 13 African countries, discussed this actual problem. There was agreement that the figures reported for African countries reflected, for the most part, the most severe cases of disability in the population – and were in fact, similar to rates for severe cases of disability reported in western countries. But what about those with more mild degrees of disability, of those who, for example, need glasses in order to read, but do not have them or cannot get them. They experience

a real limitation in activities because of this disadvantage. We do not like to think of this as a true ‘disability’ – but this person is disadvantaged as compared to others who have, or do not need glasses.

The meeting in Uganda recommended the use of **global questions for the screening of disability in a population**. These questions are based on the following principles:

1. The approach taken to screening should be based on an **activity limitation** approach.
2. The elements of **severity, time** (chronicity, i.e. acute, accidental limitations should be excluded), and **cause** should be implicit.
3. The individual’s actual use of assistive devices/technology should be included.

The following Global Screening Questions were agreed upon

1.1 Does anyone in your household ever have any difficulty in doing day- to- day activities because of a physical, mental or emotional (or other health) condition?

1. Yes, often
2. Yes, sometimes
3. No

1.2 Has this difficulty lasted, or is it expected to last 6 months or more?

1. Yes
2. No

1.3 If YES to 1.1 and 1.2,

How would you describe your difficulty?

Seeing

Hearing

Speaking

Moving around

Learning/comprehending

Movement (reaching, gripping, holding)

Others (specify)

2.1 Does anyone in your household need assistance to do day-to-day activities?

1. Yes, a lot
2. Yes, a little
3. No

The questions are intended to capture as many people with disabilities as possible, while at the same time, exclude people without disabilities.

Question 1.1 takes an **activity limitation** approach (difficulty in doing day-to-day activities) and **cause** (because of a physical, mental or emotional (or other health) condition). It also includes **severity** (Yes, often/Yes, sometimes).

Question 1.2 includes the element of **time** (lasted, or is it expected to last 6 months or more). This should exclude the more short-term, acute cases and those due to accidents.

Question 1.3 was thought to be optional, since in a population screening exercise one would be more concerned with the amount of disability, rather than the type of disability.

Now, consider that a person with a disability may have lived his/her entire life with the support and protection of his/her family and have been able, despite his/her disadvantage, to be integrated and perform well in his/her society. This person may respond to the above questions in such a way that he/she would not be counted - i.e. he/she actually has no difficulty in performing day-to-day activities – but it would be said that he/she still has a disability.

By asking **Question 2.1**, which includes the use of assistive devices/technology, one would be able to capture those who do not experience activity limitations (within their environments) but may require help or assistance of some kind to fully participate in society.

It is important for everyone who is involved with disabled people, to collect data; it is not something that should just be left to enumerators. Service providers should not be frightened of collecting data, they are in a unique position to collect very valuable data, but first, they must set their priorities and then plan how they will achieve them. Research is essential for service development; it is not a mystifying process only understood by statisticians. It is important to remember that traditional impairment categories might not cover what local populations consider to be a disability, such as women's infertility, or men's impotence.

Factors which affect data collection

- In many countries, there are so many different languages and dialects, that efficient communication is very difficult and usually confounds national initiatives that often prove impractical. Additionally, many of the key words are problematic in themselves, e.g. disability. It is advisable to avoid such terms and elicit a description of the problem or need. For example, describe the difficulty walking; describe what is preventing you from participating, and so on.
- Cultural perceptions could also confound statistical interpretations. For example, it is usual for an African family not to want to tell anyone how many children they have; they do not want to be 'counted' because of fear that something bad might happen to the family. For other reasons, the poor communities expect assistance to follow the enumeration of the people in their community, such as supplementary feeding, or income generation projects. In CBR programmes in Uganda, counting people has raised a lot of anxiety and expectations. People, especially parents of disabled children and people with disabilities, often do not feel comfortable with the focus on disability. In the 1991 census in Uganda, people with

disabilities were identified, but other vulnerable groups were not included. For example, there were no special sections for women or youth. Some of the disabled people, who were identified, still hold their identification numbers and papers, in the hope that one day they will get some assistance! This would indicate that it might be better to start a service that attracts people and while providing the service, then one might want to count them. Delegates at the conference questioned why WHO was now promoting surveys? It was explained that information is needed if useful services are to be provided. The participants argued that it was important to develop a service at national and local levels and relate them to known problems. Up to now, data have not helped service providers develop services that relate to felt needs, because, the surveys have been looking at disabilities from a medical impairment perspective. There is a need to look at disability from both, the medical and social perspectives, if useful service information is to be gathered.

Cultural perceptions can often be accessed through local stories and proverbs. These have been reported by Kisanji (1995) and help to understand local concepts and beliefs which can be used to inform surveys. For instance, data from Zambia and West Africa indicates that disability is seen in different ways that cannot automatically be grouped together, since the stories do not have disability as a common theme. Studies in Uganda (Jacobsen 2000), indicate that disability is not a concept attached permanently to somebody, but more an observation relating to a specific situation. This is a point also underscored by the ICF, where the definition of disability as an outcome of an interaction, means that the experience is a feature of the changing environmental contexts, and not a static feature of the individual. A child can therefore be perceived as disabled at school, but not disabled at home. It is this information that should be used to inform surveys.

Experiences in Uganda show that the reality of collecting data before service is provided, has not resulted in the development of services, but has resulted in survey after survey, with very little

follow-up. It is suggested that one way around this is to provide service first and then count, or, to conduct a survey, which is part of a service development programme.

THE ETHICS OF SURVEYS

The justification for disability statistics is that they help to decide how resources should be distributed, but this does not address the ethical problem of what happens when there are NO resources. Perhaps, data is needed to compare the amount of resources used for collecting this data, with the resources available for the development of service provision. The question is, could there be a more equitable distribution of resources between service provision and data collection?

QUESTIONS ASKED AT THE SESSION IN KAMPALA

- How do you get ethical approval through the research ethics committees, for doing survey research as people are identified, but no service is provided?

The ethical considerations should be verified with PWDs or their organisations, even if projects have passed through funding bodies or the universities' ethical committees and got approval in these institutions.

- Are disabled people included from the beginning?

In Zimbabwe, this has been a thorny issue, where programmes meant to benefit the disabled people were planned for them, without involving them at the planning level. The National Council of the Disabled People of Zimbabwe (NCDPZ), as an organisation representing different PWD's organisations, is very vocal about research that does not include PWDS. As a result, there is now a strong relationship between government ministries and NCDPZ to include disabled people when planning research protocols and modalities, and also engaging disabled people as enumerators where it is possible. Good statistics help Governments and other interested bodies, such as academic institutions, to know the extent of the

problem and help them to formulate and test hypotheses and theories to understand better, the nature of the problem as a basis for further research.

RECOMMENDATIONS

1. Participation of PWDs and/or their organisations and parents of disabled children, from the beginning of the research or survey activities.
2. Ethical approval should be rigorous, 'no survey without service'. It is very important to encourage service providers to be accustomed to carrying out surveys, to make sure they are reaching the target group. The research institutions should foster a relationship with the service providers, to provide a complementary service to build a good database and enable them to monitor and evaluate their interventions.
3. Central Statistical Offices (CSO) in less developed countries, should put in place structures which guarantee that data will be analysed (Census in Kenya, data so far not been analysed). There is a need to collect information that is useable. For example, the 1965 census in Uganda (Uganda Government and ILO identified 650,000 PWDs). Until 1990, people were still coming to government offices and other service providers with letters and the expectation of getting assistance.
4. It is strongly recommended that a service should be provided first and people involved should be counted later.
5. There should be a democratic distribution of funds, between survey and service, with at least equal amounts for both.
6. Issues in data collection: Data are collected for many different purposes and at many different levels. Disability is no exception. Good data is needed to:
 - Plan an appropriate intervention programme for an individual.

- Develop and provide resources for services in a local area. The data could assist in deciding whether the focus should be on prevention of illnesses resulting in impairments, rehabilitation services, or changing the environment, or a combination of all these.
- Develop, implement and monitor relevant policies at national level. For example, if there is a much higher rate of unemployment among disabled people than the general population, then a policy and legislation on employment targets for disabled people could be developed. This can only be done with national level data.
- Compare disability rates and experiences internationally, which requires national level information to be collected across a number of different countries in the same way.

Even if there are all these different levels, they can use the same framework of data collection. If the framework is the same (e.g. using the ICF at different levels of detail, with the individual level having the most detail and the national and international levels having the least), the data can be compared, pooled and so on. This will save resources, as well as allow people to communicate with each other at different levels.

7. Build the capacity of the service providers to carry out surveys to monitor and evaluate the impact of their interventions.
8. Governments to collaborate with PWDs on how and what information is required to be collected, for the purpose of improving the welfare of disabled people. Censuses provide an ideal opportunity to involve PWDs about the information necessary to be collected by the CSOs.
9. Disabled men often leave out disabled women; therefore, it is important to make a deliberate effort to include women in surveys.
10. Parents of disabled children are another important group that is usually excluded by the PWDs and viewed as outsiders by PWDs' organisations; yet, the burden of looking after disabled children

rests solely in the hands of this group. PWD organisations are usually concerned with adults and ignore early intervention services, which are essential for children with disabilities, to reduce the progression of the disability, as the child grows.

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CHAPTER 14

HIV/AIDS and Community Based Rehabilitation (CBR)

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SUMMARY

The AIDS epidemic across sub-Saharan Africa, is affecting all strata of society. This chapter examines the factors that make people with disabilities (PWDs) vulnerable to the HIV/AIDS epidemic. The social issues that lead to discrimination of PWDs are the very concerns that make them vulnerable to HIV/AIDS. These factors are inter-related and exacerbate each other. Poverty, low self esteem, lack of information, family up-bringing and negative attitudes are some of the reasons given by PWDs, their carers and service providers (including community based rehabilitation (CBR) workers), that make disabled people vulnerable to HIV infection. The role of CBR is discussed here as a contact point or door between PWDs and the various services and activities, that address HIV/AIDS. CBR should also ensure that interventions in HIV/AIDS are presented to PWDs in an accessible and acceptable form. Programmes implementing CBR should be careful not to divert from their primary objectives and concentrate on HIV/AIDS related activities, even when the interventions are targeting PWDS.

