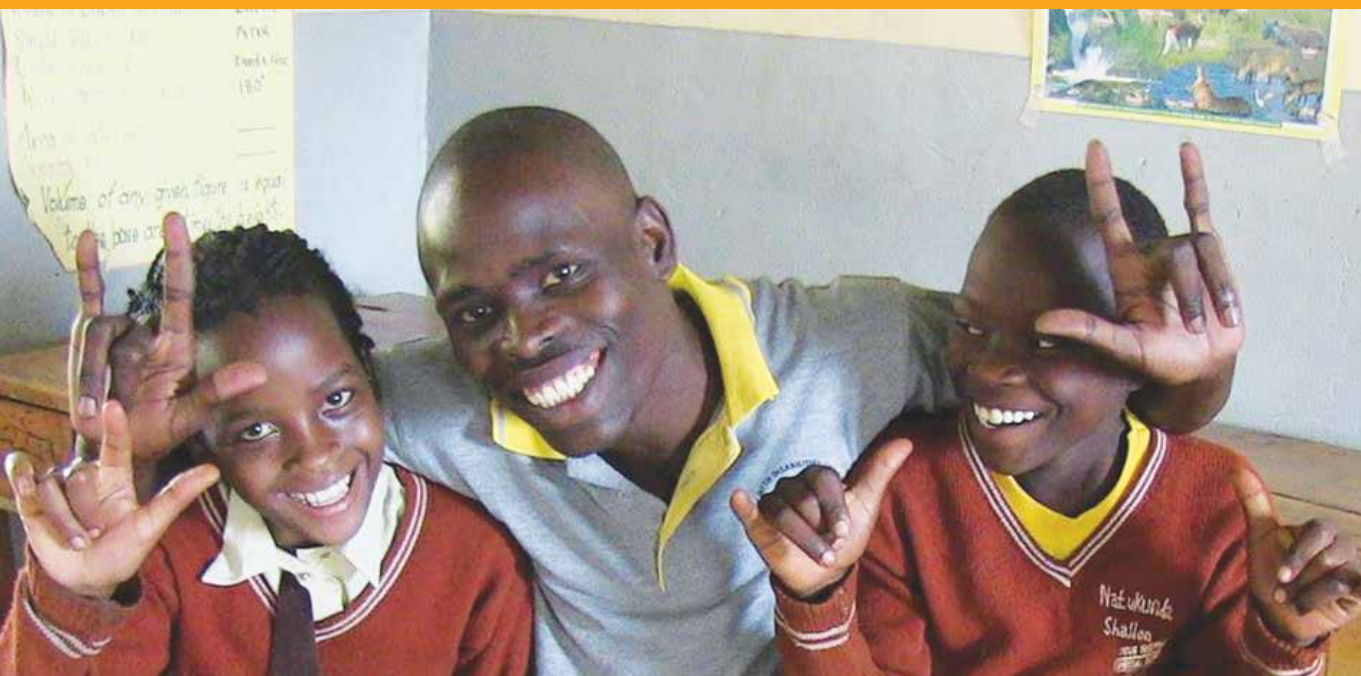


LINKING CBR, DISABILITY AND REHABILITATION



Editors

Grace Musoke & Priscille Geiser

Published by

CBR Africa Network
2013

LINKING CBR, DISABILITY AND REHABILITATION

Editors

Grace Musoke

Priscille Geiser

Published by

CBR Africa Network

2013

ISBN: 9 7 8 9 9 7 0 4 7 1 0 0 3

© CBR Africa Network
Handicap International

First Edition

CBR Africa Network 2013

E-Publication Design and Production

National Printing Press
#580, K.R. Garden, 8th Block
Koramangala, Bangalore-560 095, India
E-mail: nppbangalore@gmail.com

Cover Design

Jayaprakash K.R.
Nina Agtey

Publication Co-ordinated by

Disability, CBR and Inclusive Development Editorial Support Team Bangalore,
India
www.dcidj.org



Community Based Rehabilitation (CBR) Africa Network (CAN)

CBR Section, Faculty of Special Needs and Rehabilitation
Kyambogo University
P.O. Box 114, Kyambogo
Uganda
info@afri-can.org
<http://www.afri-can.org/>



Sponsored by

CP Charitable Trust, UK
2013

LINKING CBR, DISABILITY AND REHABILITATION

CONTENTS

FOREWORD	5
EDITORIAL	
Grace Musoke, Priscille Geiser	6
CONTRIBUTORS	10
CHAPTER 1	
Community-based Rehabilitation: an Effective Strategy for Rights-based, Inclusive Community Development	
<i>Karen Heinicke-Motsch</i>	<i>18</i>
CHAPTER 2	
The Role of the Community in CBR	
<i>Priscille Geiser, Marieke Boersma</i>	<i>24</i>
CHAPTER 3	
Building Partnerships and Alliances in CBR	
<i>Gertrude Oforiwa Fefoame, Joseph Walugembe, Ratie Mpofu</i>	<i>37</i>
CHAPTER 4	
Capacity Building in CBR: Learning to Do CBR	
<i>Huib Cornielje, John Majisi, Victor Locoro</i>	<i>52</i>

CHAPTER 5

The Link between Health-Related Rehabilitation and CBR

Alice Baingana Nganwa, Barbara Batesaki, Joyse A. Mallya 59

CHAPTER 6

The ICF as a Tool to Support CBR Planning and Management

Ros Madden, Sally Hartley, Elias Mpofu, Ali Baguwemu 72

CHAPTER 7

Evidence Base for CBR

Sunday Udoh, Joseph Gona, Carol Maholo 90

Acknowledgement 106

Appendix 1 108

Appendix 2 114

Afterword 117

FOREWORD

It is truly an honour to write the foreword to this book. This book is a recollection of the highlights from the 4th CBR Africa Conference 2010 held in Abuja, Nigeria on 26th -29th October, 2010. The conference was a historic event. It was historic not just because it was the first of its kind in Nigeria, but also because the World Health Organisation (WHO) chose the conference to launch the new guidelines on Community Based Rehabilitation (CBR) developed in collaboration with ILO, UNICEF and IDDC, for the whole of the African continent.

The conference was also special to the people of Nigeria. This is not only because it came at a time that we were celebrating 50 years of existence as an independent nation, but also because we are genuinely committed to the promotion of an inclusive society for all. Nigeria as a nation represents a true tapestry of diversity similar to the community present at the conference. The country has over 250 languages, with variant and divergent cultures, traditions, faiths and abilities; but remains the most tolerant and united nation in the world next to the United States of America. Over the years, the government of Nigeria has made it a priority to create a disability friendly environment by setting up appropriate legal structures to promote and protect the rights of persons with disabilities and other vulnerable persons in the country.

The book has the main theme of linking CBR, disability and rehabilitation to promote inclusive development in Africa. It covers broad areas from capacity building, health related rehabilitation, building evidence through research to partnerships and collaborations in CBR. Evidently, not all areas that were covered at the conference could be covered in a single book. However, it was developed in collaboration with conference participants and the CAN team to capture the main deliberations, discussions and presentations from the conference. I believe that there will be something for everybody in this book. It is also my hope that everyone working in the area of disability and CBR, including persons with disabilities will be enriched by the wealth of knowledge and practical experiences found between the pages of this book.

Chief (Mrs.) Iyom Josephine Anenih, mni
Honourable Minister
Federal Ministry of Women Affairs & Social Development

EDITORIAL

Grace Musoke, Priscille Geiser

INTRODUCTION

This book is the fourth in a series of conferences organised by the CBR Africa Network (CAN), that focus on issues related to Community Based Rehabilitation (CBR) in the African context. The contents of this book have been developed from conference presentations and discussions that took place in Abuja, Nigeria, in November 2010. While many of the chapters reflect the presentations made at the conference, others have been reinforced with additional information from discussions or relevant literature.

This conference has been a unique event in many ways. First, it was the occasion for the release and **global launch of the CBR Guidelines**, a collaborative work by the World Health Organization (WHO), the International Labour Organization (ILO), the United Nations Educational Scientific and Cultural Organization (UNESCO) and the International Disability and Development Consortium (IDDC). These guidelines are now the latest and most pragmatic tool towards operating CBR in the field, with a will to truly reflect the shift of paradigm around disability. As such, the CBR Guidelines have the potential to be a concrete tool towards realising the human rights of people with disabilities as recalled in the UN Convention on the Rights of Persons with Disabilities (UNCRPD), through a multi-sectoral and multi-stakeholder approach involving governments as well as people with disabilities, their families and communities.

The conference also provided an opportunity to explore key features of CBR and how they are enacted in African contexts. Held under the **theme “Linking CBR, Disability and Rehabilitation”**, it placed a deliberate emphasis on partnerships, between community stakeholders, within and between sectors of services, as well as across different perspectives and disciplines (including the need for measurement, research and training capacities in CBR). This book examines how services and support to people with disabilities in Africa are best delivered by multi-disciplinary teams and through mobilizing a wide range of stakeholders, including persons with disabilities themselves and their families.

The book seeks to address such questions as: who are the stakeholders if CBR is to be meaningful to people with disabilities? How can linkages be made across sectors to ensure that people with disabilities are at the centre in implementing CBR? How can the capacity of key stakeholders be built to support the development of CBR? How are health and rehabilitation linked to CBR? And how can evidence that CBR is effective be strengthened?

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. The contents not only provide an overview of present day CBR knowledge, but show how this information has been interpreted and implemented in the African context. The writers are predominantly of African origin and they ably provide an insightful view of the dynamic nature of CBR and its capacity to respond to contextually different challenges. They provide examples of their own CBR experiences and case studies of their programmes, the problems they face and how they were overcome. This is therefore another positive step in the journey of African people to share their own experiences and develop their own solutions to their problems within the context of their own cultural perspectives.

At the end of each chapter, the book provides references to the academic literature used by the authors. This information can be used by practitioners at different levels to access more information as well as to identify key players in disability and development on the continent.

WHAT THIS BOOK CANNOT OFFER

This book is not intended to be a manual on implementing CBR and therefore cannot be used as such. It does not provide a 'best' way of developing CBR programmes, but gives a description of what different people have done, in different countries and different contexts 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 of an academic style, other equally valuable chapters are more descriptive by nature and differ in style and presentation. The book intentionally gives room to a diversity of styles and points of view, as a way to stimulate the debate and nurture reflections around CBR. Therefore, the contents and opinions presented

in the various chapters do not necessarily account for, nor represent the views of the editors.

WHAT ARE THE KEY MESSAGES OF THIS BOOK?

Chapter 1 (*Community-Based Rehabilitation, an Effective Strategy for Rights-Based, Inclusive Community Development*) recalls the process for elaborating the CBR Guidelines, and provides a quick overview of their content and intended contribution towards Community-Based Inclusive Development.

Chapter 2 (*The Role of the Community in CBR*) explores what the terms ‘community’ and ‘community-based’ mean, which community stakeholders need to be mobilized and what their respective roles and responsibilities can be to ensure that CBR makes a meaningful contribution towards people with disabilities’ full and effective participation, in line with the UNCRPD.

Chapter 3 (*Building Partnerships and Alliances in CBR*) looks further into the required coordination mechanisms for a multi-sectoral and multi-stakeholder CBR to be truly functional at the local level. It highlights the importance of partnerships between the multiple stakeholders involved.

Chapter 4 (*Capacity Building in CBR: Learning to Do CBR*) lays emphasis on capacity development and the required means to secure and reinforce appropriate competencies and skills of CBR stakeholders to perform quality work.

Chapter 5 (*The Link between Health-Related Rehabilitation and CBR*) reviews the structure of primary healthcare and identifies linkages, complementarities and challenges in optimizing coordination between health-related rehabilitation and CBR services.

Chapter 6 (*The ICF as a tool to support CBR planning and management*) discusses the potential use of the International Classification of Functioning, Disability and Health (ICF) in supporting CBR planning, implementation and monitoring, and its contribution to greater evidence in CBR.

Chapter 7 (*Evidence Base for CBR*) focuses on the importance of a strong evidence base in CBR and calls for increased research and a stronger role to people with disabilities in this process.

Key resolutions from the 4th CBR Africa Network Conference (Appendix 2) were formulated and endorsed by delegates of the conference who represented

various governments, organisations and institutions (list in Appendix 1). These 9 key resolutions formulated in English, French and Portuguese, can prompt readers to examine their own CBR activities against what the conference participants collectively recommended, for example: are persons with disabilities actively engaged in the development of CBR programmes? If so, what role do they play? In what way have persons with disabilities, particularly children been supported to advocate for themselves? etc.

Eventually, the afterword to this book offers insights on **recent and upcoming developments in CBR**, including steps that followed on from this 4th CAN Conference. In particular, it highlights the launch of a CBR Global Network, links to recent publications on CBR, Community-Based Inclusive Development (CBID) and the UNCRPD, and announces the 5th CAN Conference to be held in Cairo in 2014.

WHO SHOULD READ THIS BOOK?

The people who will find the contents of this book useful are those who are interested in improving the impact of CBR in enhancing the lives of people with disabilities. Given the broad nature and multiple contributions required to operate CBR, this book may be relevant not only to people with disabilities and CBR workers, but also to Disabled People's Organisations, services providers at different levels, development actors across literally all sectors, politicians and decision-makers, donor agencies, academics, trainers, etc. In accordance with a well-known African proverb: "it takes a village to raise a child", it is therefore hoped that all can take an interest and find resources to renew their commitment and contribution to make African societies inclusive of and accessible to people with disabilities.

CONTRIBUTORS

The list of contributors mentioned here are individuals who developed the chapters in this book based on the key themes from the 4th CAN conference. They referred to actual presentations made at the conference and other literature deemed appropriate.

