

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 Acknowledgements. 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.2. 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, Turmusani 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 reinforce 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 properly TO ACHIEVE OUR AIM of including PWDs and their families and maximising their quality of life.

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.uk). 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.

Dr. Sally Hartley

Institute of Child Health
Centre for International Child Health
University College London

REFERENCES

STACEY, R. (1992). *Managing chaos*. Kogan Page Limited, London.

TURMUSANI, M. VREEDE, A. & WIRZ, S. (2002). *Some ethical issues in community based rehabilitation initiative in developing countries*. Disability and Rehabilitation Vol. 24, No 10, 558 - 564.

- VANNESTE, G. (2000). *Current status of CBR in Africa. A review*. Selected Readings in Community-based Rehabilitation Series 1. CBR in Transition Asia Pacific Disability Rehabilitation Journal, Bangalore, India.
- WHO (2001). *International Classifications of Functioning Disability and Health (ICF)* World Health Organization. Geneva. <http://www3.who.int/icf/icftemplate.cfm>
- WHO, ILO, UNESCO (1994). *Joint position paper on Community-based Rehabilitation for and with people with disabilities*. Geneva