INTRODUCTION

In the last two decades the HIV epidemic has swept across sub-Saharan Africa with an increasingly destructive force. According to UNAIDS and WHO, the epidemic has so far claimed over 14 million men, women and children south of the Sahara (UNAIDS, WHO 2000). Gains made in life expectancy are being wiped out in many countries. The recent increase in adult deaths in East Central and Southern African countries can be attributed to HIV/AIDS infection. For example, in Zimbabwe, adult mortality among men nearly tripled between 1988 and 1994 (Commonwealth Regional Health Community Secretariat for East, Central and Southern Africa, 1999). Approximately, 4 million new HIV infections occurred in the region during 2000 (Centre for Disease Control, 2001), but despite the rising prevalence in most of the sub-Saharan countries, Uganda in the mid-nineties, registered declining prevalence (Centre for Disease Control, 2001). HIV prevalence in pregnant women declined in five sentinel sites by an average of 6% between 1991 and 1995 (MOH, Uganda 1996). The overall decline in adult HIV prevalence has decreased from 14% in 1990, to 8% in 2000 (Centre for Disease Control, 2001), while in Masaka, Uganda, HIV prevalence among females aged 20-24 years, has decreased from 20.9% to 13.8%, from 1989-1997 (Kamali et al. 2000). This drop is attributed to mainly, declining incidence and partly due to AIDS related mortality. Change in sexual behavior, a result of openness that has characterised Uganda's national response, has mostly contributed to the declining trend. Transmission of HIV/AIDS in sub-Saharan Africa is mainly heterosexual, followed by mother-to-child transmission. In many African countries, blood transfusion remains an important root of transmission.

AIDS in Africa, has left a trail of socio-economic upheavals characterised by reduced income at family level, orphans and strain on health services. Traditional coping mechanisms to combat disasters have been stretched to breaking point. Every fibre of life has been affected by this epidemic.

Sub-Saharan Africa has responded to the epidemic through National Control Programmes. These programmes have focused on the following strategies:

- Promotion of behaviour change
- Condom promotion
- Minimise risk of HIV transmission through safe blood transfusion
- Early detection and treatment of sexually transmitted diseases
- Community based management of AIDS and TB
- Special focus on priority groups such as sex workers, adolescents, truck drivers etc.

International agencies, non-government organisations (NGOs) and western governments have all rallied to help governments and civil society, respond to the epidemic. Communities and family members are moving from a judgmental attitude, to one of support to the sick and orphaned. This phenomenal response to the epidemic will bring about a turn around, as already evidenced by the experience in Uganda.

PWDS, HIV

Although a lot is known about how the epidemic has affected special interest or vulnerable groups, little is known about its impact on people with disabilities. Do impairments protect them or make them more vulnerable to HIV? Are PWDs benefiting from, or contributing to the massive community, national and international response to the epidemic? A major concern of PWDs, is that the strong and rapidly expanding fight against HIV/AIDS excludes them.

CBR has been discussed at length, in earlier chapters of this book. It is a strategy that has been adopted by most African countries, as the most appropriate means to facilitate the inclusion of PWDs in the community and within national development. CBR in all its forms and colours has been in Africa longer than the AIDS epidemic, although they both experienced rapid expansion over the last two decades. How has CBR responded to the epidemic? What is the impact of the epidemic on CBR and PWDs? Does CBR have a role in fighting the epidemic?

This chapter will try to respond to the above questions. The voices of men and women with disabilities, parents of children with disabilities, CBR practitioners and ‘professionals’ across Africa were heard through a mini workshop on HIV/AIDS and CBR in Kampala, Uganda in 2001. The group grappled with the above issues concerning the HIV/AIDS epidemic and came up with a way forward through CBR in Africa.

VULNERABILITY OF PWDS TO HIV/AIDS

The complex interplay between disabled and non-disabled people over the past century has made a commendable shift in power from the latter to the former, especially at the apex of society. Negative attitudes and discrimination, however, continue to play a decisive role in shaping the lives of PWDS at all levels of social strata. Many decisions and therefore outcomes of disabled people’s lives are a result of the social environment in which their disability was born and bred.

Various social, mental and physical barriers limit participation by PWDS in their own, as well as community development. As a result of these barriers, one would assume that PWDS are protected from HIV, a disease that is often associated with interaction and participation. On the contrary, the opposite is true. Factors that hinder participation and integration of PWDS make them more vulnerable to HIV/AIDS. These same issues on the other hand, hinder access to services for the prevention and treatment of HIV/AIDS. Impairments biologically do not make PWDS vulnerable to HIV/AIDS. Societal response to the impairment is what makes PWDS an easy target for the HIV infection. The major factors that contribute to the vulnerability of PWDS to HIV, are discussed below.

The Family

The label of disability is often, but not always, attached in the home. The response to the impairment by family members plays an important role in shaping the life of the disabled person.

Overprotection by the family, was identified as an important factor in exposure to HIV infection. The overprotected child is not exposed to sexual challenges. This limited exposure results in an adolescent who is

not empowered to handle his/her own sexuality and the external sexual demands made on them. Children with disabilities often miss out on sex education, whether this includes traditional initiation ceremonies or the more modern skills for life training. Parents view their disabled adolescent as a perpetual child who does not require sex related education and must be protected from the advances of the opposite sex. Many women with disabilities (WWDs) have complained that they do not receive the same information that is given to other women. For example, when preparing for marriage, the deaf women in Uganda have taken it upon themselves to counsel deaf girls on married life because the aunt who traditionally should play this role, often neglects this or finds communication difficult. The lack of sex education and life skills render PWDs vulnerable to HIV infection.

In Africa, many PWDs continue to live with their parents even as adults. Accessibility or the lack of it, was cited as a major reason for continued stay at home. This is reported to limit the romantic exposure of PWDs. There is less privacy at home and if one does go out, the parents monitor the whole event. When PWDs get an opportunity to meet, they want to make the most of it, especially sexually. This is one reason given for the promiscuity that PWDs have observed among themselves. It was observed that HIV tends to spread among members of a disabled persons organisation (DPO) because of ‘in house sharing of partners’.

‘We stick to ourselves and mess our selves more’

Angela Balaba- WWD

The other side of the coin in the family includes the abused children and youth with disabilities. A study in the Kibwezi CBR programme in Kenya (Amref, 2000), found that sexual abusers are usually family members. This is also often the case with non-disabled children. The disabled child and youth are less likely to report abuse than other children, especially if they have been raised to believe that they are inferior to other members of the family. Others such as the mentally handicapped, may not be able to comprehend they are being abused. Some ask why they are removed from an incestuous relationship.

Although parents and carers are concerned about the sexual abuse or rape of their children, their primary concern is not the danger of getting HIV, but unwanted pregnancies in the case of girls. Many girls with disabilities from all cultures across the continent, are on contraceptives without their knowledge.

Low self-esteem is another reason that leads PWDs to have multiple partners, thus increasing exposure to HIV. Low esteem, PWDs noted, starts in the home. Low self esteem also leads to easier coercion into sexual encounters and one is less likely to report abuse. Having a lover tested for HIV before any sexual relations is difficult for women, and especially women who are already marginalised in so many other ways.

Access to Information

The HIV/AIDS epidemic has created a worldwide response with massive production of information in many languages, using multi media channels for delivery. This information blitz has not reached people with disabilities in Africa. The blind, deaf and mentally handicapped persons have especially been left out. In Uganda, deaf-to-deaf life skills education has already started to try and address the information gap. In Namibia and Kenya, work has begun to provide deaf children with information on AIDS and how to avoid it. These efforts are however, a drop in the ocean considering the size of the problem. PWDs need information designed and packaged to meet their needs. Parents of children with disabilities, need information on bringing up their child so that they can ably prepare their special child for future challenges. CBR workers need information on how to address the HIV/AIDS issue in their work. Programmes for sexually transmitted disease should include CBR programmes among their target audience.

Poverty

Poverty is a factor that is closely interlaced with the HIV/AIDS epidemic. Poverty fans the epidemic and is also the fruit of the epidemic (Cohen, 2002). Poverty related factors can affect household and community coping strategies in dealing with HIV/AIDS, and in turn the experience

of HIV/AIDS can reduce the ability of individuals to be economically productive. Disability and poverty too, have a symbiotic relationship especially in the developing countries (DFID, 2000). PWDs may experience limited opportunities for participation in education and employment, leading to increased vulnerability to poverty. The downward spiral of poverty and disability will not be dwelt upon, in this chapter.

Both men and women with disabilities are driven by poverty to use sex, as a means to meet their economic needs. Poverty also limits the choice for safe sex and for safe partners. Disabled street women in Kampala have multiple partners and do not use the condom. One lady outside the main market said, 'I have been involved with several men on the street, but I have never used a condom. The men who have sex with me do not want to use a condom'(Ruheweza, 2001).

Sexually transmitted infections (STI) increase the opportunity for HIV invasion of the body. When effective STI treatment programmes are compromised, opportunities for HIV prevention are lost (Grosskurth et al. 1999). Many disabled people who become infected with STI cannot afford treatment. Others do not know where to go for treatment, while some fear ridicule from health workers for getting STI. The presence of untreated STIs increases the vulnerability of PWDs to HIV infection.

Low Social Status of PWDs

In Sub Saharan Africa, the AIDS epidemic has been followed closely by an increase in sexual abuse of children and other sections of society, who are felt to be free of HIV, such as older persons. PWDs are among those who are assumed to be free of the virus because of the discrimination they suffer. This has increased the vulnerability of men, women and children with disabilities, to sexual abuse, rape and HIV infection. Low self esteem, communication difficulties and the low value of PWDs make redress of abuse difficult.

In agrarian societies, survival depends on physical capabilities. Women are married because they are a source of labour. Disabled women are

therefore, viewed as liabilities and have less opportunity for marriage. In addition, beauty in the African context is largely physical. Beauty of the soul rarely comes into play when choosing a spouse. The low social status of women makes WWDs less likely than men with disabilities, to find a spouse.

In Africa the ability to have children increases acceptability. In addition, children are a source of security for the future. A 34-year-old woman said, ‘I want to have another child, so that I can be assured of help in my old age.’

The difficulty in finding a partner, coupled with the need to have children makes WWDs especially vulnerable to HIV. Many WWDs are single parents during the day and married at night. Men are ashamed of WWDs as spouses, so the men visit these partners with disabilities only at night, or abandon the WWDs once conception has taken place. All these factors reduce the bargaining power of WWDs for safe sex or safe partners.

‘We are normal human beings who also need love and sex’

The assumption by society that PWDs are asexual, contributes to the vulnerability of disabled people to HIV infection. It bars information on sexuality, HIV/AIDS and its prevention from reaching PWDs. Access to health services is limited due to the negative attitude of health workers. PWDs are thought to be free of HIV and end up targets of abuse, or coercion into unwanted sex.

PWDs, like other people, have sexual needs, but do not have a strong negotiating position and consequently can end up practising unsafe sex. Parents of mentally handicapped adolescents have often raised concern over inappropriate sexual advances made by disabled children to the opposite sex. Normal sex hormones in a disabling environment make PWDs vulnerable to HIV infection.