ALI BAGUWEMU

Ali Baguwemu is a senior lecturer in the Department of Psychology and a member of Kyambogo University Governing Council. He has over 18 years experience of teaching at an institution of higher learning. His professional experience is in the area of psychology. Currently, he lectures on Educational Psychology, Cognitive Psychology, Refugee Psychology and Rehabilitative Psychology (with emphasis on psychosocial intervention for persons with disability and those affected by trauma and post traumatic disorders). He has carried out and published a number of researches in the area of development.

BARBARA BATESAKI

Barbara is the Executive Director of the Community Based Rehabilitation Alliance (COMBRA), an indigenous NGO in Uganda. She is a professional physiotherapist and has been involved in disability work for over 25 years, working in different environments ranging from; hospital, community, and ministry levels as a physiotherapist, manager of CBR projects, technical adviser and trainer.

Since 1994, she has been involved in facilitating disability/Community Based Rehabilitation trainings for different categories of people ranging from professionals to community workers including parents of children with disabilities, provided monitoring and support supervision of CBR workers. Barbara has participated in CBR programme evaluations in countries like; Uganda, The Gambia, Lesotho, Nigeria and Zambia. She also served on the CBR Africa Network (CAN) Executive Committee as Treasurer and chaired the World Confederation of Physical therapists (WCPT), Africa region.

MARIEKE BOERSMA

Marieke Boersma is a rehabilitation consultant with Light for the World, based in Ethiopia. She is a physiotherapist by profession and has been working with the

University of Gondar (North Ethiopia) to establish the first BSc. in Physiotherapy in the country. She has started a CBR programme connected to the University. She is a trainer and advisor on programme development of CBR programmes in collaboration with the National CBR Network in Ethiopia as well as for individual CBR projects in-and outside of the country. In addition, she is currently a student of the Masters of Medical Anthropology and Sociology at the University of Amsterdam, where she completed a study on violence against children with a disability.

HUIB CORNIELJE

Huib Cornielje is in physical therapy with postgraduate qualifications in health science, adult education and public health from South Africa and The Netherlands. Currently he is trainer and consultant within his own agency 'Enablement' which organizes annual international courses in Policy and Management of Disability and Rehabilitation. He is also involved in in-country training programmes in the area of Community Based Rehabilitation and in policy development and (evaluation) research of disability programmes. Huib is one of the initiators of the Dutch Coalition on Disability and Development (DCDD). He is also working as senior lecturer in area of Public Health at the University for Allied Sciences in Leiden

GERTRUDE OFORIWA FEFOAME

Gertrude Oforiwa Fefoame joined Sightsavers in 2006 and has been the Social Inclusion Advisor for Africa since 2008. She also worked with the World Blind Union Institutional Development Programme (2001 to 2006) and has remained one of the consultants to date.

Gertrude is a National/International facilitator, Advocate on gender and disability issues, a resource person on programming with focus on disability and a mentor. She is the first person with disability to receive the Excellence Award -Grand Medal Award by the President of Ghana in 2007, for her contribution in teacher education and volunteerism. In 2010, she was awarded for her distinguished contribution to women's empowerment in Ghana by TV Africa and in 2011 by Ghana Blind Union Women's Wing for her contribution to disability and gender development.

PRISCILLE GEISER

Priscille Geiser is the Head of Handicap International Technical Support to Civil Society, which promotes, develops technical positioning and supports field projects in the fields of: Community-Based Rehabilitation, Support to DPOs, Inclusive Development Policies, Accessibility, Inclusive Local Development and the Making it Work methodology. Priscille holds a Master's Degree in Political Science, and has been working for more than 12 years in inclusive development, with a focus on people with disabilities. She is involved in advocacy through the International Disability and Development Consortium (IDDC), co-chairing the CBR Task Group. She also lectured at the University of Public Health in Rennes (France), as part of the Master on Disability and Social Participation.

JOSEPH GONA

Joseph Gona is a researcher in disability studies with Kenya Medical Research Institute/Wellcome Trust in Kilifi, Kenya. He holds a Masters Degree in Community Disability studies from University College London. He was previously a special education teacher and then assessor for disabled children. Currently, he is one of the directors of a Non Governmental Organisation called 'Kuhenza-Kenya' which is involved in meeting the educational needs of children with disabilities.

SALLY HARTLEY

Sally Hartley has worked with and for disabled people in many African countries. She is presently Professor of Community Based Rehabilitation at the University of Sydney, Australia and an Honorary Professor at the London School of Tropical Medicine. She is a Patron of the CBR Africa Network (CAN). She is also one of the editors of the World Report on Disability and a contributor to the new WHO CBR guidelines. Her research has focused on developing effective partnerships with all stakeholders and using community approaches to improve the quality of life of people with communication disabilities in low income countries.

VICTOR LOCORO

Victor Locoro is a lecturer in the department of Community and Disability Studies at Kyambogo University, Uganda. With visual impairment since childhood, he represents persons with disabilities on the National Council for Higher Education

in Uganda and is a member of the Staff Development Committee of Kyambogo University Senate. In addition to his University posts, he is a member of the Board of Directors and Treasurer of Uganda National Association of the Blind. Working in the areas of community-based rehabilitation and inclusive development and implementation, Victor has published several concept papers and research papers on disability and rehabilitation.

JOYSE A. MALLYA

Joyse Mallya is a Speech Language Pathologist and has worked for several years with people with communication disorders in hospital as well as CBR programmes. She has been involved in working with parent groups of children with disabilities and has great interest in the establishment of early intervention services for children with hearing impairment. Currently she has established SIKIKA Speech Language and Hearing Services, an NGO that offers rehabilitative services for people with communication disorders. Joyse is also working part time in the ENT department at the Regional Referral Hospital in northern Tanzania.

ROS MADDEN

Ros has played a major role in the development of national disability definition, measurement and statistics in Australia since 1992, and internationally in the development and implementation of the WHO's International Classification of Functioning, Disability and Health (ICF). Ros was Co-Chair of the Functioning and Disability Reference Group, WHO Family of International Classifications Network from 2006 to 2012 and a member of the Editorial Committee for the World Report on Disability from 2007 to 2011. She currently leads the Australian ICF Disability and Rehabilitation Research Programme (AIDARRP), with research on evidence for Community-Based Rehabilitation (CBR) measurement and assessment of functioning based on the ICF, and ICF education. She is co-leader of two streams in the Centre for Disability Research and Policy at the University of Sydney: the National Disability Insurance Scheme, and Disability and Development.

JOHN MAJISI

John Majisi is a Member of Parliament in the Government of Ghana since January 2013. Before he became a Member of Parliament, he was a Lecturer at the department of Special Education and the coordinator for Community Based

Rehabilitation and Disability Studies Programme at the University of Education, Winneba. He served as a Project Manager for a community based rehabilitation project for the Visually Impaired in Krachi District. He previously worked with Sight Savers as a Support Staff and a Technical Advisor for the Professional Programmes for rehabilitation personnel, which was a joint project for the University of Education Winneba and Sightsavers.

CAROLYNE MAHOLO

Carolynne is an active member in the disability fraternity of Uganda and has undertaken a number of researches and consultancies in disability and development work. She is a lecturer in the Faculty of Special Needs and Rehabilitation, Kyambogo University since 2004. Having a Masters degree in Development studies and pursuing a PhD in Rural Development, she is currently spreading out to rural development work with an emphasis on Disaster Risk and Vulnerability Reduction.

KAREN HEINICKE-MOTSCH

Karen Heinicke-Motsch is Director of International Programmes at CBM US and coordinates CBM's global advisory working group on CBR. She has 25 years of experience in Asia and Latin America developing and building the capacity of CBR programmes using cross disability, inclusive and rights based methodologies. Karen served as Subject Matter Expert on USAID's first online course for disability inclusion, is the co-editor of Building an Inclusive Development Community (MIUSA) and co-editor of the WHO, ILO, UNESCO, IDDC CBR Guidelines.

ELIAS MPOFU

Elias Mpofo, PhD, DED, CRC is professor and head of discipline of rehabilitation counselling at the University of Sydney, Australia. Formerly professor of rehabilitation services at the Pennsylvania State University, he is recipient of three rehabilitation counselor research awards by the National Institute of Disability and Rehabilitation Research (NIDRR), the National Council on Rehabilitation Education, and the American Rehabilitation Counseling Association. He is International Representative of the National Council on Rehabilitation Education, and National Secretary of the Australian Society

of Rehabilitation Counsellors. He is editor of various publications including; Assessment in Rehabilitation and Health (2010: Pearson), Rehabilitation and Health Assessment Applying ICF guidelines (2010: Springer), Counselling People of African Ancestry (2011: Cambridge University Press), and the Australian Journal of Rehabilitation Counselling.

RATIE B. MPOFU

Professor Ratie Mpofo is Emeritus Professor and former Dean of the Faculty of Community and Health Sciences, University of the Western Cape, South Africa and currently President of Cape Mental Health, South Africa. She is a physiotherapist and a Doctor of Philosophy.

ALICE BAINGANA NGANWA

Alice Baingana Nganwa is a medical doctor with a Masters degree in Mother and Child Health and additional training in Health Services Management, Community Based Rehabilitation, Disability Research, Epidemiology, Injury Prevention, Older Persons issues and Road Safety. She has worked in disability and development for 15 years as a clinician and later as programme manager in the Ministry of Health, Uganda. Dr. Nganwa has contributed to the development of the WHO CBR guidelines and has led several research, training and evaluation teams in disability. She is a founder member of CBR Africa Network. Dr. Nganwa is currently the director of Ways for Inclusive Development (WIND).

SUNDAY UDOH

Dr. Udoh is a Public Health and Development Specialist who has worked for several years as Technical Advisor for Socio-economic Development and Community Based Rehabilitation amongst persons and communities affected by leprosy and disabilities in Nigeria. He has a deep interest in the monitoring and evaluation of Community Based Rehabilitation interventions. He is currently the Chair of the International Federation of Anti-leprosy Associations in Nigeria (ILEP) and Country Director of The Leprosy Mission-Nigeria.

JOSEPH WALUGEMBE

Joseph is Country Director for Action on Disability and Development (ADD) International in Uganda. With experience stretching over ten years, Joseph

has worked with disability agencies both at national and international level. He sits on boards of several national and international organisations, has authored papers and conducted training on disability rights and development in several countries. Joseph is an active advocate for disability inclusion and mainstreaming in Uganda; working within the disability fraternity to advocate for policy formulation and implementation in favour of people with disabilities.

CHAPTER 1

Community-based Rehabilitation: an Effective Strategy for Rights-based, Inclusive Community Development



Copyright © Olivier Asselin

David Amuzu, 12, sits among his classmates school in the town of Amasaman, Ghana on Thursday January 17, 2008. "I can't see what the teacher is writing on the blackboard", he says. The pigment that gives skin its colour - called melanin - is also a key element in the development of the eye. Because of the absence of melanin, most people with albinism have poor eyesight, especially from a distance.

CHAPTER 1

Community-based Rehabilitation: an Effective Strategy for Rights-based, Inclusive Community Development

Karen Heinicke-Motsch

Summary

The 4th CBR Africa Conference held in Abuja, Nigeria was the occasion of launching the CBR Guidelines, co-authored by WHO, ILO, UNESCO and IDDC. These guidelines are the result of intense collaboration involving a wide range of contributors, and is the most comprehensive and practical document to guide CBR interventions towards improving the lives of people with disabilities in a meaningful way. This chapter tracks the process of elaborating these guidelines and highlights the prominent facts reflected in this document.

Introduction

There are some areas of development where the small scale and the marginalized are innovating and accumulating important lessons for the larger development community. Disability in development is one of these areas. Disability, like gender, is a cross-cutting development issue that needs to be taken into account throughout project cycle management (see www.cbm.org for a useful tool for disability inclusive PCM) and across the sectors of development. Community-based rehabilitation (CBR) is a useful strategy for implementing a cross-sectoral, human rights based approach to inclusive development. The experience of CBR can provide practical lessons learned and methods to the wider development community.

Experiential evidence shows that the benefits of development initiatives often do not spread widely: remaining instead, either with a section of the population or in large cities. People who live in far off places or in city slums often do not benefit. Employing community-based approaches, development can be more equitable, more realistic, more relevant to the people involved and more sustainable. CBR has been in existence for over 20 years. Originally articulated as a predominately health sector approach using primary health care methodologies, it has since evolved into a multi-sectoral, rights-based approach for community development targeting and involving people with disabilities, their families and their organizations as primary stakeholders. As a strategy, CBR seeks to further the inclusion and meaningful participation of people with disabilities in society by:

- Removing the barriers to development that people with disabilities face;
- Delivering quality services and programmes;
- Addressing the causes of disability; and
- Bringing persons with and without disabilities together on an equal basis.

In achieving these aims, CBR helps reduce poverty and improve the lives of everyone in the community.

Background to the CBR Guidelines and development process

The World Health Organisation (WHO) introduced the concept Community Based Rehabilitation (CBR) in the early 1980s. CBR was designed to enhance the quality of life for people with disabilities through community initiatives. To facilitate this, WHO published a CBR Manual, 'Training in the community for people with disabilities' in 1989. Since then, there have been many developments within and outside the disability sector.

Based on these global developments and as a result of stakeholder consultation, ILO, UNESCO and WHO updated the CBR Joint Position Paper (2004) and restructured CBR as a strategy for rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of people with disabilities. The purpose of this Joint Position Paper was to describe and support the concept of CBR as it is evolving, with an emphasis on human rights and a call for action against poverty. The Convention on the Rights of Persons with Disabilities (CRPD) aims to ensure that they enjoy human rights on an equal basis with others. Guidelines on how to implement CBR is a response to the demands created by the publication of the Joint Position Paper and the Convention on the Rights of Persons with Disabilities.

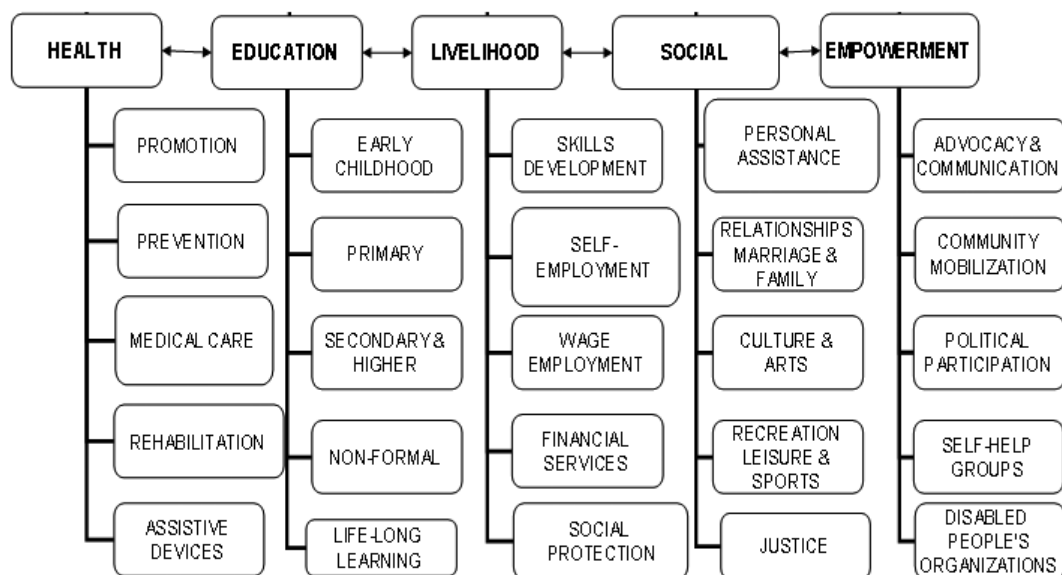
The CBR Guidelines have been developed by three UN agencies: WHO, ILO and UNESCO, together with the International Disability and Development Consortium (IDDC, see: <http://www.iddcconsortium.net/>). It is being actively supported by 13 International Non Governmental Organisations (NGO) including Disabled People's Organisations (DPO). Over 150 experts from across the globe contributed to the draft guidelines which were field tested in 25 countries. The CBR Guidelines were launched in 2010, at the 4th CBR Africa Network (CAN) Conference in Abuja and are downloadable on WHO website at: www.who.int/disabilities/cbr/guidelines/en/.

Content of the CBR Guidelines

The guidelines have five major components: health, education, livelihood, social and empowerment. Beside these five components, the CBR Guidelines also focus on management of some special scenarios including CBR and HIV/AIDS, CBR and leprosy, CBR and mental health and CBR in crisis situations.

These guidelines provide guidance on how to: develop and strengthen CBR programmes; promote CBR as a strategy for community-based development involving people with disabilities; support stakeholders in meeting basic needs and enhancing the quality of life of people with disabilities and their families; and encourage the empowerment of people with disabilities and their families.

The guidelines outline a multi-sectoral, cross-disability, rights-based approach supporting stakeholders to access the full range of mainstream and disability-specific services and opportunities. Each chapter provides an overview of key concepts, identifies goals and outcomes, and suggests activities for reaching these goals. The accompanying matrix illustrates the comprehensive and multi-sectoral nature of CBR. The framework focuses on the key domains of well-being and development: health, education, livelihood and social welfare. It also identifies the empowerment of people with disabilities and their families as the foundation for CBR programmes and key to accessing benefits in those domains.



As reflected in the CBR Guidelines, the foundation of CBR includes the eight core principles of the Convention on the Rights of Persons with Disabilities:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women; and
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Two additional principles are central to CBR work: empowerment (including self-advocacy) and sustainability.

There have been significant changes over the past two decades in the field of disability with improved legislation, instruments and new approaches. But people with disabilities themselves continue to face significant barriers to equal participation in their communities. The Convention on the Rights of Persons

with Disabilities is a call to action, that provides clear standards for human rights, inclusion and equality. Capacity building of people with disabilities, their organizations and communities is essential, if the rights and freedoms of persons with disabilities are to be achieved.

Today, CBR is practised in over 90 countries and is increasingly seen as an effective strategy for inclusive development and, more recently, as a means of implementing the Convention on the Rights of Persons with Disabilities. The concept of inclusive development has gained momentum over the last few years, with more donor governments and development organizations committing to implementing programmes that include people with disabilities. The CBR strategy provides an important mechanism for ensuring that inclusive development policies have a positive impact at the local level and on the poorest and most marginalized people with disabilities.

References

- WHO (1989). Training in the community for people with disabilities: <http://www.who.int/disabilities/publications/cbr/training/en/index.html>
- ILO, UNESCO, WHO (2004). Community Based Rehabilitation: A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities, Joint Position Paper. http://whqlibdoc.who.int/publications/2004/9241592389_eng.pdf
- IDDC, ILO, UNESCO, WHO (2010). Community Based Rehabilitation Guidelines. <http://www.who.int/disabilities/cbr/guidelines/en/index.html>

CHAPTER 2

The Role of the Community in CBR



Copyright © Olivier Asselin

A partially blind man (right) helps a visually impaired friend navigate while walking down a street in Dakar, Senegal, on Wednesday February 3, 2010.

CHAPTER 2

The Role of the Community in CBR

Priscille Geiser, Marieke Boersma

Summary

This chapter aims at capturing how CBR relates to the notion of community, and what the role of community is, in realising a holistic CBR in line with a comprehensive CBR matrix. It reviews the key ingredients for a truly community-based CBR to function, and explores further the role of community stakeholders in CBR, including community authorities, community-based organisations, people with disabilities and their organisations and families.

What does community mean?

It is interesting to note that in a prolific discourse about CBR, little or no attention has been paid to the key words that make up for the acronym ‘Community-Based Rehabilitation’, and to their definition. ‘Rehabilitation’ has actually been redefined from functional or health-related rehabilitation to a broader definition in line with article 26 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) covering “the areas of health, employment, education and social services”. Hence the CBR Guidelines indicate a clear direction for CBR “towards Community-Based Inclusive Development”. However, ‘community’ and ‘community-based’ remain vague terms whose scope is rarely defined. This lack of a harmonised definition of ‘community’ resulted in different collaborators forming contradictory or incompatible assumptions about CBR. As an initial step towards understanding the role of community in implementing the CBR Matrix, it is essential to clarify these key notions and their implications.

The meaning of ‘community’ differs when used by sociologists, biologists, geographers, political scientists, etc. Each definition however, entails the idea of cohesiveness and reflects that a group shares some things in common. In biological terms, a community is a group of organisms or species interacting and sharing

an environment. For geographers, community can be understood as a coherent geographical space or catchment area with common characteristics. Sociologists will tend to emphasise social and/or geographical connections between people¹. Eventually, 'community' also has a political dimension and refers to a small administrative division, in most cases the lowest level of government structure. This definition is of particular interest in the field of CBR: on the occasion of the international consultation reviewing CBR, WHO has emphasised this political sense by defining community as "*the smallest administrative area in which people live*"². This prompts us to encompass community authorities as part and parcel of and strategic community stakeholders. The preferred definition can have great implications on the way CBR is understood and implemented. The point at this stage is not to advocate the use of a unique definition, but to underline that the emphasis placed on particular elements of the definition strongly influences models of CBR. This diversity of definitions should not obscure the diversity of stakeholders within a community, each playing a specific role in implementing CBR.

Equally important is the role given to the community in CBR, which can be tracked in the expression 'community-based'. There are differing interpretations that greatly impact on the vision behind CBR. 'Community-based' has sometimes been understood as merely 'based in the community', '*happening at the level of the community*', or '*located in the community*'. This interpretation may result in CBR interventions planned as delocalised rehabilitation interventions, such as mobile camps and other outreach strategies³. 'Community-based' may also be understood as '*based on the community*', '*relying on the community*'. This emphasises that CBR is not only as an intervention brought from the outside and happening in the community, but practised as a strategy that strongly involves the community, its members and resources in development. Eventually, 'community-based' can

-
1. In What Is Community? An Evidence-Based Definition for Participatory Public Health, a community is defined as "a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings". Kathleen M. MacQueen, Eleanor McLellan, David S. Metzger, Susan Kegeles, Ronald P. Strauss, Roseanne Scotti, Lynn Blanchard, and Robert T. Trotter, 2001. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446907/>
 2. International Consultation to Review CBR, WHO, 25-28 May 2003, Helsinki
 3. In this perspective, "if people with disabilities are enabled to access counselling, are made aware of their rights and home visits are conducted to help people with disabilities function independently, then a CBR project may be considered successful, even though it has not involved community leaders and other citizens"; Sarah Rule, Fiona Poland, Joseph Gona In search of the *community in community-based rehabilitation*. In CBR: Inclusive Policy Development and Implementation, edited by Sally Hartley and Joan Okune, University of East Anglia, 2008.

also be understood as ‘initiated from’ or ‘driven by’ the community. This approach goes one step further in giving the initiative to the community to decide and/or lead rehabilitation, and in building a sense of responsibility.

The understanding of ‘community-based’ significantly influences the way CBR is understood, implemented and the preferred levers for action. *Participation of the community is a constitutive element of CBR, and should prompt CBR planners to integrate CBR within general community development.*

New opportunities for an increased role of the community

The CBR Joint Position Paper (2004), as well as the CBR Guidelines (2010), both encourage CBR practitioners to address four major challenges. First, as seen above, the understanding of ‘community-based’ and the importance of community participation challenges CBR to succeed in mobilising communities to become welcoming and to actively engage in including people with disabilities. A second challenge is to ensure that CBR contributes to realising human rights of people with disabilities. Third, the challenge of a multi-sector approach means that CBR should assure access to mainstream services and opportunities in all sectors (not only functional rehabilitation). Finally, there is also a challenge in coordinating between the many stakeholders involved. Evolutions on the international scene – specifically the entry into force of the UNCRPD and increased trends of decentralisation – provide new opportunities to take up these challenges.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD)

The UNCRPD creates new obligations for States to promote, protect and fulfil the human rights of people with disabilities, and ensure they access opportunities on an equal basis with others. As both a human rights instrument and a development tool, this international convention brings attention to the connection between disability and poverty. It calls for action to find solutions that are adapted to developing countries where the majority of people with disabilities live. In answer to this, participatory, rights-based CBR interventions offer a possible strategy to realise the UNCRPD in developing countries.

For donor countries, article 32 on *International Cooperation* implies that all development or humanitarian aid efforts should be inclusive of and accessible to people with disabilities. This provides further ground for promoting CBR

as a strategy within general community development, contributing to realise the rights entailed in the UNCRPD. Article 19 on *Living independently and being included in the community*, is another important reference calling for actions to ensure that people with disabilities “have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community” and that “community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs”.

In the context of Africa, the social, cultural and economic conditions in most communities in Africa may help to generate social cohesion and networks. But the rights-based model of CBR may seem distant and theoretical or too ‘individualistic’ to many African communities. A challenge thus remains to work towards ‘Africanizing’ CBR through linking CBR with African human rights activists. It calls for the disability movement in Africa to adopt dynamic advocacy and communication strategies that speak about disability from an African perspective.

Decentralisation reforms

The past few decades have seen growing trends among developing countries to conduct decentralisation reforms. Local authorities are thereby delegated new responsibilities to decide on priorities of the community development agenda and corresponding budget to implement actions. This has been accompanied by an increase in decentralisation cooperation initiatives, through partnerships between local governments in the South and their counterparts in the North. However, local governments rarely receive corresponding support to undertake these new responsibilities, which include social responsibilities towards all community stakeholders, including people with disabilities. Consequently, they lack the capacities to address the needs of groups that are traditionally excluded. This context provides new opportunities to promote CBR as a means for local governments to engage in a participatory and inclusive planning of development for the community they administer. Thereby, CBR can fully fulfil its mission as a “strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities”⁴.

4. CBR, *A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities*, ILO, UNESCO, WHO, Joint Position Paper, 2004.

Towards inclusive local development

Building on these opportunities, new solutions and mechanisms can be explored to address the challenges of making CBR, more participatory, holistic, rights-based and sustainable. For example, instead of designing a strategy focused on people with disabilities, in which the community would then need to be mobilised, it is interesting to look at the community development strategy (e.g. the local development plan) and work together with concerned community actors to build it or adapt it to priorities of people with disabilities. This approach is the one that guides Handicap International's Inclusive Local Development projects. It gives a new emphasis to participation of people with disabilities as citizens and active stakeholders of their community through influencing community decision-making (in line with UNCRPD articles 3, 4.3 and 29 in particular).

Community stakeholders and roles

The strategy is embedded in the decentralised system and targets all of its major stakeholders. A community – whatever the definition we retain – is composed of a diversity of people, institutions and organisations that work as a system. They can be grouped into three major groups according to their role: (1) those representing people with disabilities, i.e. people with disabilities themselves, their families and their representative organisations; (2) those defining and regulating community priorities and strategic orientations, i.e. community decision-makers, local governments or traditional authorities; and (3) those providing the range of service options that are necessary for all community people to enjoy their lives to the fullest, i.e. local development stakeholders in all sectors, including Community-Based Organisations (CBOs), NGOs, public and private service providers. It is essential that each type of actor plays its role in order for the community to function well.