AIDS CAUSES DISABILITY

It is estimated that 1/3 of people with AIDS develop a disability(s), an area which is receiving growing interest (Harworth & Turton, 1993). With access to anti-retroviral drugs and chronicity of AIDS, it is likely

that rehabilitation programmes will not only have to deal with disabled people with HIV/AIDS, but also with people who have been disabled by AIDS.

ORPHANED CHILDREN WITH DISABILITIES

Africa has 92% of the estimated 13 million children who have been orphaned worldwide by AIDS (UNICEF, 1999; UNICEF, 2002). It is estimated that 4-5% of these orphans have disabilities (UNICEF 1999, UNICEF 2002). Unlike other orphans, relatives are reluctant to take on children with disabilities (CWDs) in their families. Sick mothers therefore, worry more about their child with disability and try to prepare them to be self-reliant. This is often not possible.

THE ROLE OF CBR IN HIV/AIDS PREVENTION AND CONTROL

CBR programmes in sub-Saharan Africa do not directly address the issue of HIV/AIDS in their programmes, yet, the epidemic affects all people in Africa and especially PWDs who are more vulnerable to the infection. By enhancing the profile and value of PWDs, CBR does, in a round about way, address the epidemic.

CBR has an important role to play in the prevention and management of HIV/AIDS and should participate in all programmes that are aimed at addressing the epidemic. HIV/AIDS interventions should also include CBR, among the strategies.

The holistic approach to disability is one of the hallmarks of CBR. Unfortunately, most interventions through CBR in Africa, omit the sexuality of PWDs and the factors that affect this aspect of life. As CBR improves activity and participation, it is important to ensure that integration is accompanied by social skills that protect PWDs from sexual exploitation and exposure to HIV.

The primary role of CBR is therefore, dealing with the roots that make PWDs vulnerable to HIV. The families of adults and children with disabilities must be helped to raise PWDs who are confident and able to

refuse unsafe sex. Families need to recognise that children with disabilities will one day be adults with sexual desires, which they will have to learn to deal with. CBR should therefore be a vehicle of information to PWDs and their families, on sex and the HIV epidemic.

More difficult, but just as important, is the need for CBR to address the need for communities to protect PWDs from sexual exploitation. There is a need to awaken social consciousness to the plight of WWDs. Some of the more vulnerable disability groups such as the blind, deaf and mentally handicapped persons need special attention. Although CBR should spearhead the protection of PWDs, care needs to be taken to avoid hindering the opportunities to have children.

CBR should be a point of entry for PWDs to access HIV prevention programmes. For example, CBR should challenge HIV projects to provide information packaged for different disability groups. The dissemination of this material can be done either by DPOs, or the HIV prevention organisation, with the CBR programme playing a contact or facilitatory role.

Many communities in Africa have responded to epidemics with community initiatives that take care of the sick with HIV. The CBR programme needs to ensure that PWDs who have AIDS, have access to the services provided by community based AIDS support organisations.

Where disabled orphans are concerned, the CBR workers need to ensure acceptability and integration of these children in their new homes.

DPOs, together with CBR programmes should network with district, regional and National HIV organisations (government and NGOs), to ensure that PWDs and their families access and participate in HIV prevention and treatment interventions.

CBR needs to work with research programmes to identify information gaps that PWDs have about the epidemic. Socio-cultural issues that surround disability and HIV/AIDS need to be studied and interventions planned. The role of CBR may not be in conducting the actual research, but to bring the disability issue to the attention of researchers in HIV.

CONCLUSION

The issues that limit participation of PWDs are the very factors that make them vulnerable to HIV infection. If CBR is to remain relevant to this population group, their families and the communities in Africa, CBR must address HIV. Strategies to ensure that available interventions reach PWDs and their families need to be formulated. CBR must take care that the programme continues to focus on promoting participation of PWDs in community development. Direct interventions concerning HIV/AIDS health promotion to PWDs, should as often as possible, be done by other organisations. The role of CBR is merely to open the door for PWDs and their families, to access these interventions. In opening the door, CBR will have to build networks that are wider than the traditional liaisons with disability related organisations.

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CHAPTER 15

Future Participation and Sustainability of CBR: The Way Forward

Jack Mirembe, Sally Hartley.

(Participation from the UNISE ‘CBR team’ and all conference participants is acknowledged).

SUMMARY

The opportunity for the conference participants to share their experiences provided a rich source of inspiration for all those involved. It is the intention of this chapter to share this inspiration and suggest some ways forward, that will facilitate the development of CBR programmes. The first part of the chapter summarises the key issues that arose from the presentations, discussions and deliberations, drawing together constructive ideas and developing a vision for the way forward. These included, ‘The key ingredients of CBR in Africa’ which were ratified by the conference participants. The second part of the chapter reports on four specific tasks relating to the key issues, which the conference participants agreed to take forward. These were, the development of national associations of CBR workers, initiatives to improve the capacity for sharing information about good practice, a review of the development of training on CBR and the organisation of another conference on CBR

in 2004. Finally, readers of this chapter are invited to participate by contacting the people responsible for the different initiatives and contributing their own efforts and ideas, to those that have already started. They are also invited to use the ideas outlined here, within their own settings, as a basis for developing further ideas.

**THE WIDER THE PARTICIPATION, THE GREATER THE
IMPACT!**

IT IS UP TO YOU!

ARE YOU GOING TO PARTICIPATE?

HOW? WHEN?

WHAT WILL YOU DO?

KEY CHALLENGES FOR CBR WITHIN THE AFRICAN CONTEXT

The key challenges for CBR identified at the conference were fourfold.

1. The need for a working definition of CBR.
2. The need to raise awareness on the role of participation in effective CBR programmes.
3. The need for CBR training and practice to be documented and synchronised nationally and inter-continently.
4. The need for all the stakeholder groups to have a clear understanding of their role in the CBR process and to know how this relates to the roles of others.

1. The need for a working and flexible definition of CBR

Presentations and discussion at the conference highlighted an urgent need to establish a working definition of CBR within the African context. It was observed that the lack of such a definition or a common understanding, has led to confusion and mis-information and is now hindering the further development of CBR programmes. The participants

of this conference accepted the positive role that has been played by the Joint Statement on CBR, made by WHO, ILO and UNESCO (1994), but felt that a more context specific guideline was required.

The deliberations on what constitutes a CBR programme, discussed in Chapters 1 and 2, illustrated the dynamic nature of CBR and the context specific influences on its development. It is recognised that it is this flexibility and the capacity to respond to contextually different challenges, which have been a great strength in the early development of CBR. This flexibility has allowed the local people to interpret and develop CBR in many different directions and this has contributed significantly to the broad and holistic understanding that has now emerged. The participants of the conference rose to the challenge of establishing a working definition of CBR, by creating and ratifying 10 key ingredients that they perceived should either exist within CBR programmes, or should be used to provide a vision for future plans and development. These key ingredients are listed in the following box.

KEY CBR INGREDIENTS FOR AFRICA

- 1. CBR must take a rights-based approach, empowering disabled people and their families.**
- 2. CBR must involve disabled people, parents and their organisations from the start.**
- 3. CBR must enable key stakeholders to access information on all issues, including HIV/ AIDS.**
- 4. CBR must be holistic; it must look at people with disabilities in totality.**
- 5. CBR must advocate for appropriate legislation and policies.**
- 6. CBR must enhance self-advocacy of disabled persons.**
- 7. CBR must develop long term and short-term plans together with all stakeholders. It must 'be strategic'.**

- 8. CBR must ensure inclusion of disability issues in all development programmes. It must collaborate with all sectors.**
- 9. CBR must take into consideration local cultures, resources and practices.**
- 10. CBR must address issues of poverty among disabled people and their families.**

2. The need to raise awareness of the role of participation in effective CBR programmes

The participants recognised the essential role that participation plays in effective CBR programmes. However, they also recognised that the participatory process is on a continuum. Participation is not something which can be considered present or absent, but something that has small beginnings, for example, the partnership between parents and their children, between two people with disabilities, between two professionals. It is important to nurture these relationships, to build on them and to value their importance, so that they can grow in frequency and strength and eventually form a corner-stone of all initiatives.

The process of participation is seen to include the sharing of information, ideas and responsibilities. Participants recognised that this should be a two-way process for effective outcomes and one based on co-operation of all the stakeholders. The stakeholders identified at the conference, besides disabled people themselves, included parents and relatives of disabled children and adults, other community members associated with the families, including a wide variety of professionals, Government bodies and non-government organisations including disabled peoples' organisations and funders.

The conference itself, strove to achieve a high level of participation, by including representatives from as many stakeholder groups as possible, in all stages of planning and execution. Many presenters spoke from first hand experience of having a disability themselves, or having a disabled child themselves. People from all the stakeholder groups shared

the responsibility of running the sessions. One of the strongest feedback messages from the participants, was how participatory the conference had been and how they would not have believed it possible, if they had not seen it for themselves.

3. The need for CBR training and practice to be synchronised nationally and inter-continently

The presentations from the conference revealed the presence of a considerable amount of CBR training in many African countries. This took place in two main forms, in-service and institutionalised. There was some evidence of exchange programmes between African countries, but the content of the training was seen to be diverse and generally unknown to others carrying out similar training programmes, whether this be in other countries, or even within the same country. It was observed that there was little synchronisation of these training programmes in terms of complementary information and expected levels of achievement. Uganda was highlighted as an example, in that, it had several training programmes at different levels, but little integration between the programmes offered and complementary areas of the programmes remained unknown. Participants felt there was a need to harmonise the CBR training curricula by sharing information through documentation of research and publication in working papers, reports, journals and newsletters.

4. The need for all the stakeholder groups to have a clear understanding of their role in the CBR process and to know how this relates to the role of others

A great deal of time at the conference was given to sharing and exploring the different roles and perceptions of the stakeholders. From this process, it was clear that each group had a very valuable contribution to make to the whole process, but no group could manage the process alone.

The role of trainers has already been touched upon, but the presentations and discussion from the Government representatives illustrated the high level of commitment and energy that has been directed by some African

countries, in shouldering the responsibility for setting the best structures in place, to nurture the empowerment of disabled people and their families. It illustrated the importance for up-to-date information being made available to the people responsible and for mainstreaming the policies relating to people with disabilities. A multi-sectorial approach was required to develop structures that could handle this process with sufficient funding, to make such ideas a realistic proposition. It highlighted the need for economic empowerment.

People with disabilities and their organisations (DPOs), emphasised the need for their involvement at all stages of the process. They recognised and appreciated the role of the professional and shared some of the problems they face within their own structures. They also shared the painful process of learning which is taking place, in order for them to achieve sufficient harmony to make even more positive contributions.