CBR interventions should therefore pay attention to: (1) strengthening capacities of people with disabilities, their families and communities capacities to take part in community decision-making and engage in strategic advocacy at local level; (2) strengthening the capacities of community authorities/ local governments to efficiently manage their community and address key issues of exclusion; and (3) strengthening local development actors' capacities to welcome and include people with disabilities on an equal basis with others. In addition, relationships and partnerships are essential to ensure that a coordinated, comprehensive and inclusive response is provided in answer to the needs of communities, including

the needs of people with disabilities. As much as the arrows between the boxes of the CBR Matrix are important, coordination mechanisms between community stakeholders are critical. This is illustrated in the diagram below.



How to engage community stakeholders in working together towards successful CBR?

Working with communities in CBR is demanding. As seen, it requires strategies for true mobilisation of people. It requires working with a plurality of community stakeholders to help them perform their role. And it requires coordination amongst these stakeholders so that the community becomes an enabling system. Three examples of how this can be done at different steps of a CBR project, are developed in the following.

At the beginning of a CBR project, a joint analysis of the situation of people with disabilities can be conducted. *This local participatory diagnosis or participatory community appraisal*⁵ mobilises local authorities, people with disabilities and local development stakeholders on the identification of how people with disabilities really live in this community and what their experiences are. In Mali, this has been conducted in 10 District Councils in the region of Gourma Rharous. A steering committee including locally elected decision-makers and DPOs decided on the methodology and objectives, and 2-person teams of surveyors including a person

5. See more details about this methodology in: *Inclusive Local Development, how to implement a disability approach at local level*, E. Plantier-Royon, P. Geiser, Handicap International, 2009. English: http://drt.handicap-international.fr/uploads/tx_hidrtdocs/DLIFrBd.pdf; French: http://drt.handicap-international.fr/uploads/tx_hidrtdocs/DLIFrBd.pdf

with a disability collected information surveying 110 people with disabilities, 20 DPOs, 9 schools and 5 health centres. The results were presented in a multi-stakeholder community workshop. The diagnosis for example, showed that 99% of people with disabilities estimated that their priority needs were not met; that the 9 schools surveyed are not accessible physically; etc. This was the starting point for the community, including local authorities, to identify priorities and start thinking about possible solutions.

Another initiative to foster collaboration amongst community stakeholders around disability issues, is the development of an *inclusive local development plan*, or a community disability action plan. Following the local participatory diagnosis in Mali, local DPOs took part in consultations to elaborate the district council development action plan. This was done together with local authorities, services providers and other development actors, as per the decentralisation reform modalities. Based on their analysis of the local situation of people with disabilities, disability-related priorities were included in each of the 10 district councils' action plans of the Gourma Rharous region. Corresponding budgets were allocated, which resulted in new community infrastructures made accessible, increased access to school for children with disabilities, increased employment opportunities, or reduced stigma, depending on the activities prioritised.

Eventually, coordination amongst community stakeholders is also required to ensure a continuum of services for people with disabilities, which is necessary to cover for the varied and evolving needs of a person throughout a lifetime. This can be facilitated through establishing *community-level, cross-sector referral mechanisms*. Following on from a similar local participatory diagnosis in Mozambique (Maputo and Matola), focus has been given to access to services by people with disabilities. A directory of existing mainstream community services using pictograms to indicate accessibility of services was produced. This directory is now of particular use by agents of community social services who play a major role in informing and referring people with disabilities towards appropriate services⁶.

6. See the directory of services in Portuguese: Actores et serviços sanitários e sociais nos Municípios de Maputo e Matola, Handicap International, RAVIM, 2010. The methodology and results of the local participatory diagnosis conducted in Maputo and Matola have been documented in: People with disabilities in the suburban areas of Maputo and Matola, Local Assessment: social representation of disability, socio-economic situation, access to health and social services, local stakeholders system, Handicap International, RAVIM, April 2010. English version: http://www.hiproweb.org/uploads/tx_hidrtdocs/Relatorio_GB_BD.pdf; French: http://www.hiproweb.org/uploads/tx_hidrtdocs/DiagnosticLocalMaputo_RAVIM_HI_avril2010.pdf; Portuguese: http://www.hiproweb.org/uploads/tx_hidrtdocs/SyntheseDiagnosticoLocalDeficienciaMaputo2010_01.pdf

Roles of community stakeholders

In this section, the authors propose to focus on the specificities of each type of community stakeholder.

The role of community authorities

Talking about CBR from a human rights perspective reminds us that this is the responsibility of the government to ensure that people with disabilities can enjoy these human rights on an equal basis with others. States – especially those who have ratified the UNCRPD and therefore have new international obligations – should ensure that all types of services, including rehabilitation services, are available, inclusive and accessible to people with disabilities. This also implies a financial responsibility, part of which can be devolved to local governments through decentralisation reforms.

This ultimate responsibility of the State to ensure that human rights are promoted, respected and fulfilled for all does not necessarily mean that the government – at national or local level – has to do it all. Implementation can be delegated to other stakeholders, including NGOs and CBOs. At the community level and in the context of decentralisation reforms, it is *essential that CBR strategies are planned and monitored in close association with the government, in particular local governments*. This relates to its role of regulating the offer of services and ensuring that all can enjoy their rights. This is also a key principle to guarantee community ownership, and sustainability of CBR interventions on a minimum level, and should be considered, whatever be the context.

What may vary according to the context is the involvement of the government in implementing CBR. There are advantages and disadvantages. On the positive side, CBR implemented by the government is likely to be more sustainable, including longer-term staff employment. It enables an easy access to other complementary mainstream government services such as health or education. On the negative side, government-led CBR may lack flexibility and in some contexts may not be able to reach out to grassroots levels. It is important to always carefully assess the pros and cons, and anticipate the risk for an NGO to create a parallel system that would relieve the government from its responsibilities or reduce sustainability.

The role of community based organisations

Community-Based Organisations (CBOs) may sometimes be responsible for implementing a CBR programme at the community level. To the best possible

extent, this should be done in close collaboration with community authorities ensuring that this delegation of a local government's responsibility is well integrated in the community development strategy and receives related financial support.

As this has been discussed earlier, there are several CBR models and CBOs will not necessarily be primarily responsible for CBR implementation. CBOs have however a significant role to play in any CBR intervention. As groups organising parts of a community's population around a common objective, they are critical interlocutors to mobilise, as CBR seeks to embed disability as a priority within the agenda and preoccupations of a community. CBOs include for example faith-based organisations, social groups, sports associations, youth/ students groups, trade unions, DPOs, political parties, women groups, etc. Recognising people's multiple identities, CBR needs to work with such groups towards better inclusion of children with disabilities amongst children, towards better representation of workers with disabilities within trade unions, etc. CBOs are important factors of socialisation, social acceptance, and reflect the level of inclusiveness of a community. They can be a vehicle of important messages related to prevention, pass on information on disability and demonstrate practically, that people with disabilities full participation is not only possible, but also beneficial to the community.

The role of people with disabilities and their organisations

As a specific type of CBOs, Disabled People Organisations (DPOs) are very special actors in CBR. Representing the voice of people with disabilities, they are critical interlocutors who should have a say in the design, implementation and monitoring of CBR. By voicing the concerns of people with disabilities, they contribute to a CBR response that truly fulfils priorities of and needs of people with disabilities. When DPOs are not yet created or organised as such, self-help groups can perform a similar role. Associations of parents or families of people with disabilities may also be relevant information relays to ensure that the perspective of those to whom CBR is intended, is at the heart of CBR planning and realisation. The CBR Guidelines prompt this systematic involvement as a way to abide by the general principles of the UNCRPD, in particular Article 3 and 4.3. Specific attention is given to this in the Empowerment Component of the Guidelines, which is presented as cross-cutting to all others (Health, Education, Social and Livelihoods).

Although it is not the main focus of this chapter, the authors wish to recall that DPOs' involvement in CBR should be systematic and approached as an empowering strategy. In many African countries, there is a positive wave of disability rights. This chapter also wants to be a call towards the disability movement in Africa to take leadership in implementing communication and advocacy strategies to make disability a major concern. DPOs can and need to play a critical role as catalysts, to make people with disabilities realise about their rights and take an active part so that CBR is no longer driven only by development stakeholders. This essential part of CBR needs to be carried out by people with disabilities to tell communities how they want to be considered, and to enrol community stakeholders in their battle. Finding appropriate interventions that respond to the African perspective on disability, requires transformative approaches piloted by African disability activists.

The role of families

Eventually, as a close and direct support to people with disabilities, families are also essential stakeholders in CBR. Families can play a key role in providing support, advocating for the rights of their member who has a disability, finding creative solutions, facilitating participation in the community, etc. In order to do this efficiently, they need to be empowered. This means ensuring that families are connected together, build their self-esteem and confidence, acquire basic skills to develop the abilities of people with disabilities at home, and access sufficient knowledge to support and inform about existing solutions and support options.

The situation is however not always easy. For children with disabilities, who are particularly vulnerable, maltreatment can come from within the family. Causes are numerous: poverty, a lack of knowledge, shame and trying to keep relations with the community, regarding a child as sexless, a lack of access to education and justice services, can all lead to maltreatment. Disability can also be a cause. Working with families is therefore essential for CBR programmes to prevent and identify maltreatment, and to find relevant solutions to protect children. Working to promote acceptance of the child with a disability by his/her own family is a major form of child protection. By acting on other causes, CBR programmes and staff can also reduce causes of maltreatment (e.g. poverty, lack of access to services), working with families as allies. DPOs and children's groups are also for many children with disabilities, the place where they realise that the violence

committed against them was wrong and where they found the courage to step out of a violating environment⁷. Families can play a leading role in improving DPO's reach out to children with disabilities. Families should also take a leading role with the help of CBR programmes to facilitate access to services, full respect and protection of the rights of their member who has a disability.

Conclusion

To conclude, if it is to succeed, community-based rehabilitation needs to get back to its core ingredients, and consider community as a driving force. It needs to work with *all community stakeholders* (from DPOs to families, local authorities and local services) to help them play their specific role according to their respective responsibility. It also needs to work on *improving interactions between these stakeholders*, so that everyone plays their part and that the community functions as a strong, cohesive social net that takes care of the diversity of its members. African communities have strong assets to succeed in taking up this challenge and can make a decisive contribution in making this happen.

References

AXELSSON C (2008). A Guidance Paper for an Inclusive Local Development Policy, background information, tools for action at local level, support material, Handicap International, SHIA, Handikapp-Förbunden, International Disability and Development Consortium.

English: <http://www.make-development-inclusive.org/toolsen/inclusivedevelopmentweben.pdf>

French: <http://www.make-development-inclusive.org/toolsfr/inclusivedevelopmentwebfr.pdf>

BOERSMA M (2009). Violence against Ethiopian children with disabilities, the stories and perspectives of children. University of Amsterdam. [http://www.dcdd.nl/data/1232447618817_MAS_scriptie_Marieke\[2\].pdf](http://www.dcdd.nl/data/1232447618817_MAS_scriptie_Marieke[2].pdf)

BOTWEY D (2003). Report on the dissertation for an MA degree for University of Leeds, UK.

BOTWEY D (2010). Presentation on the role of the community in implementing the CBR matrix, CBR African Network Conference, Abuja, Nigeria.

CASWELL P. (2010). Presentation on the link between CBOs and DPOs and the CBR matrix, CBR Africa Network Conference, Abuja, Nigeria.

FRANCISS E. (2010). Presentation on the role of the family in implementing the CBR matrix, CBR African Network Conference, Abuja, Nigeria.

HANDICAP INTERNATIONAL, RAVIM (2010). Actores et serviços sanitários e sociais nos Municípios de Maputo e Matola. Portuguese: <http://www.handicap-international.fr/fileadmin/documents/publications/MaputoDirectorioPt.pdf>

-
7. See: Boersma, J.M.F. (2008) Violence against Ethiopian Children with Disabilities, the Stories and Perspectives of Children. Amsterdam, Master Thesis, University of Amsterdam. <http://www.dcdd.nl/default.asp?3892>

HANDICAP INTERNATIONAL, RAVIM (April 2010). People with disabilities in the suburban areas of Maputo and Matola, Local Assessment: social representation of disability, socio-economic situation, access to health and social services, local stakeholders system.

English: http://www.hiproweb.org/uploads/tx_hidrtdocs/Relatorio_GB_BD.pdf;

French: http://www.hiproweb.org/uploads/tx_hidrtdocs/DiagnosticLocalMaputo_RAVIM_HI_avril2010.pdf; Portuguese: http://www.hiproweb.org/uploads/tx_hidrtdocs/SyntheseDiagnosticoLocalDeficienciaMaputo2010_01.pdf

GEISER P., ZIEGLER S., ZURMUHL U. (July 2011). Support to Organisations Representative of People with Disabilities, Handicap International Policy Paper, Handicap International. http://www.hiproweb.org/uploads/tx_hidrtdocs/SupportToDPO.pdf

HARTLEY S., OKUNE J. (Eds) (2008). CBR: Inclusive Policy Development and Implementation, University of East Anglia, Norwich, UK.

IDDC, ILO, UNESCO, WHO (2010). Community Based Rehabilitation Guidelines. <http://www.who.int/disabilities/cbr/guidelines/en/index.html>

ILO, UNESCO, WHO (2004). Community Based Rehabilitation: A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities, Joint Position Paper. http://whqlibdoc.who.int/publications/2004/9241592389_eng.pdf

MACQUEEN K., McLELLAN E., METZGER D., KEGEKES S., STRAUSS R., SCOTTI R., BLANCHARD L., TROTTER R. (2001). What Is Community? An Evidence-Based Definition for Participatory Public Health, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446907/>

PIATTA F., (2010), Rights in Action, Good practices for Inclusive Local Governance in West Africa, Benin, Burkina Faso, Mali, Niger, Senegal, Sierra Leone, Togo, Handicap International.

English: http://www.ak-project.com/IMG/pdf/rapport150PDesiciph_GB_PRODP104_301110.pdf

French: http://www.ak-project.com/IMG/pdf/rapport150PDesiciph_FR_BD_251110.pdf

PLANTIER-ROYON E., GEISER P. (November 2009), Inclusive Local Development, How to implement a disability approach at local level, Handicap International.

English: http://www.hiproweb.org/uploads/tx_hidrtdocs/DLIGbBd.pdf

French: http://www.hiproweb.org/uploads/tx_hidrtdocs/DLIFrBd.pdf

CHAPTER 3

Building Partnerships and Alliances in CBR



Copyright © Olivier Asselin

A man reads the newspaper to a visually impaired friend in Dakar, Senegal, on Wednesday February 3, 2010.

CHAPTER 3

Building Partnerships and Alliances in CBR

Gertrude Oforiwa Fefoame, Joseph Walugembe, Ratie Mpofu

Summary

This chapter explores the place of partnerships in CBR. Partnerships are essential in CBR at different levels: between a variety of sectors to ensure a holistic answer for the multiple and evolving priorities of a person; between professionals and CBR workers within the same sector of services (with the example of health-related rehabilitation); and between a wide range of stakeholders, including people with disabilities, families, services and local authorities. The chapter first addresses the issue of relationships between CBR and other rehabilitation professionals in the provision of services to people with disabilities. It focuses on why services for people with disabilities should be interlinked and then draws on practical examples from Uganda and South Africa, to illustrate that such linkages can be established through inter-professional education within a university setting. The authors further highlight the factors that hinder the development of such partnerships and conclude by suggesting steps that could be taken into consideration to establish and/or strengthen collaborations for systematic and purposeful relations between governments, civil society, persons with disabilities and their families.

Partnerships towards a multi-sectoral and multi-stakeholder CBR

Partnership is central to CBR and can be explained as a relationship in which two or more entities share skills, knowledge, resources and tasks to achieve a common goal. A partnership will fail if it is not based on trust. It calls for the full and co-ordinated involvement of all levels of society: community, intermediate and national; seeking the integration of the interventions of all relevant sectors, and aims at the full representation and empowerment of persons with disabilities. This foundation of a relationship built on common purpose and trust allows for joint participatory planning, shared tasks, transparency and accountability, and as relations and challenges occur along the way, there is also a need for flexibility and a willingness to change and grow, sharing success and failure.

As a strategy for disability-inclusive development, CBR strongly depends on successful partnerships, of a more or less formal nature, to be woven between a wide range of stakeholders at community level. The CBR Guidelines call for a multi-sectoral approach, and for partnerships across sectors of services (health, education, social and livelihoods) and across types of services within a same sector. It also calls for a rights-based, multi-stakeholder approach enabling the active participation and empowerment of people with disabilities and their organisations, in partnership with other community stakeholders.

The need for working relationships

In order to establish the need for a working relationship between CBR and other rehabilitation services, one must reiterate the goals of the two interventions. CBR aims at providing optimum opportunity for rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. The purpose of health-related rehabilitation is to restore some or all of the person's physical, sensory, and mental capabilities that were lost due to injury, illness, or disease, to "enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life" (UNCRC, Article 26). Both interventions involve processes whereby one regains strength, (re)learns skills or finds new ways of doing things in daily living to live meaningful lives.

Close examination of the two interventions suggest a continuum of service provision that calls for a strong partnership for effective and efficient delivery. While CBR workers are broad-based service providers who are able to provide a number of services in the community and are located in the community, most of the other health-related rehabilitation service providers, such as physiotherapists, psychologists, speech therapists, orthopaedic surgeons and nutritionists, are professionals often based in intermediate and tertiary centres. Meanwhile, in developing countries, the majority of the target users, persons with disabilities, often live in rural communities. Specific service interventions that illustrate the need for working partnerships between CBR and other rehabilitation services include: person-centred assessment of individual situations to guide appropriate interventions, training of CBR personnel, specialist knowledge to guide service provision by CBR actors; and grassroots experiences and knowledge required by other service providers to shape their programmes. CBR workers often do not have all the skills and resources and therefore require the complementary

expertise of other service providers, in particular, regarding health-related rehabilitation. For instance, referral is essential after eye screening, even if done in collaboration with ophthalmic nurses. Some people may have their sight restored through surgery, while others may require the services of low vision therapists and counsellors. Likewise, continued support provided by CBR actors at community level is often much needed as a follow-up after an intervention by a therapist. Most functional rehabilitation or primary health centres provide no or only limited orientation for the use of assistive devices. Charles Appiah Adjei, a disability leader and advocate, former Senior Programme Officer of Action on Disability and Development (ADD) in Ghana and current administrator of Ghana Society for the Physically Disabled, explains that often, limited orientation is given to physically disabled persons when they are provided support by middle or tertiary-level therapists. It therefore behooves CBR stakeholders, including Disabled Peoples Organizations (DPOs), family members and CBR workers, to continue to support people to adequately use and adjust the devices for maximum benefits for the person, but also to raise awareness of health professionals on community realities for optimum collaboration.

People's priorities evolve throughout their lifetime; the spectrum of services required for a comprehensive rehabilitation process requires a varied expertise which needs to be well coordinated; in other words, partnerships are central to enable full and effective inclusion of people with disabilities. Partnerships are necessary to ensure the continuum of services within the sector of health-related rehabilitation, but also across sectors, between health services and other educational, social and economic services through a holistic and 'no-gap' approach.

As 'gate-keepers' and often the first contact for people with disabilities at community level, CBR workers need sufficient levels of knowledge, skills and resources to address a variety of situations and demands, and ensure effective referral. Training and refresher courses have to be offered by an equally broad range of service professionals to equip CBR workers with the required capacities and know-how, including networking skills which are essential for CBR workers to tap on and mobilise existing community resources. Partnerships are therefore also an essential component of a comprehensive and continuous learning process of CBR workers. Specialists who are anxious to improve the delivery of services for optimum benefits for people with disabilities need to acknowledge and activate grassroots knowledge and resources delivered through CBR.

Are there working partnerships in CBR?

The earlier paragraphs have established the need for a working relationship between CBR and other rehabilitation services. Now let us consider whether there have been such partnerships. Before the introduction of CBR in the early 1990s, rehabilitation services for people with disabilities where they existed, were often isolated and/or delivered in centres. Most of these centres were providing only a specific category of services, and in all likelihood, different services were managed under different ministries without any coordination. This resulted in frequent gaps as for instance, corrective surgery was provided at the hospital without interaction and coordination with orthopaedic services to delivering assistive devices after the surgery. Today, CBR has the potential and in many cases has already proven successful in developing and enhancing collaboration between different experts, within the world of health and also between health-related rehabilitation and the many other services required for people to live meaningful lives, with a maximum autonomy and freedom of choice. In this perspective, CBR brings in another dimension towards improving people's effective access to services required, for the full enjoyment of their human rights.

Some of the collaboration mechanisms employed in CBR include the establishment of committees made up of representatives of the major actors at the community level. These include, among others, health, education, agricultural and social workers; parents, DPOs, and opinion leaders. This multi-stakeholder, multi-sectoral approach creates effective linkages, both vertically and horizontally. It aims to build ownership at the local level and to facilitate referrals to the intermediate level.

This practice is gaining currency among programmes supported by NGOs and at the national level, commissions/committees and coalitions are being formed and encouraged. However, these national CBR committees in many countries of Africa often become dysfunctional or collapse when donor funding ends. It often takes the disability movement considerable time to advocate for its revitalization, as illustrated through the experience in Ghana and Sierra Leone.

Further reflection is therefore needed to address the issue of the extent to which this practice can be embraced and supported by governments, and the mechanisms, resources and structures required for this to be sustainable. It is urgent to engage more into finding how partnerships, which are required at so many levels within CBR and between CBR and other experts, can be

institutionalised to operate satisfactorily and make the most of existing resources to support optimum impact.

CBR partnerships: field experiences from Uganda

The complementary role between Non-Governmental Organizations (NGOs) and government in the provision of Community Driven Development (CDD) is of growing importance. This is of no exception to the promotion of Community Based Rehabilitation.

According to Uganda's Poverty Eradication Action Plan (PEAP) 2004-08/09, Community based Rehabilitation is the Uganda government's strategy for ensuring full integration of Persons with Disability in community development programmes and poverty eradication efforts. This is reiterated in the National Development Plan (2010-2014).

The growing numbers of NGOs in Uganda (from about 1000 in 1986 to more than 100,000 by 2009 – review of the NGO board), is in part, founded on the basis that NGOs are supposed to augment government's efforts of promoting equitable development. This is particularly exemplified in the social service sector, where NGOs have directly complemented government objectives of providing equitable and accessible education, health, and water and sanitation services among others.

Community based rehabilitation is another theatre where the concept of "Public-Private Partnership" has been played out with reasonable success notably:

- **Piloting:** Most programmes commence with a manageable pilot from which to learn lessons. Likewise, implementation of the 'comprehensive' CBR model by the Uganda government was initiated through a pilot project in one district with full sponsorship of the Norwegian Association of the Disabled (NAD). This enabled government and other NGOs to learn how comprehensive CBR works.
- **Joint Planning:** In 2000, the Government of Uganda developed the first national CBR strategic plan, which aimed to bring all CBR initiatives under a common framework to promote effective tracking. This strategic plan was in part realised by a considerable involvement of several mainstream NGOs and Disabled Peoples Organizations (DPOs), which were implementing varying levels of CBR programmes.
- **Scaling up:** According to the Ministry of Gender, Labour and Social Development (MGLSD). Medium Term Development Framework (MTEF)

CBR coverage will be extended from 4 districts by 2008 to all districts of Uganda by 2012. However, Government's funding will extend to 18 districts by 2012. It is expected the other districts will be covered by programmes of NGOs.

- **Coordination and monitoring:** On the realisation that CBR initiatives in Uganda were fragmented; full of duplication and inconsistent with acceptable minimum standards, the MGLSD created the national CBR steering committee. Chaired by the minister, it was to bring together all major actors into the CBR arena, to regularly share information about their programmes.
- **Regulation and Harmonization:** In relation to the earlier mentioned points, the 2008 review of Uganda's progress towards implementing comprehensive CBR found that several CBR projects/programmes of NGOs were characteristically inconsistent with internationally recognized standards. The Government developed the CBR guidelines with the view of providing a commonly acceptably national reference point for all CBR implementers.
- **Innovation and modelling:** The life of a strategy is to be found majorly in its ability to evolve with the demands of the day. This calls for creativity by implementers and in CBR, NGOs have been in the lead of coming up with new models of delivering CBR. Notably in Uganda, the comprehensive Eye Services (CES) Model by Sight Savers is a creative way of blending eye care, inclusive education and CBR into an effective web that provides a continuum of services. Action on Disability and Development's "Disability and Development in the Community" approach presents a revolutionary way of mobilizing community members to work with disabled persons in finding local solutions to local problems of PWDs.
- **Co-funding:** There are several examples of direct co-funding for CBR programmes by Government and NGOs. The best example is to be found in Sight Savers CES model, which largely thrives on government infrastructure, personnel and systems.
- **Human resource development:** There are several corroborative efforts between government and NGOs in the development of professionals to enrich CBR delivery. Notably, the Community Based Rehabilitation Alliance trains CBR resource persons with partial funding from government, trainees from paramedical schools receive attachment to COMBRA to get a community experience during their training, and several NGOs sponsor CBR workers to Kyambogo University, etc.

- **Policy formulation:** While the function of policy formulation is primarily that of government, it is better performed when it is done through a consultative process. Several legislations of Uganda which are anchored in CBR have emerged through a consultative process between NGOs and government, including the PWD Act, the NCD Act etc.
- **Reporting:** Like all programmes, CBR needs to share its success stories, challenges and lessons. All annual reports of government (2000 to 2008), will always show the roles of both government and NGOs, and the same applies to those of NGOs. Reporting through the Convention on the Rights of PWDs is now the highest form of reporting and currently, the government is compiling its initial report, while the NGOs are preparing an alternative report and one of the perimeters is the extent to which CBR has been implemented.
- **Evaluation:** Measuring of the impact of CBR programmes, either by the Government or NGOs requires feedback from across the board. A government official evaluated the Sense International programmes because the focus was to be the extent of integration of initiatives in the government system. Likewise, the evaluation of the Government's CBR programmes in 2008, drew majority of its respondents from NGOs.
- **Referral system:** For the CBR chain to be completed there has to be an effective referral system. In Uganda, referral happens across the NGO and government services. In Tororo for example, people with eye conditions identified through the government model services were referred to the St. Benedictine hospital for medical interventions. In Mbarara the district local government has a powerful system for identifying PWDs who need rehabilitation services. They are referred to Organized Useful Rehabilitation Services (OURS).
- **Networking and exposure:** Experience sharing is encouraged across CBR programmes, and this in Uganda happens in both directions: government staff learning from NGO pilot schemes, and NGO staff learning from government programmes. In some instances, government and NGOs organize joint learning visits. For example, in 2005, Sense International organized an exposure visit for CBR officers from government and NGOs to learn from Kenya's experience of providing services to deafblind people using CBR strategies. The lessons helped to effect a transition in Uganda, away from a predominantly institutionalized service delivery to a community led one, for deafblind people.
- **Research:** This is important to improve the body of knowledge. At Kyambogo University, the CBR Action Based Disability Research Project, is promoting

research in new ways of teaching CBR using the leaved experiences of disabled persons.