Professionals shared the difficulties they face in changing their exclusive structures and superior attitudes, and working towards a more inclusive sharing approach, without losing the essence of their standards of practice and professional commitment. They recognised the need for a more participatory approach, utilising the wisdom of the local culture. An illustration of their commitment to this resulted in long ‘after hours’ sessions in conjunction with representatives of people with disabilities, concerning access to information about HIV/AIDS, through CBR programmes. The importance of this activity and the need for networks between CBR and HIV programmes, to develop and supply information that was appropriate and user friendly to people with disabilities, was highlighted.

The contributions from parents and community members, illustrated the extraordinary commitment made by this group and their degree of involvement and commitment left all the participants full of admiration. The parents shared their frustrations about the difficulties experienced in achieving recognition, in finding resources to carry out their ideas but nevertheless, expressed their appreciation for the support of other stakeholder groups.

Representatives of non-government organisations saw themselves as promoters of the complementary role that all stakeholders need to play, the need to network between all parties and to share the workload and responsibility. They identified the problem of overtaxing the family members and the community and expressed fears and suspicions, that people worked towards their own agendas more often, than out of consideration for the welfare of the target group.

The level of participation by donors at the conference was perhaps the 'weakest link', but the excellent paper presented, raised many of the very difficult issues that need to be faced by all participants. These included the misgivings about achieving participation when roles have very different agendas, the issue of transparency and community involvement and the difficulties of a holistic funding approach.

FOUR SPECIFIC TASKS

The conference participants agreed to take forward four specific tasks as a first step, in meeting some of the challenges outlined in the previous section. They were:

1. The development of national associations of CBR workers.
2. Initiatives to improve the capacity for sharing information about good CBR practice.
3. Review of the development of training on CBR in Uganda as an initial step in synchronisation of training programmes.
4. Organisation of another conference on CBR in 2004, in Southern Africa (possibly Zimbabwe).

1. The development of national associations of CBR workers

It was agreed that, where possible, participating countries should start CBR associations. The aim of these organisations would be:

- To create a linkage between all the stakeholders in the development and sustainability of CBR programmes.

- To provide a forum where they could share information.
- To lobby and advocate for disabled people and their families.

It was agreed, that conference participants would go back to their countries and motivate other CBR workers to form associations. This would be done in liaison with existing bodies.

The recommended process for setting up these organisations would be:

- to identify a working group and arrange some meetings,
- set up a constitution and establish the aims of the association in accordance with the local needs and the ideas expressed above, as a guideline only,
- elect officers, develop a plan of action with a timetable and lines of accountability and canvas for members,
- set up mechanisms for dealing with membership.

Once a number of national organisations had established themselves and created communication links, then regional and Africa-wide associations could be formed. It was felt that regional associations would come later, once the national organisations were active. This later stage would involve an African Charter Working Group, to be set up.

Nine participating countries agreed to take this initiative forward and the conference participants who agreed to spear-head this initiative were:

Uganda - Paul Ojwang. UNISE, P.O. Box 6478. Kampala. Fax 256 041 222961 unise@swiftuganda.com

South Africa - Agnes Okosi c/o Chief J.M.Dlami, Cheshire Home Box 1344, Elukwatini 1191. Fax 27134833169.

Tanzania - Khalfin-Khalfin. Khalfin@cats-net.com

Kenya - Shaya Asindua. c/o AMREF Kenya Nairobi. Kibwezi Office Kibwezi@amref.org

Senegal - Dione Abdoulaye. Ministry of Education, Senegal. adione@avu.org

Sierra Leone - Aprilus Damba. c/o Sir Milton Margi Cheshire Homes
Tikono Road, Box 150. Sierre Leone. Fax 23232308

Zimbabwe - Servious Dube. s.dube@ich.ucl.ac.uk. Obert Ndawi
University of Zimbabwe Department of Curriculum and Arts Education.
Fax 263 433 3407

Ethiopia - Makedas Gebretensay. c/o Save the Children Fund
scukethiopia@scf.org.uk

Zambia - Siame Musonda. c/o Leonard Hermansen.
H.hermansen@london.leonard-cheshire.org.uk

2. Initiative to improve the capacity for sharing information about good CBR practice

This initiative aims to facilitate stakeholders to share experiences concerning CBR practice throughout Africa. It is based on the perception that many good CBR initiatives take place, but the practitioners involved either do not have the time or skills to share these experiences, or, they do not see the need. The conference participants felt that a lot of good CBR work took place in Africa, but the 'oral tradition' often prevented the people concerned, from documenting their activities. Difficulties in communication between countries, a lack of resources and poor motivation and writing skills, all, contributed to this problem. The result was that the rest of the world thought very little was happening in CBR in Africa and community programmes were making the same mistakes over and over again, and failing to learn from other initiatives.

As a first step in the process, this initiative proposed to produce an edited volume of CBR experiences in Africa. Key co-ordinators would be identified and authors from different countries would be approached to write different chapters. Two editors would be appointed and there would be a series of writers' workshops. The workshops would be carried out at training institutions in Africa such as UNISE, KISE and TMI. The time frame for this programme suggested that two writing workshops would be carried out by 2003, the final manuscript produced by 2004 and the book published by 2007. The team identified to carry this initiative forward is:

Dr. Alice Ngunua. Ministry of Health, Kampala, Uganda

Dr. Joseph Kisanji. Tanzania Global Development Learning Centre, Stabon Robert Street, IFM Building, Tanzania. k.kisanji@avu.org

Mr. Moses Ddamulira. UNISE, P.O. Box 6478. Kampala, Uganda. Fax 256 041 222961 drcunise@swiftuganda.com

Dr. Sally Hartley. Institute of Child Health, 30 Guilford Street, London Wc1N1EH. UK. s.hartley@ich.ucl.ac.uk

Dr. Susan Rifkin. London School of Tropical Medicine, Keppal Street. London WC1N UK. sbrikinl@cs.com

3. Review of the development of training on CBR, as an initial step in synchronisation of training programmes

The participants of the conference identified a wide variety of training programmes in CBR, ranging from very formal Masters' and PhD programmes, to informal in-service training of a short duration. The knowledge of the different training programmes and the difference between the courses remains unclear. There is a need firstly, to gather information about the nature of the courses and then to synchronise them, so that individuals can progress from one to another in a hierarchical and productive fashion. There is also a need to promote the inclusion of courses on CBR, as part of other education programmes such as training for nurses, doctors and teachers and a need to establish training courses for other interested groups such as parents, government officials, donors etc. As a first step towards addressing these issues, it was agreed that Uganda would take the lead by documenting their training programmes and making proposals about synchronisation and future development. This information would be made available to other countries in Africa and a similar initiative would be encouraged.

The participants who agreed to lead this initiative were:

Mr. Edward Kisolo Kimuli. Director, UNISE. P.O. Box 6478. Kampala. Fax 256 041 222961 unise@swiftuganda.com

Moses Ddamulira. Disability Resource Officer, UNISE. P.O. Box 6478. Kampala. Fax 256 041 222961 drcunise@swiftuganda.com

4. Organisation of another conference on CBR in 2004, in Southern Africa (possibly Zimbabwe).

The participants saw another conference as a forum for sharing information across Africa, and for following up on the initiatives already agreed upon. They saw a need to have future conferences to provide the focus required for the action groups to be motivated to continue and to report back at the next conference. They felt that a theme should be identified by an organising committee that should be based in the host country, and would be in consultation with the CBR association of that country. It was agreed, that the next conference should be held in Zimbabwe, (with other offers from West Africa and Ethiopia) in 2004. The criteria for the choice of the country was that it should be reasonably secure, a lead person had been present at the Uganda conference, the country had experience of CBR and that it was in a different region of Africa other than Uganda. The organising committee would seek funding for the conference from donors.

The participants who were identified to lead this initiative were:

Servious Dube. Research Fellow, Institute of Child Health, 30, Guilford Street, London. WC1N 1EH. s.dube@ich.ucl.ac.uk

Obert Ndawi Paradzai. University of Zimbabwe, Department of Curriculum and Arts Education. Tel: 263 4 333407

Readers of this Chapter are very welcome to join any of these initiatives by contacting the people concerned.

The more people who participate, the better the outcome will be!

REFERENCES

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Acknowledgement

The contents of this book are based upon the conference that was hosted by the Uganda National Institute of Special Education (UNISE), between 10th and 14th, September, 2001. Warm thanks are due, to the Institute and its staff for making all the participants feel welcome and for looking after them so well during their stay. Acknowledgements are particularly due, to the catering staff who tirelessly provided refreshments, so that deliberations could continue with energy and enthusiasm.

The conference and the publication of this book could not have taken place without the financial support of the Norwegian Association of the Disabled (NAD), (Norway) and the CP Charitable Trust (UK), who provided the funds to sponsor the conference, publish and distribute this book. This contribution is gratefully recognised and appreciated.

Invaluable support was also given by staff from the Centre for International Child Health (CICH), Institute of Child Health (ICH) University College London, UK, as well as the Central Ministries of Gender, Labour and Social Development, Education, Sports and Health, in Uganda. The organisations and NGOs involved in the Disability Movement in Uganda, were equally supportive.

The Conference took place on schedule and was well attended by representations from Denmark, Ethiopia, India, Kenya, Liberia, Namibia, Senegal, Sierra Leone, South Africa, Tanzania/Zanzibar, a substantial number from Uganda as host country, the United Kingdom, Zambia and Zimbabwe. There were a total of 140 participants, including the presenters, and the ideas and rich experiences shared through their participation, are presented in this book.

The Conference also benefited from guest speakers in the persons of the Minister of Gender, Labour and Social Development, the Honourable Zoe Bakoko Bakoru (Mrs), at the official opening; Minister of State for Disability and Elderly Affairs, the Honourable Florence Nayiga Sekabira

(Mrs.), at the official dinner and the Minister of Health, the Honourable Brig. Jim Muhwezi at the official closing, represented by Dr. Dawson B. Mbulamberi from the Ministry of Health.

The conference was masterminded and organised by a Steering Committee, listed below, chaired by the Director of UNISE, Mr. Edward Kisolo Kimuli. Particular thanks are due, to the considerable efforts of the Co-ordinator, Mr. Stephen B. Maloba, whose organisational skills were ably demonstrated when, at the final hour he was called away to a family crisis, yet all the arrangements were in place for the conference and all went smoothly during his absence, a true measure of exceptional organisational skill. Great appreciation is also due to Mr. Charles Brewer, a representative from the CP Charitable Trust, who performed the role of conference recorder. Without his organisational skills and diligent collection of the presentations and discussions, the publication of this book would not have been able to capture the rich experiences shared by all.

Acknowledgement and thanks are also due, to Dr. Maya Thomas, for agreeing to publish and distribute the text to a wide network of people involved in disability-related work worldwide, and to her colleague Mrs. Nina Agtey, who has undertaken the desk editorship of the book. Thanks are also due to Chris Serwaniko from the Publications Department of UNISE, for the cover design of the book, to the Medical Illustrations Department of The Institute of Child Health, London, for the maps and other illustrations in the book and to Dee Grant, Research Assistant, ICH, for her assistance with the final editing.

CONFERENCE ORGANISING COMMITTEE

Mr. Edward Kasolo Kimuli	Director UNISE/Chairman
Ms. Mary Stella Atim	Institute Secretary
Mr. Stephen B. Maloba	Conference Co-ordinator
Dr. Sally Hartley	University College London
Mr. Samuel Masiga	Ministry of Gender, Labour and Social Development

Mr. Philip Wabulya	Makerere University
Dr. Alice Nganwa	Ministry of Health
Mrs. Margaret Kabango	Ministry of Health
Mr. Lawrence Eron	UNISE
Mr. Patric Ojirot	Media
Mrs. Solome N. Kimbugwe	Uganda Society For Disabled Children (USDC)
Mr. Basil Kandyomunda	USDC
Ms. Eseza Mirember	Ministry of Education and Sports
Mr. Negris Onen	Ministry of Education and Sports
Ms. Phoebe Katende	German Leprosy Relief Agency (GLRA)
Mrs. Barbra Batesaki	COMBRA
Mr. Fredrick Bwire	Action and Development on Disability (ADD)
Mr. Jackson Mirembe	UNISE
Mr. Paul Vincent Ojwang	UNISE
Mr. Moses Ddamulira	Secretary – UNISE

Implementation and support team

Mrs. Margaret Kiryahika Kyembabazi	UNISE
Mr. Godfrey Olwol	UNISE
Ms. Christine K. Kazairwe	UNISE
Mr. Gabriel Nixon Okeny	UNISE
Mr. Richard Tebandeke	UNISE

Mrs. Betty Kasavubu	UNISE
Ms. Jane Masajjage	UNISE
Mr. Chris Serwaniko	UNISE
Mr. Shepherd Kyagaba	UNISE
Mrs. Esther Dibele	UNISE
Mr. Caleb Musimenta	UNISE
Mr. Dan Alenyo	UNISE
Mr. Peter Musibala	UNISE
Mr. Charles Ndawula	UNISE
Ms. Margaret Namutebi	UNISE
Ms. Jane Kisuule	UNISE
Mr. Stephen Mabonga	UNISE
Ms. Carol Acan	UNISE
Ms. Lydia Orishaba	UNISE
Ms. Sarah Nalunga	UNISE
Ms. Jane Nakyeyune	UNISE
Ms. Auma Jane	UNISE
Mr. John Ukurboth	UNISE
Mr. Charles Brewer	CP Trust. U.K.
Mr. Andrew Bwogi	UNISE
Mr. Servious Dube	University College London U.K.

ORGANISATIONS THAT PARTICIPATED IN THE CBR CONFERENCE

Ministries

1. Ministries of Gender, Labour and Social Development
2. Ministry of Education and Sports
3. Ministry of Health

NATIONAL ORGANISATIONS

1. National Union of Disabled Persons of Uganda (NUDIPU)
2. Uganda National Association of the Blind (UNAB)
3. Uganda Society for Disabled Children (USDC)
4. Uganda Deaf Blind Parents' Association (UDBPA)
5. Mulago Hospital

LOCAL COUNCILS OF

1. Lira
2. Pallisa
3. Sironko
4. Tororo
5. Bushenyi
6. Mukono

NON-GOVERNMENTAL ORGANISATIONS

1. Action on Disability and Development (ADD)
2. Christian Blinden Mission (CBM)
3. Community Based Rehabilitation Initiative NGO (CBRI)
4. Association for Spina bifida and Hydrocephalous Uganda (ASBAHU)
5. German Leprosy Relief Association (GLRA)
6. Community Based Rehabilitation Alliance (COMBRA)
7. Health Care Nsambya

UNIVERSITIES

1. Makerere University CBR, Makerere University Students' Guild
Makerere University Library. Uganda
2. University College London, U.K.
3. Nkumba University, Uganda

APPENDIX 1

List of Contributors

Shaya Asindua

Shaya is currently working for AMREF, Kenya, as a programme co-ordinator for coastal and eastern regions. She is in charge of their CBR programmes and works together with partners in health and community development towards establishing better lives for disabled people. She has led the field in developing and adapting the CBR concept into something that is meaningful, for people in Africa and she has shared her vision with workers in other African countries. She has a social background with a Masters degree in Social and Community development from Manchester University, UK.

Angela Balaba

Angela Balaba sustained a fracture of the spine in 1988, when she was a social science student at the University of Nairobi, in Kenya. She is a single mother of two. She works as a social worker /counsellor on a home-based HIV programme with St. Francis Hospital Nsambya, Kampala, Uganda.

Barbara Batesaki

Barbara is a Physiotherapist by profession. She works as a coordinator of CBR Programmes and a trainer with the Community Based Rehabilitation Alliance (COMBRA).

Olive Bwana

Olive is a civil servant in the Ministry of Finance, Planning and Economic Development, Treasury Department, in Uganda. She is the chairperson of Uganda Parents of Deaf/Blind Association and a pioneer in sensitising parents of children with multiple impairments.

Servious Dube

Servious has twenty-years experience of working in development, environmental health, and disability management within Government and non-government service delivery and research institutions in Zimbabwe. He has also worked in other African countries including Ethiopia and Kenya. His experience has included the following responsibilities:

- Advising boards on policies towards children’s programmes
- Planning and co-ordinating programmes
- Budgeting and management
- Supervising and training staff

Mekdes Gebretensay

Mekdes was born in 1957 and is married with two sons. She has a B.A. in Psychology and an M.A in Special Needs Education. She has worked with children who have been orphaned, abused or have an impairment for the past 18 years. This has involved providing community rehabilitation services, including training parents, carers and community groups, and carrying out research projects related to these activities. She has also worked with poor women on economic interventions. She is presently the disability co-ordinator for Save the Children (SCF), in Ethiopia.

Sally Hartley

Sally has extensive experience of working for and with people with disabilities in many different African countries. She has worked for NGOs, Governments and International organisations in management, teaching and research activities. She is presently a member of the disability teaching and research team in The Centre of International Child Health (CICH), the Institute of Child Health (ICH), London University, UK. She co-ordinates the ‘African Disability Research and Training Programme’, which supports the development of CBR training at UNISE, Kampala, Uganda.

Basil Kandyomunda

Basil is a Social Worker who has worked to improve the welfare of children in Uganda. He is presently a training officer for the Uganda Society for Disabled Children (USDC), where he is currently a member of the Executive Council.

Maria Kangere

Maria has worked with disabled people as a physiotherapist in Uganda, for over 20 years. She is a Founder Member and Executive Director of Community based Rehabilitation Alliance (COMBRA) which has spearheaded training of grass-root workers in Uganda. Maria has a special interest in working with children with cerebral palsy and their families. She is presently doing research into the evaluation of CBR programmes at The Institute of Child Health in London UK.

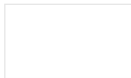
Joseph Kisanji

Joseph is an Education Consultant at the Centre for School Improvement and Educational Innovation in Dar es Salaam, Tanzania. He was formerly Director of the Tanzania Global Distance Learning Centre, a Lecturer/Senior Lecturer in Special Education at University of Manchester (UK) and Dar es Salaam (Tanzania), where his teaching duties included training in Community Based Rehabilitation (CBR). He managed the UNESCO Sub-regional Project for Special Education in Eastern and Southern Africa, which was based in Kenya, for six years. His research interests include inclusive education, culture and disability, indigenous education, community-based rehabilitation and the education of persons with hearing, visual and intellectual impairments.

Mohammed Kisubi

Olive Kyohere

Olive is deputy headmistress of Mengo Senior School in Uganda, an advanced level mixed Secondary School, where she teaches Biology and has been a teacher for 23 years. She is also wife to the Medical Director of Mengo Hospital, a Christian Missionary Hospital. They



have four children, the youngest is now aged 14 years. He developed hydrocephalus when he was about a year old, he is confined to a wheelchair. The challenges Olive faces as they try to give him a meaningful life and future, are what motivated Olive to research into the social integration of children with Hydrocephalus and Spina Bifida. This subsequently led Olive to attend the course at UNISE, where she was part of the pioneer group of the Post Graduate CBR programme in 1996.

Mitchell Loeb

Mitch is a Canadian Epidemiologist working in Norway in the area of health and rehabilitation. He has practical experience of applying the concepts of ICF in research and in Namibia.

Jackson Mirembe

Jack is a civil servant at the rank of Director for Gender and Community Development. He has made significant contributions to the development of Government CBR programmes in Uganda and CBR training programmes at the Uganda Institute of Special Education (UNISE). He is widely travelled and an experienced practitioner in the field of CBR.

Jane S. Mpagi

Jane is a civil servant at the rank of Director for Gender and Community Development in the Ministry of Gender, Labour and Social development in Uganda. She has contributed immensely in the field of Gender equity, welfare of vulnerable groups in policy development and implementation.

Herbert Muyinda

Herbert is a social scientist working in sociology and management and has been involved in research for over 10 years. He has particular interest in the field of disability because he has a disability himself. He has carried out a study on the rehabilitation of children with physical disabilities in Ugandan rural areas. Herbert is currently working with the Child Health and Development Centre, Makerere University. He is

coordinating the Nutrition and Early Childhood Development Project in Western Uganda. He is particularly interested in children and mothers with special needs.

Obert Ndawi

Obert Ndawi is a senior lecturer at the University of Zimbabwe, in the Faculty of Education, Department of Curriculum Development. His research interests are in special education. Dr O. Ndawi has written several books and published intensively in the field of special education. He like reading and traditional Zimbabwean and classic music.

Benon Ndaziboneye

Benon is currently the principal Programme Officer in Action and Development on Disability (ADD), in Uganda. He was formerly an active member of the National Union of Disabled Persons in Uganda (NUDIPU) and in this capacity, he has made a remarkable contribution in the area of co-ordinating organisations and programmes for disabled persons in Uganda.

Alice Nganwa

Alice is Principal Medical Officer in the Uganda Ministry of Health in the Department of Rehabilitation and Disability. She is a widely travelled person who has contributed immensely in Rehabilitation and Primary Health Programmes in the Africa Region.

Vincent Paul Ojwang

Paul is a full time Lecturer in Community-based Rehabilitation (CBR) at the Uganda National Institute of Special Education (UNISE). He has participated in several research programmes in CBR in collaboration with the Uganda National commission for UNESCO and the University of London.