- **North-South corroboration:** Both governments and NGOs are instrumental in promoting exchange of information, expertise, technological and financial resources between the North and South.

All the points discussed demonstrate the ground for practical corroboration between government and NGOs in the delivery of sustainable CBR programmes. Unfortunately, the extent to which this is actualized is often wanting. Lack of partnership between Government and NGOs has significantly constrained CBR in reaching its full potential. Therefore, the paper calls for systematic, structured and purposeful partnership between government and all other players in the design, delivery, monitoring and evaluation of CBR programmes.

Collaborative Inter-professional CBR at the University of Western Cape

The following sections aim to draw the readers' attention to the changing face of CBR, and to the links that can be created to improve CBR practices through mobilising inter-professional education. This is explored through the example of the University of the Western Cape in South Africa.

With the evolution of the CBR concept from Alma Ata Declaration in 1978, to the CBR Guidelines launched in the Conference, CBR is now rightly identified as a poverty reduction strategy, enrooted in community development, connected with the human rights agenda and benefiting from increasing information flows in a globalized world.

The following factors have been key to the success of CBR in improving the lives of people with disabilities: partnerships with disabled people and communities, community ownership, government commitment, and also good communication and special backup from professionals working together. The 2003 Review of CBR conducted by WHO brought higher recognition to the role that Disabled Peoples' Organisations (DPOs) can play in educating people with disabilities in different issues and in promoting positive role models.

Specific interest has also been paid to explore the extent to which Inter-professional Education and Collaborative Practice (IECP) could contribute to strengthen CBR within national health systems. As explained by a student leader, "inter-professional education... [can be defined as] an opportunity to not only change the way we think about educating future health workers, but is an opportunity

to step back and reconsider the traditional means of healthcare delivery. I think that what we're talking about is not just a change in educational practices, but a change in the culture of medicine and health-care"¹.

The six regional offices of WHO collected case studies on IECP and CBR. A literature review was also carried out with responses mostly coming from America, Europe and Japan – fewer from Africa. Participants described how IECP manifested itself in their environment and the barriers and facilitators to this type of practice. Further analysis made it clear that a strong political framework that encourages inter-professional education and team work is essential, as well as shared governance models and an enabling legislation. At a practical level, inter-professional health care teams function most efficiently with shared clinical pathways and a common patient record. It is also very important to develop health care leaders who will ensure that such models are put in place in functioning teamwork and inter-professional education in health care services.

The Faculty of Community and Health Sciences (University of the Western Cape, South Africa) includes Schools of nursing, public health and natural medicine, as well as Departments of physiotherapy, occupational therapy, human ecology and dietetics, psychology, social work and sports. IECP has been driven through three different approaches, of which the Interdisciplinary Community Based Practice module (ICBP) is the most significant. The purpose of this module is to facilitate²:

- Openness in communication across disciplines
- Understanding of perspectives of other professionals
- Increased knowledge of the range of skills of others
- Self-questioning of personal prejudice and stereotyped views
- Positive sensitivity towards other professionals and their values
- Teamwork skills needed for problem solving
- Opportunities to meet others not normally part of clinical placements
- Awareness of areas of crossover and overlap in knowledge and skills
- Understanding of differences in professional language
- Understanding community needs and different cultures

1. World Health Organization. (2010). Framework for Action on Interprofessional Education and Collaborative Practice. Available on http://www.who.int/hrh/nursing_midwifery/en

2. Adapted from: Parsell and Bligh, "Educational principles underpinning successful shared learning. Medical Teacher", 1998.

Students were prepared to conduct orientation, needs analysis, interviews, focus group discussions, surveys and evaluations. They discussed health and social community concerns with local communities and prioritized with them through an action plan. A day was dedicated to involve all community and professionals in a focus group discussion on a given topic, e.g. domestic violence, HIV/AIDS, nutrition etc.

This enabling experience was found very successful to encourage students to be confronted with real work, away from lecturing and traditional research. It enhances the benefits of cross-discipline work and definitely calls for more collaborative work to achieve better results in CBR.

Obstacles and suggestions to enhance partnerships in CBR

Factors that hinder partnerships in CBR

- There are some levels of barriers created by government structures that compartmentalize different facets of service provision. Health, education and social services and welfare, for instance, come under different service arms of government and do not naturally collaborate. Clinical and public health personnel have a different focus. There are certain official structures that guide their placement and operations, that do not encourage easy collaborations across the different sectors. Meanwhile the equalization of opportunities for people with disabilities is a multi-disciplinary affair requiring collaboration of all actors, right from decision-making to implementation and evaluation.
- Professionals engaging the provision of disability-related services are too scarce. An entry requirement for training is often high and the length of training is long (a minimum of three years for most therapists). These factors do prevent CBR workers who have gained some exposure and developed interest in the related fields, from venturing into some of these professional areas because of the long training periods.
- At times, there is also a lack of sufficient understanding by some of the broader range of professionals involved in rehabilitation of their roles within the CBR set-up. They are not aware of the way in which their knowledge can best be used to support social inclusion of people with disabilities.
- Lack of adequate assessment centres: the multidisciplinary approach adopted when doing assessments at centre level is a good illustration of the need for collaboration between the CBR worker and other rehabilitation providers. Yet,

such centres are scarce. For instance, in Ghana, there is only one functioning assessment centre.

- Distance between CBR programme actors and other rehabilitation providers: in the example of Ghana mentioned earlier, the assessment centre is in the capital city Accra. Similar example is in the Gambia, where the tertiary eye clinic and low vision centre is in the capital city. This either delays or prevents CBR actors from utilizing the services. It is costly, difficult to travel and time consuming as it often requires several visits to obtain a comprehensive service.
- Cost of uptake of services: the distance for rural communities to access services as well as the cost of services including transportation, affects the uptake of service. The economic status and/or ignorance of families of people with disabilities living in rural areas regarding the long-term benefit of intervention may also make them reluctant to take advice from CBR workers.
- Complacency on the part of both CBR actors and other service providers: some CBR workers and actors regard themselves as self-sufficient, capable of handling most issues and therefore, may not reach out or give recognition to the role of other professionals. Some professionals also consider their roles as being too specialised and do not prioritise engagement in CBR programmes.
- The anxiety to uphold professionalism does not encourage services professionals to share more skills and resources with CBR staff, for fear of diluting the quality of services. Transferring skills to 'non-specialists' always raises the issue of reasonable limitations to this transfer to ensure that quality, sustainability and benefits for people with disabilities are not compromised.
- Differences of perceptions between grassroots and centres: CBR workers and specialist functional rehabilitation providers' perception may differ significantly. This may even concern the initial diagnosis of impairment and different perceptions of who is to be considered disabled. For instance, a person with low vision living in a rural community, who is able to perform most house chores with minimal challenge may not be given attention by the family and CBR worker, as there is no major obstacle for this person to participate actively in community life. A rehabilitation expert however, may be interested in restoring or enhancing residual vision as part of a professional ethic, demanding that the maximum capacity is restored. Eventually, what matters the most, are the priorities as identified by the person her/himself. Such

situations require strong partnerships between the person with a disability, the CBR worker, the family and other professionals as necessary, confronting experts and valuing peoples' aspirations first.

Suggestions and way forward

- Government should develop policies and structures that support and complement CBR. Provision of an environment that enables partnerships between different levels in the same area of services, as well as linkages between different services, is essential.
- The need for policies that support cost of uptake of services has to be established and/or intensified by including the required services in health insurance packages, by ensuring free medical care for people with disabilities, as well as through other social protection mechanisms.
- The numbers of service providers complementary to CBR need to be increased. To achieve this, efforts in training mid-level cadres has to be intensified, and training provided with an appropriate mindset, emphasizing collaboration and adaptation to community set-up, rather than a sterile opposition between specialist and grassroots approaches. Innovative ways of training therefore need to be introduced, enabling flexibility: for example, consideration has to be given to more modular courses. This allows continuous professional growth over a period of time while working.
- Distance training options with intensive practical attachment need to be explored and expanded, as a means to develop CBR workers capacities.
- Government and NGOs should increase scholarships for such trainees, so that financial constraints do not prevent motivated staff from engaging in skill development.
- Other community and specialised cadres need to be exposed to disability, disability-related studies in general and CBR in particular, as part of their curriculum during training, i.e. disability and CBR as a strategy to operationalise the principles of the UNCRPD need to be mainstreamed into the curricula of community stakeholders. Exposure to disability studies will enable them to appreciate the role of CBR and how their own roles are critical for the equalisation of opportunities for people with disabilities. For example, all students in teacher training in Ghana take courses on special needs education. Sightsavers and their partners including DPOs are advocating for similar adjustment in Sierra Leone and Liberia.

- The role of assessment centres, the multi-disciplinary approach that exists, the practice of referrals done by assessment centres and follow up support after placement are a unique illustration of effective partnerships between CBR and other services involved in rehabilitation. Availability of sufficient assessment centres staffed with the right rehabilitation officers working closely with CBR actors is necessary to ensure continuum of service delivery, and subsequent improved outcomes for people.
- Emphasis has to be placed on the person with disability in a way that empowers him/her to make decisions and gain autonomy. If programmes are person-centred, and the aim is to offer services tailored to each person, partnership building will become necessary. Specialists, whether providing health-related support, counselling or educational services, need to recognize that there is a continuum of services that do not end at a clinic, a school or an office. DPOs, family members, CBR workers and other community actors all have roles to ensure inclusion of the person.
- To get over differences of perceptions, people need to learn to collaborate more. For instance, primary health care stakeholders can transfer basic knowledge and skills to the community, especially to CBR workers. The health sector also needs in turn to make efforts to ensure that health-related rehabilitation is part of primary health care and that personnel are adequately trained in a rehabilitation aimed at optimizing people's inclusion.

Conclusion

A person-centred, rights-based approach is essential to the success of all development programmes. This is all the more important when considering programmes in emerging areas such as CBR. Without collaboration between CBR workers and the other various service providers, without proactive facilitation of processes that include people with disabilities as key players in close coordination with others, their human rights are unlikely to be realized. Governments, NGOs, professionals, academia, DPOs, family and all need to shift their minds and create conducive environments to ensure that effective partnerships exist between CBR and the broad range of other services required for people to live meaningful lives.

References

DISABILITY/Resources/280658-1172608138489/ PovertyDisabElwan.pdf

ELWAN, A. (1999). Poverty and disability: A survey of the literature. World Development Report 2000/2001 Social Protection Discussion Paper 9932. World Bank Group. Retrieved August 25, 2007, from http://siteresources.worldbank.org/Ghana_1996--an_ophthalmologist's_experience/ www.ncbi.nlm.nih.gov/pubmed/9296862

HARTLEY, S (1998). Service development to meet the needs of “people with communication disabilities” in developing countries. Disability Rehabilitation 20, 277-284. WHO (2005) Retrieved October 14, 2007,

HARTLEY, S. (Ed) (2002) CBR-A Participatory Strategy in Africa. University College London. <http://www.ableize.com/clinics-amp-practitioners/rehabilitation/> - Disability Directory of disabled information aids and mobility services; <http://www.aiaer.net/ejournal/vol19107/23.htm> -Rehabilitation of the Disabled Women: Need of a holistic approach ; <http://www.eenet.org.uk/resources/docs/lessncbr.php> - PartnershipwithDisabled people, Parents and the community: LessonsfromCommunityBasedRehabilitation (CBR) in SouthernAfrica

MINISTRY OF LABOUR AND HUMAN WELFARE; (1998) Tasting the Fruits of the CBR Programme, Evaluation of the CBR Programme in Debub Region; Ministry of Gender Labour and Social Development. Asmara. Ethiopia, Pg 16

NGANWA A, DDAMULIRA M, MWESIGYE J (2004) ‘Is It Ours? ‘An Evaluation of Tororo District CBR Programme; Ministry of Gender, Labour and Social Development, P.O. Box 7272, Kampala, Uganda. Unpublished report.

TARIMO E, WEBSTER E G (1994). Primary Health Care Concepts and Challenges in A Changing World: Alma Ata Revisited; Division Of Strengthening Of Health Services, WHO, Geneva. Unite For Sight, Inc. - Ghana Eye Care Professionals Encouragewww.uniteforsight.org/.../ghanaeyecareprofessionals.php

ILO, UNESCO, WHO (2004). Community Based Rehabilitation: A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities, Joint Position Paper. http://whqlibdoc.who.int/publications/2004/9241592389_eng.pdf

WHO,UNICEF (1978). Primary health Care, A Joint Report by the Director-General of the WHO & The executive Director of the United nations Children’s Fund, International Conference on Primary Health Care Alma-Ata, USSR, 6th-12th September 1978, Pg2, Geneva.

CHAPTER 4

Capacity Building in CBR: Learning to Do CBR



Copyright © Olivier Asselin

Disabled girl in a wheelchair among peers in a classroom in Dakar, Senegal, on Thursday February 4, 2010.