Susan Reynolds-Whyte

Susan is a professor at the Institute of Anthropology, University of Copenhagen. She has been doing field work in Uganda, at intervals

since 1969 and leads a programme to strengthen research capacity in the field of health. Together with Benedicte Ingstad, she edited 'Disability and Culture' (University of California Press 1995). They are currently working on a new volume entitled 'Disability in Local and Global Worlds' to which she and Herbert Muyinda will contribute a chapter based on the study they are doing, of the tri-cyclists in Busia

Susan Rifkin

Susan B. Rifkin has held academic appointments at a number of European Universities, including the London School of Hygiene and Tropical Medicine and the London School of Economics. She has helped to establish a network of community based health programmes in Asia and Masters degree courses at the University of Heidelberg in Germany and the Tropical Institute of Community Health and Development in Kisumu, Kenya.

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Marjie's original training is in the field of Speech and Language Therapy and Audiology. She has been involved in CBR training in South Africa and also in the CBR movement. Presently she is involved in research into disability and is working on the new International Classification of Functioning for WHO in Geneva.

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Peace is Vice President, Uganda National Action on Physical Disability (UNAPD) and a woman activist. She holds a degree in nutrition.

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Maya is a policy advisor and training manager in disability rehabilitation. Her work in south east Asia and Africa includes the training of organizations in systems of management, policy planning, strategy development in disability rehabilitation and evaluation of disability programmes. She is Editor of the Asia Pacific Disability Rehabilitation Journal and an Honorary Research Fellow at the Centre for International

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M.J. Thomas is a psychiatrist by profession and has two decades of experience in training medical graduates. He is also a member of the governing boards of organizations involved in health and welfare services. He is now the senior consultant psychiatrist at Manipal Hospital and Mallya Hospital, Bangalore, India and is involved in training different levels of medical graduates. The other part of his professional work includes policy analysis and planning for development organisations involved in disability rehabilitation and health.

Aisha Yousafzai

Group Discussion Questions Generated by the Conference Organising Team

During the conference, time was set aside for group discussions based on the on-going presentations. These discussions were guided by different sets of questions. At the conference, the views and ideas expressed in these sessions were shared with all the participants at a plenary session at the end of the day. These ideas have, to a large extent, been incorporated into the main text of the relevant chapters presented in this book.

The discussion questions used to stimulate these ideas, are reproduced below and can be used by readers with their own discussion groups, to examine problems and generate possible solutions relevant to their particular setting. The questions can be used with groups of students, of parents, of government officials etc. They can be used section-by-section, or selected one-by-one from different sections, as the users wish. They could also be used as a basis for developing a fuller set of questions about any of the areas they cover. They could be used for a series of discussion, over a period of time and the outcome or product of these discussions could be published for wider circulation. They could be used to address service issues, rights issues, research issues as well as focussing on participation in CBR and how this can be achieved. We hope that our readers will find them useful.

Group work questions for considering ‘What is CBR?’

1. What is the definition of CBR in the African context?
2. What experience do you have, in the implementation of successful CBR strategies?
3. What challenges do CBR programmes face, in your country?
4. What are your possible responses, to face these challenges?

Group work questions for considering controversies in CBR

1. Should CBR be started as an external initiative?
2. Should CBR be started only when there is an expression of need, from the community?
3. Does a ‘social model’ address the ‘real’ rehabilitation needs of people with disabilities?
4. Is CBR expensive, if so, for whom?
5. Is CBR the answer for all disabled people, or only a selected few?
6. Can volunteers in CBR, ‘afford’ to volunteer?

Group work questions for considering ‘participation’ as a CBR strategy

1. What is the definition of participation in the CBR context?
2. What experiences do you have, in promoting participation in your CBR programmes?
3. What strategies have you used to promote participation?
4. What strategies have been successful (unsuccessful) and why?
5. What can African countries do, to promote more successful levels of participation?

Group work questions to consider professionals’ role in CBR

1. What strategies can professionals use, in the development of CBR programmes?

2. What barriers do they face, in introducing CBR strategies?
3. What professional roles promote participation of PWDs in CBR programmes?
4. What can professionals do, to promote government's participation in the implementation of CBR programmes?
5. What can professionals do to promote participatory strategies that include PWDs?
6. What can professionals do, to encourage NGO's participation in CBR programmes?
7. What can professional's do, to promote participation of parents and communities in the implementation of CBR programmes?
8. What can professionals do, to promote donors' participation in the implementation of CBR programmes?
9. What challenges do professionals face, in playing their roles?

Group work questions for considering Government's role in CBR

1. What strategies can governments use in the development of CBR programmes?
2. How does your Government promote human rights?
3. How is your Government promoting participation in CBR?
4. What barriers do they face, in introducing CBR strategies?
5. What can your government do, to promote professionals' participation in the implementation of CBR programmes?
6. What can your government do, to promote the participation of PWDs in CBR programmes?
7. What can your government do, to facilitate NGOs' participation in CBR programmes?
8. What can your government do, to promote the participation of parents and communities in the development of CBR programmes?

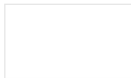
9. What can your government do to promote donors participation in CBR programmes?

Group work questions for considering the role of PWDs in CBR

1. What strategies can PWDs use, in the development of CBR programmes?
2. What barriers hinder them from introducing these strategies?
3. How can these barriers be overcome?
4. What can PWDs do, to promote government participation in the implementation of CBR programmes?
5. What can PWDs do, to facilitate NGO involvement in CBR programmes?
6. What can PWDs do, to promote the participation of parents and communities, in CBR programmes?
7. What can PWDs do, to encourage donors to fund CBR programmes?
8. What can PWDs do, to encourage professionals to participate more, in the development of CBR programmes?

Group work questions for considering the role of parents and community members in the promotion of CBR

1. What strategies can parents and community members use, to encourage government participation in CBR development?
2. What barriers are there, in introducing CBR strategies to parents' groups?
3. What barriers are there, for introducing CBR strategies into the community?
4. What can parents do, to promote professionals' participation in the implementation of CBR programmes?
5. What can community members do, to help parents participate in CBR programmes?

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6. What can parents do, to encourage government participation in CBR programmes?
 7. What can parents do, to promote NGO and donor involvement in CBR programmes?
 8. What can parents do, to involve the communities in the development of CBR programmes?

Group work questions considering the role of donors in CBR

1. What strategies can donors use, in the development of CBR programmes?
2. What barriers exist for donors, in introducing and developing CBR programmes?
3. How can donors make sure, that they are supporting effective CBR programmes?
4. What can donors do, to promote professionals' participation in CBR programmes?
5. What can donors do, to encourage NGO participation in CBR programmes?
6. What can donors do, to promote parents' and communities' participation in CBR programmes?
7. How can donors interrelate with governments, so that the CBR programmes develop in a participatory way?

Group work questions considering the role of NGOs in CBR

1. What strategies can NGO's use, in the development of CBR programmes?
2. What barriers do they face, in introducing CBR strategies?
3. What NGOs' roles, promote participation of PWDs in CBR? How can these be strengthened?
4. What can NGOs do, to strengthen government participation in CBR?

5. What can NGOs do, to strengthen participation of PWDs in CBR programmes?
6. What can NGOs do, to strengthen participation of parents and communities in CBR programmes?
7. What can NGOs do, to promote the professional involvement in CBR?

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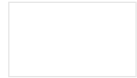
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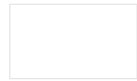
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DD	Action on Disability and Development
CBR	Community Based Rehabilitation
CBR	Community Based Rehabilitation Alliance
CBRN	Community Based Rehabilitation National
CDA	Community Development Assistant
CWD	Children With Disabilities
DANIDA	Danish Aid Agency
DPAR	Disability Prevention and Rehabilitation Section
DPO	Disabled Peoples' Organisations
DSI	Danish Council of Organisations of Disabled Persons
ITEK	Institute of Teacher Education Khombogo
MOH	Ministry Of Health
NACWOLA	National Community of Women Living With HIV/ AIDS in Uganda
NAD	Norwegian Association of the Disabled
NGO	Non-Government Organisation
NUDIPU	National Union of Disabled Persons of Uganda
NUWODU	National Union of Women with Disabilities of Uganda
PWD	People with Disabilities
RAISA	Regional Initiative in Southern Africa
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections
SWAA	Society of Women and AIDS in Africa
UN	United Nations
UNAB	Uganda National Association for the Blind
USDC	Uganda Society for Disabled Children
VSO	Voluntary Services Overseas
WWD	Women With Disabilities

APPENDIX 5

Useful Manuals for CBR Programmes

BAILEY, Donna (Eds)

Child-to-Child : a resource book. Part 1. Implementing the child-to-child approach. Part 2 Child-to-Child activity sheets

2nd ed.

London : Child-to-Child Trust, 1994, 80 p + 168 p.

Location: HY3 BAI

Healthlink record number: 20848

BOEIJEN, Annemiek van (et al)

Tricycle production manual

Delft : Delft University of Technology, Feb 96, 212 p ill.

Location: HQ3.597 BOE

Healthlink record number: 26966

Child-to-Child

I can do it too

(Child-to-Child Readers - level 2.)

Essex : Longman Group UK Ltd, 1989, 48 p.

Location: HQ1.4 WAL

Healthlink record number: A888

CRAIG, Ursula

The ageing process

London : HelpAge International, 1992, [loose].

Location: HB8 CRA

Healthlink record number: 15132

DILLI, David

Handbook : accessibility and tool adaptations for disabled workers in post-conflict and developing countries

Geneva : ILO, 1997, 46 p.
Location: HQ3.59 DIL
Healthlink record number: A1179

DISABILITY AWARENESS IN ACTION (DAA)

Disability awareness in action : disabled women
(Disability Awareness in Action Resource Kit No 6.)
London : DAA, 1997, 32 p.
Location: FC/ HQ1 DIS
Healthlink record number: 27036

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Disability Awareness in Action : who and what we are. Media information
(Resource Kit No 1.)
London : DAA, 1992, 40 p ill.
Location: HQ1.4 FLE
Healthlink record number: 24381
This resource kit has six volumes that can be ordered

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Disability Awareness in Action : organisation building
(Disability Awareness in Action Resource Kit No. 4.)
London : DAA, 1994, 67 p.
Location: FC/ HQ1 FLE
Healthlink record number: 27020

GIBBS, Sara, MANN Gillian, and MATHERS, Nicola

Child-to-Child : a practical guide. Empowering children as active citizens
London : Child-to-Child, May 2002, 63 p ill.
Location: HY3 GIB <http://www.child-to-child.org/guide>
Healthlink record number: 31031

HOUSE, Helen and MORRIS, Jenny

Let's communicate : a handbook for people working with children with communication difficulties

Geneva : Rehabilitation Unit, WHO : and : New York : UNICEF : and : Harare : Ministry of Health, Zimbabwe, 1997, [503 p].