CHAPTER 4

Capacity Building in CBR: Learning to Do CBR

Huib Cornielje, John Majisi, Victor Locoro

“The practice of rehabilitation without detailed knowledge of the ordinary lives of people with disability is like the sound of one hand clapping” (M Miles, 2002)

Summary

The authors of this chapter all have ample experience in training CBR personnel at various levels. They strongly believe that CBR trainers should make use of modern adult education principles and methods. The CBR Guidelines do not provide clear-cut solutions and answers to all the needs experienced by personnel working in the field of CBR and certainly not to the needs of persons with disabilities. Realising that no standard and uniform answers can be given to the training needs of CBR personnel forms the basis of content of this chapter. There are no recipes and prescriptions for the often complex problems field workers or CBR managers are confronted with. The authors share the conviction that CBR needs agents of change; proactive resourceful persons who have been trained and prepared to work together with persons with disabilities, families, communities, governmental and non-governmental organisations to jointly find solutions for problems, to think ‘out of the box’ and to become problem solvers. Synchronisation of training at national levels may be of importance and benefit to all concerned stakeholders, while it remains important to ensure maximum contextualised CBR development.

Training in CBR

Reviewing the training scene in CBR is a daunting task, which seems to be a challenging assignment for someone interested in pursuing a degree in adult education or social sciences. It is not possible to give in this chapter, a complete overview of global CBR training programmes. However, there are a number of developments that warrant some discussion. The authors observe a couple of developments in current training of CBR personnel.

The banking approach in training and education is still alive!

In spite of good intentions, there is still a tendency to train CBR field workers in the traditional way i.e. offering short training programmes, preferably as short as possible, as this is liked by donor organisations who like to go for the 'quick fix', easy and cheap solutions. It appears that the shorter the training, the better the programme would be. Those who are involved in adult education know better that it takes time to educate people, teach them new competencies, and they know that people learn in different ways. Consequently, a variety of more modern adult education methodologies is required to ensure that all trainees are learning effectively.

Formal training and informal training in CBR

CBR training is of various and at times dubious length. While short training programmes that focus on specific cadre and having specific objectives, such as training programmes for managers in CBR; train-the-trainer programmes, or CBR leadership training, have a place and role to play in the arena of capacity building in CBR, such length of basic training for CBR field staff is by far too short. There are fortunately developments that take into consideration that prospective fieldworkers are faced with challenges and tasks that require a far more intensive training. However, short training of volunteers may be justified as long as these volunteers play a limited and time-limited role in CBR. As soon as it is expected that they play a more or less formal role in the CBR field, such training is usually taken as not sufficient. On the contrary, it requires intensive training – both theoretical and practical – to take on the task of becoming key CBR staff; formally employed in clearly defined function and with roles that focus on establishing and developing CBR at local levels. Such staff could be the backbone of CBR systems that are so much needed in many parts of the world. There are trends in many parts of the world which have led to the development of more formal training programmes at college and university levels, leading to diplomas and degrees. In such formal education programmes, one should be aware of the fact that those highly qualified people won't be interested in the work that needs to be done at field level, in and with the communities.

'Rehabilitation for All doesn't need training at all'

There is however, a tendency of people who believe that CBR does not require specially trained cadres. They believe that CBR is an approach that needs to

be adopted across sectors and eventually generates categories of all sorts of professionals and practitioners who just, as part of their profession, will contribute and 'do' CBR. If such a development is realistic, it is yet to be seen. The authors of this chapter believe that such a development may easily lead to watering down the practice of CBR rather than securing sustainable developments in CBR. As long as CBR is not having an established identity, it runs the risk of being ignored or forgotten. The survival of CBR lies largely in its much needed professionalization or institutionalisation. Without formal government involvement, without being part of rehabilitation systems, the CBR approach will remain vulnerable and prone to being ignored.

Can we abolish community-based rehabilitation personnel?

CBR is clearly an approach towards developing a more inclusive society. As such it requires efforts from all spheres of life and sectors to become inclusive and ensure the full participation of persons with disabilities. CBR thus needs a strong multi-sectoral focus, as disability is a cross-cutting development issue. Thus, it means that in order to make CBR a success, all professional training should have a disability awareness component in it. In practice, it would mean that the health sector should be made aware of the needs and demands of persons with disabilities; the educational sector should become inclusive to persons with disabilities; the social sector should focus their work on the acceptance and participation of persons with disabilities; the livelihood sector should ensure that persons with disabilities enjoy the same entitlements and access to work and employment as every other citizen, and empowerment of persons with disabilities should become a deliberate strategy to enable persons with disabilities to live a life equally as their non-disabled peers. While these principles are fundamental to CBR, the inclusion of persons with disabilities is not automatically taking place. It requires training of mainstream organisations and professionals, both in formal and informal settings e.g. at universities and colleges, as well as at the workplace through seminars and workshops.

On the other hand, specifically trained rehabilitation personnel remain to play an important role in the area of community based rehabilitation: both the professional staff such as therapists, social workers as well as CBR cadres themselves. CBR without specially designated personnel may all too easily become a nice philosophy without having any practical meaning for people with disabilities, their families and communities. It is like having rights without having access to

services and not being able to claim entitlements. The road to inclusion for all, indeed needs a deliberate strategy and requires cadres of staff that make this change to happen.

Learning to do CBR requires more!

“If your only tool is a hammer, every problem (including opening a bottle) looks like a nail. You break a lot of bottles that way” (Unknown source)

Learning to do CBR requires special cadres and the training of these cadres needs to focus on the much needed structural changes in society which are usually impediments to the growth of CBR. This means that CBR personnel should be trained to meaningfully execute their role and be able to contextualize CBR in different cultural settings to enable CBR to be appreciated by stakeholders.

Based on decades of experience and on the starting points of the CBR Guidelines, it is obvious that we don’t need mini-therapists, or the “extra pair of hands” of the rehabilitation professional. The new CBR thinking requires CBR cadres who are liaison persons or linking pins between the various sectors. They need to be aware of the network of resources and services available; they need to be networkers; they most of all need to be agents of change and problem solvers themselves. Such a role will ensure that persons with disabilities and their families are enabled to come into contact with the right mainstream resources, or at times with special services that are required.

Such a more contemporary role of the CBR cadre has serious consequences for the type of training that is needed. It requires a different training philosophy and training methods. It requires that trainees are equipped to become multi-functional and multi-skilled; that they become ‘out of the box thinkers’. Various modern adult educational methods need to be used to equip such a cadre; both for the cadre at grassroots level and at a more intermediary level. Conscientization, reflective analysis, critical thinking skills and creative thinking are necessary components of such a training programme. This certainly cannot be achieved with old-style frontal classroom teaching. Rather, it should have strong practical community based training assignments; theoretical lessons in the form of experiential learning through, for instance, case study analysis, role play, syndicate work and interactive teaching.

The CBR Guidelines among many other publications and manuals do not give guarantees that CBR is being done in the way it is envisaged by those who worked

for so many years on these Guidelines. It is paramount that the Guidelines alone are not making the necessary change to happen. Probably the most single – but also most challenging - factor that can make change happen is the change of mindsets. Mindsets cannot be changed by conventions, declarations and law. Mindsets can be changed by giving living examples and by conscientizing people about those norms and values that do not lead to an inclusive society. Mindsets can also be changed through training and education.

CBR Guidelines – training packages – standardization of training (materials)

The need to synchronize CBR training programmes arose out of the first CBR Africa Conference held in Uganda in 2001. Currently, 10 years down the line, there moves into the direction of so-called training packages. That may be a useful and necessary development and putting training in the centre of much needed developments. However, there is a risk that packages will be seen as being prescriptive. Besides, there is the risk that such packages will consist of too easy and too simple training materials. There is without doubt a great need for CBR training materials. Yet, such materials will never be able to replace trainers and/or facilitators! While there are advantages of – at least – some standardized forms of training, CBR training requires that the C of the approach will continuously be taken into account. Without contextualizing CBR, CBR is doomed to fail. The authors strongly believe that governments should come into the driving seat of setting the parameters for CBR development: they should develop policies. Within these given parameters, CBR should be allowed to develop within the local context and thus maximum freedom for contextualization should be allowed. Similarly, basic guidelines of training may be useful and offering certain standards for training; yet maximum freedom in contextualizing training should continually be allowed.

While the above principles appear logical and much needed, there are however, important benefits of more synchronization of CBR training programmes as well; certainly at a national level. CBR Africa Network (CAN) carried out an evaluation of existing training programmes in Uganda to establish their similarities, differences and relevance to the needs of beneficiaries (Nganwa, et al, 2003). That evaluation recommended synchronization of long duration training programmes and validation/accreditation of short duration courses and some non-formal programmes.

The benefits of synchronization are as follows:

- It gives continuity of training from one level to another e.g. certificate to diploma and diploma to degree;
- It could greatly contribute towards and improved quality of training and subsequently trainees;
- It can be a major step forward towards recognition and helps to improve the status of CBR through accreditation and transfer of credits; and
- Last but not least, it can form a facilitator in the much needed sharing of – scarce - resources and experiences and may help to execute joint training and joint research and development programmes.

References

CORNIELJE H, VELDMAN E (Eds)(2011). The Dream of Inclusion: powerful CBR training materials. Published October 2011, Enablement.

CORNIELJE H, FERRINHO P (1995). Community Development Skills: essential component in the training of community rehabilitation facilitators at the Institute of Urban Primary Health Care in South Africa. - CHASA Journal of Comprehensive Health, Vol. 6, No 1, pp 28-32, January/March 1995.

CORNIELJE H (1994). The Development of Critical Thinking Skills in the Primary Health Care Workers Courses at the School for Primary Health Care in Alexandra, South Africa. Adult Education and Development, No 42, Germany, June 1994.

NGANWA A, MIREMBE J, KISANJI J (2010). An Evaluation of CBR Training Programmes in Uganda, CAN Consultancy report, 2003.

IDDC, ILO, UNESCO, WHO (2010). Community Based Rehabilitation Guidelines. <http://www.who.int/disabilities/cbr/guidelines/en/index.html>

CHAPTER 5

The Link between Health-Related Rehabilitation and CBR



Copyright © Olivier Asselin

A health worker vaccinates a child against polio in the village of Gidan-Turu, northern Ghana on Thursday March 26, 2009.

CHAPTER 5

The Link between Health-Related Rehabilitation and CBR

Alice Baingana Nganwa, Barbara Batesaki, Joyse A. Mallya

Summary

Health care plays an essential role in achieving quality rehabilitation of persons with disabilities, most especially within CBR programmes. The authors of this chapter review the structural composition of primary health care and CBR and outline the overlap in both interventions. Opportunities for creating linkages are discussed and the challenges that usually arise through working across the two sectors, of health and social services respectively, are identified and expounded with a practical example of an NGO in Uganda and a speech and language therapy unit in Tanzania. The chapter further discusses the gaps of human resources in health-related rehabilitation and concludes by making suggestions aimed at positioning health-related rehabilitation within CBR.

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Article 26 (Habilitation and Rehabilitation) outlines measures State Parties should undertake to ensure people with disabilities are able to access health-related rehabilitation including:

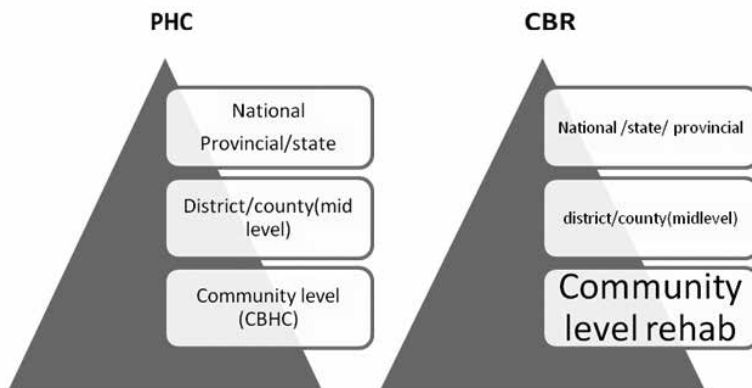
“... appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”.

Article 26 further states that services must begin at the earliest possible stage, should be based on multidisciplinary assessment of individual needs and strengths and should include provision of assistive devices and technologies.

Health-related rehabilitation is a rights-based approach that involves scientific approaches to promote health and wellbeing which include restoration of movement and function when someone is affected by injury, illness or by developmental or other disability. Health-related rehabilitation services are provided by a broad range of personnel including medical professionals, such as physiatrists, nurses; therapy professionals, such as occupational therapists, physiotherapists, speech therapists; technology specialists, such as orthotists, prosthetists; and rehabilitation workers, such as community based rehabilitation workers. Services can be offered in a variety of settings, including hospitals, clinics, specialist centres or units, community facilities and homes. The stage at which rehabilitation occurs and the type of intervention required, in most cases determines which setting is appropriate. The main focus is to empower persons with disabilities, the family and the community towards inclusive societies enabling participation of all.

Structural and organisational comparison between Primary Health Care and CBR

Pyramids of Care: the two concepts of primary healthcare and CBR are both based in the community and have structures that link up to the national level as shown in the diagram.



Their mandates define the components which are:

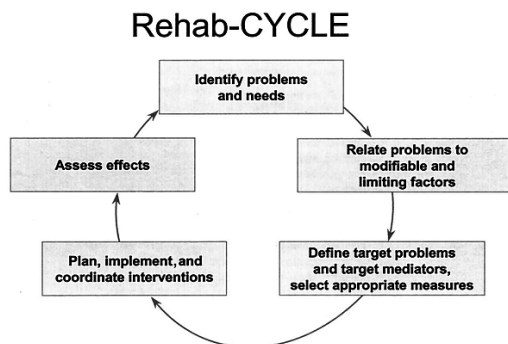
- For Primary Health Care: promotive, preventive, curative and rehabilitative health services
- For CBR: the health, education, social, livelihood and empowerment components of the CBR Matrix.