Location: HQ3.29 HOU

Healthlink record number: 245

International Labour Office and Rehabilitation Staff Training and Research Programme for Africa

Visiting speakers/panel of speakers

(Course Leader's Guide : Component 10.)

Harare : International Labour Organization (ILO), 1993, 5 p.

Location: HQ1.4 INT

Healthlink record number: A637

This resource kit contains 10 volumes, these can be ordered

INTERNATIONAL LABOUR ORGANISATION (ILO)

Code of practice on managing disability in the workplace

(Tripartite Meeting of Experts on the Management of Disability at the Workplace, Geneva, October 2001.)

Geneva : ILO, 2001, 28 p.

Location: HQ5.8 INT <http://www.ilo.org/public/english/standards/relm/gb/docs/gb282/pdf/tmemdw-2.pdf>

Healthlink record number: 31065

LEVITT, Sophie

We can play and move: a manual to help disabled children learn to move by playing with others

London : AHRTAG [now named Healthlink Worldwide], 1987, 56 p.

Location: HQ6.1 LEV FLM/BUL/HQ6.1 LEV

Healthlink record number: A426

Maczka, Kathy and Darnbrough, Ann and Birkitt, Deborah

Simple aids for daily living

London : AHRTAG, 1987, 73 p.

Location: HQ3.59 MAC

Healthlink record number: A465

PUNANI, Bhushan and RAWAL, Nandini

Visual impairment handbook

2nd ed

Ahmedabad : Blind People's Association, 2000, 479 p.

Location: HQ3.3 PUN

Healthlink record number: 26536

SHIA

Starting Communication with Deafblind Children

Kenja, FSDP/SHIA, 1998,

Location: HQ3.7 Shi

Healthlink record number: 31112

WERNER, David and BOWER, Bill

Helping health workers learn : a book of methods, aids and ideas for instructors at the village level

Palo Alto : Hesperian foundation, 1973, various ill.

Location: HX1.2 WER

Healthlink record number: 01591

WERNER, David

Disabled village children: a guide for community health workers, rehabilitation workers and families

Palo Alto : Hesperian Foundation, 1987, 672 p.

Location: HQ6.1 WER

Healthlink record number: 01575

WERNER, David

Nothing about us without us

Palo Alto : Health Wrights, 1998, 360 p.

Location: HQ5 WER

Healthlink record number: 20620

WIMAN, Ronald

The disability dimension in development action : manual on inclusive planning

Finland : UN, 1996, 180 p.
 Location: HQ WIM
 Healthlink record number: 21521

World Health Organisation and World Confederation for Physical Therapy and World Confederation of Occupational Therapist

Promoting the development of young children with cerebral palsy

Geneva : WHO, 1993, 80 p.

Location: HQ3.53 WOR

Healthlink record number: A458

World Health Organisation (WHO)

The education of mid-level rehabilitation workers : recommendations from country experiences

Geneva : WHO, 1992, 60 p.

Location: HQ5.18 WOR

Healthlink record number: I205

World Health Organisation (WHO)

The education of mid-level rehabilitation workers

Geneva : WHO, 1992, 60 p.

Location: HQ5.18 WOR

Healthlink record number: A467

World Health Organisation (WHO)

Promoting the development of infants and young children with spina bifida and hydrocephalus : a guide for mid-level rehabilitation workers

Geneva : WHO, 1996, 72 p ill.

Location: HQ3.59 WOR

Healthlink record number: 20518

World Health Organization (WHO)

Promoting the development of young children with cerebral palsy : a guide for mid-level rehabilitation workers

Geneva : World Health Organization, 1993, 80 p.

Location: FC/ HQ3.53 WOR

Healthlink record number: 28106

APPENDIX 6

Useful Websites on Disability from SOURCE

Compiled by Kerstin Schaefer

MULTILATERAL

United Nations Educational, Scientific and Cultural Organisations (UNESCO) <http://www.unesco.org/education/educprog/sne>

Keywords: Legislation/Policy/ Inclusive Education/ Vulnerable Groups/

United Nations Special Rapporteur of the Commission for Social Development on Disability

United Nations

<http://www.un.org/esa/socdev/enable>

Keywords: Disability & rehabilitation/ Disability in Society/ Policy/ Human Rights/ Legislation/ Definitions/ Models

E-Mail: un-spec.rapp@telia.com

Keywords: Disability in Society/Legislation/ Awareness raising/ Advocacy/ Human rights

UNICEF

<http://www.unicef.org>





World Health Organisation (WHO)

<http://www.who.int/hpr/rhb/index.html>

Keywords: Health/ Disability and Rehabilitation/ impairment and intervention

NGOS

Action on Disability and Development

<http://www.add.org.uk>

Keywords: Disability in Society/ Organisations for and of Disabled People/Human Rights/ Advocacy/Awareness Raising

This NGO focuses on the social model of disability

BOND

<http://www.bond.org.uk>

Keywords: development/ non-governmental organisations/ vulnerable groups

British overseas NGO for development combines a number of non-governmental organisations working in the development field.

Christoffel Blinden Mission (CBM)

<http://www.christoffel-blindenmission.de>

Keywords: Organisations for disabled people/ Disability in Society/ Human rights/ Advocacy/ Awareness raising/ Legislation

An organisation that originally focused on the work with blind people but now working in other fields as well.

Handicap International

<http://www.handicap-international.org>

Keywords: Disability and Rehabilitation/ Disability in society/ Landmines/ Organisation for disabled people/ Vulnerable groups/ Awareness raising/ Advocacy/ Impairments and Interventions/ An organisation that won the Peace Nobel Price in 1997


Healthlink Worldwide

<http://www.healthlink.org.uk>

Keywords: Disability and Rehabilitation/ Disability in Society/ Awareness raising

An organisation that publishes literature on various development aspects includes disability and development.

International Disability and Development Consortium

<http://www.iddc.org.uk>

Keywords: Disability in Society/ Awareness raising/ Advocacy/ Organisation of disabled people/ Organisation for disabled people

IDDC is an International Consortium that promotes the inclusion of disability into mainstream society.

Japanese Society for Rehabilitation of Persons with Disabilities

<http://www.jsrd.or.jp/index-e.html>

Keywords: Disability & Rehabilitation/ Disability in Society/ Legislation/ Participation/ Healthcare/ Education/ Employment/ Accessibility

Leonard Cheshire International

<http://www.leonardcheshire.org>

Keywords: Disability and Rehabilitation/ Organisation for Disabled People/ Health care/ Impairment and Intervention/ Education/ Employment

Leonard Cheshire International operates in the UK and overseas.

Oxfam

<http://www.oxfam.org.uk>

Keywords: Vulnerable groups/ Healthcare/ Education/ Employment



Save the Children

<http://www.savethechildren.org>

Keywords: Vulnerable groups/ Disability in Society/ children

Save the Children is an organisation that promotes the rights of children world-wide. There are various publications available from this site.

DPOS

Danish Council of Organisation of Disabled people

<http://www.disabiliyt.dk>

Keywords: Disability in Society/ Human rights/ Organisation of disabled people/ Advocacy/Awareness Raising/ Legislation

An excellent site offering country related documents on organisations, donor agencies and worldwide relevant websites.

Disabled Peoples International

<http://www.dpi.org>

Keywords: Disability in society/ human rights/ Organisations of disabled people/ Advocacy/ Awareness raising/ Legislation

This site is associated with the disability rights movement.

Disabled People's Association Singapore

<http://www.dpa.org>

Keywords: Disability in society/Advocacy/Organisation of disabled People

EDF (European Disability Forum)

<http://www.edf-feph.org/en/welcome.htm>

Keywords: Disability in society/ Organisation of Disabled People/ human rights/ Awareness raising/ Advocacy/

EDF is a European umbrella organisation representing more than 37 million disabled people in Europe.

Institute of Independent Living

<http://www.independentliving.org>

Keywords: Disability in Society/ Organisations of disabled people/
Human rights/ Legislation/ Vulnerable groups/ Socio-economic factors

National Council on Disability

<http://www.ncd.gov>

Keywords: Disability in Society/ Organisation of Disabled People/
Legislation/ Awareness raising/ Human rights/ Advocacy

SHIA

<http://www.shia.se/englishshia.htm>

Keywords: Disability in Society/ Organisation of disabled people/
Human rights/ Advocacy/ Awareness Raising/

SHIA is a non-governmental organisation of disabled people and is actively involved in development co-operation.

World Institute on Disability (WID)

<http://www.wid.org>

Keywords: Disability in Society/ Advocacy/ Policies/ Education/
Independent living

The World Institute on Disability (WID) is an internationally recognised public policy centre organised by and for people with disabilities.

PUBLICATIONS

Ability Network

<http://www.abilityns.ca>

Ability Network Canada's cross disability magazine

Asia Pacific Disability Rehabilitation Journal

<http://www.aifo.it/english/apdrj/apdrj.htm>

An excellent journal on disability issues in the Asian Pacific Region

publishing articles reflecting on the changes in community based rehabilitation through the last few decades.

BBC News/Disability

http://www.news.bbc.co.uk/hi/english/health/newsid_502000/502155.stm

BBC News Online looks at some of the issues connected to disabled access to health, social services and education.

Choice

<http://www.choike.org>

“Choike” is a portal made from a Southern perspective, intended to help users with a specific interest in the issues of particular concern for developing countries.

Disability Information for Students and Professionals

<http://www.abilityinfo.com>

This site offers about 200 links and points to books and journals about disability issues.

Disability Now

<http://www.disabilitynow.org.uk>

UK based newspaper about disability.

Hesperian Foundation

<http://www.hesperian.org>

The Hesperian Foundation is a non-profit publisher of books and educational materials. The training manuals are written for people with little formal education. The books can not be ordered from the website but the site has a free printed order form.

International Disability News Ticker

<http://www.abilityinfo.com/ticker.html>

A newsletter covering International Disability Issues and inviting “disability discussions”.


Norwegian Policy

<http://www.usaid.gov/about/disability/DISABPOL.FIN.html>

Norwegian Policy on inclusion. Also look at:

<http://www.norad.no/norsk/files/incluionofDisability.doc>

South African Health Knowledge Network

<http://www.sahealthinfo.org>

Keywords: Vulnerable groups/ Disability and Rehabilitation/ Disability in Society

Papers and documents**CHILDREN****Bernard Van Leer Organisation**

<http://www.bernardvanleer.org>

Programmes and information relating to early childhood, including publications on child development.

CRIN

<http://www.crin.org/crc/nattop.htm>

Organisation focusing on child's rights, the Convention on the Rights of the Child is available from this site.

Consultative Group on early childhood care and development

<http://www.ecdgroup.com>

Useful information and contacts relating to programming of children aged 0-8 years.

International Society on early Intervention

<http://www.weber.u.washington.edu/~isei/>

An organisation that provides a framework and forum for professionals from around the world to communicate about advances in the field of early intervention There is a large focus on children with disabilities.



Plan International

<http://www.plan-international.org>

Child focused development organisation working in projects relating to health, education, income generation and the environment.

Redda Barnen

<http://www.rb.se/engindex.htm>

Swedish Organisation dealing with issues relating to children in developing countries.

Save the Children USA

<http://www.savethechildren.org/index.html>

Organisation dealing with issues related to children in developing countries.

Save the children UK

<http://www.savethechildren.org>

Organisation dealing with issues related to children in developing countries.

World Vision

<http://www.wvision.org/>

Zero to Three

<http://www.zerotothree.org/index.html>

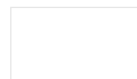
Information for parents and professionals about children aged 0-3 years.

EDUCATION

Eenet

<http://www.eenet.org.uk>

An excellent site focusing on inclusive education. This site is constantly updated and publications from the South are made available on the net.



Family Village Inclusion Resources

<http://www.familyvillage.wise.edu/education/inclusion.html>

USA site on inclusive education.

PERCEPTION

Care and feeding of the long white cane

<http://www.nfb.org/books/books1/canetc.htm>

A site that explains in detail how people with vision impairment should use the cane.

Royal National Institute of the Blind

<http://w.rnib.org.uk/ww>

A site with a lot of resources and publications on vision impairment.

Sight Savers International

<http://www.sightsavers.org.uk/>

An organisation working overseas focusing on vision impairment and the prevention of vision impairment.

WHO

<http://www.who.int/pbd/>

A site presented by the World Health Organisation on vision and hearing impairment and its prevention (English and French).

World Blind Union

<http://www.wbuga.org/>

An organisation that works on blindness prevention; teaching literacy through Braille; enhancement of the status of blind women, ageing and blindness; access to new technology; human rights; vocational rehabilitation; the particular needs of people who are Deaf and blind; the establishment of self-help organisations of blind people in developing countries.

REHABILITATION

Centre for International Rehabilitation Research Information and Exchange

<http://www.cirrie.buffalo.edu/>

A database of International Rehabilitation Research is available from this site and a list of journals that are indexed and available.

Fru: The Association of Rehabilitation in Developing countries

<http://hem.fyristorg.com/fru/tvaaneng.htm>

A site that focuses on rehabilitation in developing countries, it includes a section on CBR.

Rehabilitation International

<http://www.rehab-international.org/>

An excellent site with a number of publications that are focusing on rehabilitation. but include a human rights aspect

LEARNING DISABILITY

Autism Resources

<http://www.autism-resources.com/>

A website that gives guidance about autism and presents publications that are available.

Disability Now

http://www.disabilitynow.org.uk/search/24_learn.htm

A site that focuses on learning impairment such as Autism, Brain Damage, Down's Syndrome, Dyslexia and Learning difficulties.

Inclusion International

<http://www.inclusion-international.org/>

This website promotes inclusion concerning all disability groups. It is translated into English, Spanish, French and German.

MIUSA (learning disabilities)

<http://www.miusa.org/general/publications/learningdisabilty2.html>

This website points to a number of organisations that are referring to learning disabilities.

National Center for learning disabilities

<http://www.nclld.org/>

This center offers information, resources and referral services.

The Forest Bookshop

<http://www.forestbooks.com/system/index.html>

A publisher that offers books on learning impairment and hearing impairment.

The International Dyslexia Association

<http://www.interdys.org/index.jsp>

An association that provides a forum for parents, educators and researchers to share their experiences, methods and knowledge.

Hearing Impairment

Eenet

<http://www.eenet.org.uk/deaf/initiat/interps.shtml>

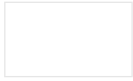
Initiatives for deaf Education in the third world

Services for hearing impaired people in rural settings

The deaf Resource Library

<http://www.deaflibrary.org>

The Deaf Resource Library is a virtual library — an online collection of reference material and links intended to educate and inform people about Deaf cultures in Japan and the United States; as well as deaf and hard of hearing related topics.



World Federation of the Deaf

<http://www.wfdnews.org>

A site that offers publications and latest news and resources on hearing impairment, a discussion forum is available from this site and various links are made to regional and international organisations dealing with hearing impairment.



CBR

A PARTICIPATORY STRATEGY IN AFRICA

Editor
Sally Hartley

Published by:
The Centre for International Child Health, London

CBR

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Uganda, September 2001**

**Editor
Sally Hartley**

**The Centre for International Child Health
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The Role of Local NGOs in Promoting Participation in CBR

*Basil Kandyomunda, Servious Dube,
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Role of Donor Agencies in Promoting Participation in CBR

Mohammed Kisubi

Collecting Disability Statistics: A Participatory Strategy?

*Marguerite Schneider, Mitchell Loeb,
Jackson Mirembe, Shaya Asindua,
Servious Dube, Sally Hartley*

HIV/AIDS and Community Based Rehabilitation (CBR)

*Alice Baingana Nganwa, Barbara Batesaki
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Future Participation and Sustainability of CBR: The Way Forward

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Acknowledgement

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the Conference Organising Team

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Appendix 6 : Useful Websites on Disability from SOURCE

FOREWORD

FROM THE GOVERNMENT OF UGANDA

It was indeed a special honour and privilege for Uganda that Uganda National Institute of Special Education (UNISE), Kampala, was chosen as the venue for the 1st Africa Regional Conference on CBR, held from September 10th – 14th, 2001. Its general theme ‘A Participatory Strategy for Africa’ merged perfectly with the theme of the new millennium ‘Full Participation and Equality’.

As the host country, we tried to establish and encourage contacts between persons with disabilities (PWDs) and able-bodied people working for rehabilitation and inclusion in the medical, technical, educational and social fields. Thus, an extensive and varied programme was developed comprising keynote presentations, group work, and plenary sessions. In addition, a mini workshop on HIV/AIDs and CBR was organised by the Ministry of Health.

We believe that this Conference has succeeded in bringing people of various nations, closer to each other, thus creating a basis for further talks and meetings. Furthermore, the Conference has succeeded in making the able-bodied persons better aware of the problems of persons with disabilities, and, last not least, it has given PWDs an opportunity to express their views themselves. The ideas expressed, are all presented within the pages of this publication.

I am happy and delighted that the conference touched my heart as a politician and a spokesperson of PWDs in Uganda. Firstly, that disability remains a human rights issue. So long as persons with disabilities are denied the opportunity to participate fully in society, no one can claim that the objectives of the Conference have been achieved.

Secondly, that it is the responsibility of governments to ensure full participation and the end of discrimination against their disabled citizens. There will be no framework for change until the legislators put it in

place. A major point of pressure in the new millennium will be to ensure that actions on behalf of PWDs, are within the mainstream of social, cultural and economic measures and not set apart as something ‘done for’ persons with disabilities.

Thirdly, that economic difficulties and recessions should not be used as an excuse for delaying actions. As a politician, I know that decisions will be made only on visible and tangible problems. People should not be hesitant about approaching their elected representatives as well as their governments and bombarding them with strong arguments for progress.

If whatever was discussed and concluded, is implemented in time, the words at the end of this book will have a practical meaning.

Let me conclude with the words of wisdom by Nelson Mandela: ‘Those who deny others their freedom are not themselves free. They are locked behind the bars of prejudice’.

Florence Nayiga Sekabira (MP)
Minister of State For Disability And Elderly Affairs
Government of Uganda

FOREWORD

FROM NORWEGIAN ASSOCIATION OF THE DISABLED

After more than two decades of Community Based Rehabilitation, it is realised that the concept and the practices worldwide have been subject to constant changes. On one hand, this has resulted in a wide range of perceptions and interpretations of what CBR is. On the other, it has resulted in considerable accumulation of experience and knowledge. It is felt that both these aspects necessitate bringing together key stakeholder in the field of CBR in order to utilise the immense learning potential that lies in a systematic sharing of experiences and knowledge. On this background an initiative was taken by the ICH-London and a group of African stakeholders to arrange an African Regional Conference on Community Based Rehabilitation. The conference was held in Uganda in September 2001.

As a major donor behind the conference, we were pleased to see the very high level of participation from all stakeholder groups at the conference, and the intense participation of the persons with disabilities and parent groups throughout the process.

The report in front of you is one tangible result of the discussions held at the regional conference. It contains experiences and reflections of key stakeholders within CBR from 14 countries, and will hopefully both contribute to a more mutual and holistic understanding of the CBR concept and bring about development of new initiatives. At the same time, it is hoped to stimulate creativity and diversity enough to ensure a flexible approach with ability to meet specific needs of persons with disabilities.

For NAD, the report represents an important documentation of a strategic area that has had our main attention for more than 10 years. Nevertheless, this report should not merely be seen as a way of capturing the essence of the deliberations that took place at the

conference, but can hopefully serve as a guide to those engaged in community based rehabilitation as well as to those engaged in community development internationally, making them consider and include persons with disabilities in their planning and implementation.

Lars Ødegård
Secretary General
Norwegian Association of the Disabled

FOREWORD

FROM ICH, U.K.

It is a great pleasure to be invited to write the Foreword to this publication. I have read the manuscript with great interest and congratulate the contributors for the collection of chapters, which draw upon different experiences of CBR.

The scene is set in the opening chapter, written by Maya and MJ Thomas, whose contribution to developing thoughtful scrutiny of CBR is known to all who read the Asia Pacific Disability Rehabilitation Journal, which they edit. The majority of contributions are from Uganda with contributions from South Africa, Kenya, Zimbabwe, Ethiopia and Europe and includes chapters written by managers of CBR programmes, by parents and by researchers.

Paul Ojwang writes a careful account of the history of CBR in Uganda and the way in which training in CBR has developed in this country, and staff from the Centre of International Child Health are proud to have been associated with these ventures. The chapter by Mpagi and that by Kandyomunda, Dube, Kangere and Tensay explore the important issue of the role of NGOs and government services in the development of CBR programmes in Uganda and other African countries. A careful chapter by Reynolds and Muyinda describes an ethnographic study of the economic role, as bicycle taxi drivers, of a group of people with disabilities in Busia. This chapter and one by Schneider and colleagues remind us all of the importance of collecting careful accurate records to support the further development of CBR. Alice Nganwa and colleagues explore the important, under-researched and under-served issue of HIV/AIDs and disability.

Together, this volume provides an important contribution to understanding how CBR operates in Africa as we enter the new millennium and points ways forward for the future. The proceedings of an earlier conference in Zimbabwe was one of the few sources of published information about CBR in Africa and this publication provides a much needed update. It is to be hoped that further conferences of this kind will form the basis of future publications which will be equally thought provoking.

Sheila L. Wirz

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University College London