Health professionals need to understand the CBR Concept for them to;

- Appreciate the importance of early identification, assessment and provision of relevant intervention.
- Understand the role of CBR Workers, family, community and local artisans in health related rehabilitation and the importance of building their capacity in terms of training and providing the CBR workers with the basic necessities/incentives to ably carry out their role.
- Understand the multi sectoral approach to rehabilitation and the role of the different stakeholders
- Be mindful of the socio economic effects of the rehabilitation programme and the disability in general.

People with disabilities require health services for general healthcare needs like the rest of the population. General health services include health promotion, preventive care (immunization, general health screening), treatment of acute and chronic illness, rehabilitation and appropriate referral for more specialized needs when required. These needs should all be met through primary healthcare at primary, secondary and tertiary levels. Within low-income and lower middle-income settings, CBR programmes can promote and facilitate access to healthcare services for people with disabilities and their families. The programmes can assist people with disabilities to overcome access barriers, train primary health care workers in disability awareness, and initiate referrals to health services.

There is therefore, a wide overlap between primary health care and CBR, particularly within the health component. This is further demonstrated in the following which shows the rehabilitation cycle:



Source: Steiner WA et al. Use of the ICF model as a clinical problem-solving tool in physical therapy and rehabilitation

To guide healthcare professionals in successful rehabilitation management, Stucki and Sangha(1998) developed the Rehab-CYCLE. The ultimate goal of the Rehab-CYCLE is to improve a patient's health status and quality of life by minimizing the consequences of disease. It is a structured approach to rehabilitation management that includes all tasks from problem analysis to the assessment of the effects, thereby centrally involving the patient in clinical decision-making. The emphasis is on the patient's perspective, taking into account the patient's needs and preferences, and discussing therapy goals.

Linking health-related rehabilitation and CBR in programmes

Health-related rehabilitation is the foundation, which promotes and contributes to the realisation of the other four components CBR-social, education, empowerment and livelihoods. Its absence reduces the effectiveness of all other CBR efforts. Even when the environment is maximally improved, there will always be a need for treatment of health conditions, reducing the impact of impairments, and preventing or treating complications. Health care services including health-related rehabilitation should be accessible to persons with impairments as a right. Thus, health-care workers including general clinicians with orientation in health related rehabilitation and rehabilitation professionals, such as physiatrists, rehabilitation doctors and a broad range of therapists, have the potential to take up a number of roles in CBR depending on cultural and socio-economic circumstances. This can be through:

- Preventing disabilities and long-term consequences of diseases and injuries, by making timely and relevant interventions (for instance, in management of burns)
- Educating and training people with disabilities and their families on the importance of proper medication and dosage, or in positioning and movement in performing physiotherapy
- Promoting self-reliance
- Counselling
- Building capacity of other healthcare staff
- Ensuring health promotion and disease prevention
- Providing curative and rehabilitation services

- Being team leaders and managers of CBR programmes
- Advocating with people with disabilities, local communities as well as the healthcare professionals
- Advising governments, NGOs and local communities on establishing CBR programmes including recruitment of skilled personnel.

Challenges in developing the link with CBR

The reality is that CBR programmes often have a small and informal link with health-related rehabilitation. In some cases, a misinterpretation of the CBR shift of paradigm towards a social and rights-based approach may result in sidelining rehabilitation medicine and care, as associated with the medical model. Within the health system, functional rehabilitation itself is often relegated to the periphery of primary health care and often appearing in ‘unfunded priorities’ in district and national programmes.

The consequences of the gap in linkages are inadequate services to patients, including people with disabilities, often leading to slow recovery and to secondary disabilities. For example, a child with Cerebral Palsy (CP), who is required to visit a CP clinic once or twice a month will not be in a position to continue the exercise at home because the parent does not have the required device at home. However, if the parent receives skills in utilising locally available resources, found within the home setting, and is taught how to continue the rehabilitation exercise at home, the child will gain milestones.

Since the majority of persons with disabilities live in rural communities, CBR programmes usually take the initiative to develop linkages with experts in health-related rehabilitation. The CBR programme provides transport and allowances to enable health professionals based in district and referral hospitals to reach specific CBR project areas. At the outreach point, the CBR volunteers and supervisors will have identified people who have impairments that require rehabilitation. The team assesses and provides advice and treatment and refers some clients to the next level for surgery or intense physiotherapy. Unless the CBR programme supports the referral process, very few clients actually reach the district and regional level for expert intervention. This is particularly true for parents of children with disabilities who need physiotherapy in the early stages of development. It becomes close to impossible to access the services when they are told to take the child to hospital on a regular basis.

The disadvantage of linkages between CBR and primary healthcare is that they are donor-dependent and not sustainable. The linkage breaks down when the project cycle ends. Another bottleneck is when an area has several donor-led CBR programmes, they tend to divert medical professionals from the main hospital to the outreach services. The therapists, on the other hand, are attracted to outreaches because of the extra money they earn. As a result, the clinic in the hospital is marginalized. This is especially so, if the station has one therapist or specialized clinical officer. The in-patients are also affected and worse still the head of the health facility does not appreciate the role of the rehabilitation profession. This has often led to conflict between the rehab professional and their non-rehab line manager.

Another challenge is the CBR programmes which are established quickly to meet targets in terms of numbers of people with disabilities reached. Such projects will not invest in training community volunteers thoroughly, but focus on bringing professionals to the community. In such settings, rehab professionals then go beyond their role of training, supervising and managing difficult clients to carrying out primary rehabilitation. Such an approach is not beneficial to clients particularly children with complex disabilities, who require daily therapy and closer supervision of parents to ensure the children are receiving exercises and are correctly positioned. The CBR project will have reached its targeted numbers but only a few clients will have received meaningful interventions and little or no skills will remain in the community. It is in such CBR programmes that the children with disabilities revert to the pre-CBR state once the programme stops.

Health-related rehabilitation is usually planned for in the CBR programmes, but not consistently within the government health sector. Clients of rehabilitation programmes are often perceived as a smaller group, unlike malaria patients or children who require immunization. Specialists in rehabilitation medicine address the stage of disease where curative care providers feel they have failed and refer the patient to rehabilitation. The curative clinicians do not appreciate the role of rehabilitation medicine early in the process. A consequence of this is that rehabilitation personnel tend to be more linked to an active CBR programme, than to their parent sector (health services).

Experience from Uganda – The case of the Uganda Society for Disabled Children

Uganda Society for Disabled Children (USDC), a Uganda registered NGO, implemented CBR among children with disabilities and their families in several districts in Uganda. USDC attempted to strengthen the base within Primary Health Care (PHC), while supporting teams of health specialists to reach children with disabilities. The support to the PHC base included rehabilitation of the physiotherapy/occupational therapy departments, establishment of orthopaedic workshops and in-service training of therapists, especially in developmental disabilities. USDC succeeded in getting health-related rehabilitation on the agenda of PHC programmes at district and hospital levels. The districts started recognizing the role of rehabilitation and including it among the priorities for funding. In some districts, this included taking the rehabilitation team on PHC outreaches, although this did not work well due to different target groups of the outreach team. For instance, the rehabilitation team would take half-an-hour assessing a client, while the immunization team would have covered 30 children during the same time span.

This disjointed effort to address the rehabilitation component of PHC demonstrates the challenges that arise from add-on programmes rather than inclusive systems. Disability was simply added to a preventive/curative outreach team and this may meet process indicators and policies that call for including disability, however, the reality is that little has been achieved.

Cadres in health-related rehabilitation

In sub-Saharan Africa, with the exception of South Africa, health-related rehabilitation cadres are allied health workers and paramedical officers. They include ophthalmic clinical officers, physiotherapists, occupational therapists, orthopaedic technologists, technicians and orthopaedic officers. They are based in regional and district hospitals. In larger hospitals such as regional or provincial units, they may work alongside ophthalmologists, orthopaedic and Ear, Nose and Throat surgeons. In some countries, health specialists are only available in national referral hospitals. Medical rehabilitation workers in district hospitals are led by medical officers, often with public health specialization, but who do not appreciate the role of rehabilitation medicine. This means that such services are not high on the list of funding priorities. When a CBR programme supports the work

of a health worker with equipment, maintenance and outreach, the confidence of the rehabilitation team tends to lean towards this external hand since the inner system does not provide adequate support. The shift in alliance coupled with poor support from PHC where rehabilitation medicine has its base, does not contribute to sustainability of the health-related rehabilitation service.

Speech and Language Therapy in Tanzania – Muhimbili National Hospital

In 1980, a speech and language therapy unit was established at the Muhimbili National Hospital and from 1990-1998; it was employing 2 speech and language therapists. One was a volunteer from Voluntary Services Overseas (VSO) based at the national referral hospital and the other at a referral hospital in the northern region. However, VSO stopped sending Speech and Language Therapists in late 90s.

The workload for speech therapy services became overwhelming and made individualized direct or intensive treatment sessions not possible with clients. At the same time, the treatment programme involved; assessment, counseling, advising and providing a home training programme. Family participation was also emphasized. It therefore meant that follow up appointments were scheduled according to the severity of the problem and the distance the person had to travel to the hospital.

In essence, it was a medical-model treatment programme based within the hospital and had the advantage of a multidisciplinary team consisting of physiotherapists, occupational therapist, psychologist, psychiatrist, a physician and Ear, Nose and Throat specialist. However, in most cases the service ended at the hospital. Due to the increased demand for speech therapy services, therefore, there was need for alternative treatment services to benefit a majority of people. Consequently, the CBR concept of a decentralized approach to rehabilitation that encompasses the philosophy of offering services to a large number of people with disabilities, in their own communities, was adopted.

Training of Human Resource in health-related rehabilitation

An important long-term strategy is to ensure availability of health care workers at all levels with special emphasis in the community. They could be trained within the

country but for nations with a small population, it may be cost effective to train them outside the country. As far as possible, Government should take responsibility for the training. In addition, all health workers in their basic training require a measure of rehabilitation medicine. All doctors and other health workers should graduate with knowledge of CBR and a clear understanding of their role in providing the five elements of the health component (see CBR Matrix). The detail of knowledge will depend on the cadre of health worker. For example, whereas a physiotherapist will require more detailed knowledge about mobility assistive devices, a midwife will require more in-depth communication skills with women with disabilities. Some key components such as adopting a person-centred approach, understanding the multi-dimensional and contextual nature of disability, and practical tips to be truly inclusive and accessible will be essential to all professionals.

The training of health workers is often difficult to influence even during curriculum review. Changes in demographic and disease patterns exert pressure on curricula for health workers. For CBR to have a long term influence on health training, there is need for CBR managers, promoters and partners to invest in at least a Ph.D in CBR within the health training institutions. This will be a powerful and respected leverage for the programme to positively influence the training of health-related rehabilitation workers.

Additionally, although community rehabilitation workers are trained to provide training, therapy, stimulation and give advice to parents, many of them do not receive training in intervention methods for some disabilities such as communication disorders. They should therefore be given additional training to enable them treat people with communication disorders within the community setting. Aspects of the training could cover normal development of communication, disorders of communication, development and stimulation of verbal and non verbal communication, assistive devices and behavior problems of children with communication disorders. They could also address retrograde regressive cultural practices and beliefs within the community which are harmful.

Suggested solutions to position health related rehabilitation in primary healthcare

Linking health-related rehabilitation to CBR, or in some situations within primary health care, is a long-term process that may take between five and twenty years

depending on the level of action. If the process is at district level, it will take a shorter time than at the national level. The latter may require policy change with subsequent implication for training of human resources in health.

Healthcare providers perceive people with disabilities as recipients of services, an attitude derived from the medical model, but this is slowly changing; and where it still exists it must change. Patients including people with disabilities, have a right to make decisions. Health professionals should discuss treatment or rehabilitation plans with the client, in view of assessed needs and priorities of the person, who may include the family.

People with disabilities should be empowered to understand the services they need to receive from healthcare professionals. For instance, the issue of therapy is not about who is providing the services but the relevance of the services in light of his/her needs, convenience as regards accessing the services and the approach of the service provider.

Health-related rehabilitation should be securely positioned in primary health care. This requires that PHC programmes include rehabilitation in their plans, budgets, human resource allocations, supervision guidelines and output and outcome indicators to measure service delivery. PHC systems need to appreciate the unique role that rehabilitation plays in CBR, which is beyond mere outreach support, to providing a functional referral system. This calls for leadership in both PHC and CBR that thinks outside the box. Usually it is leadership from CBR that takes the initiative to talk to PHC programme managers about the need for rehabilitation services. It is often CBR that supports the establishment of health-related rehabilitation. In some instances, the rehabilitation specialists may take the initiative. Where national guidelines on health-related rehabilitation are lacking or absent, the UNCRPD could be used to explain the policy/legal framework for providing rehabilitation services and the relevant sector supported to start the service. In Uganda, where decentralization is deeply entrenched, it is easier to start the service at district level. In situations where there are few rehabilitation professionals, governments could invest in building capacity of Community Based Rehabilitation workers to ensure that they acquire more knowledge and skills to be able provide relevant support in regard to health related rehabilitation to families of persons with disabilities . Besides training, the national and local government budgets should provide for incentives for the CBR workers.

The next level is to expand from the existing ad-hoc arrangements based on goodwill of leaders in healthcare to development of policies, guidelines and standards. In this case, the rehabilitation service which was developed to demonstrate evidence of the benefits of CBR can be mainstreamed into Government rather than NGO budgets. Roles also need to be defined, especially the following:

- **Assistive devices:** who produces assistive devices; is it the private sector or government. If government, is it the health sector or social development? Where do funds come from to pay for them; is it the social department? Is it the health sector? Is it the client/donor?
- **Referral for rehabilitation:** Completing a referral form is not enough. Who pays for the transport, the medical fees and the up-keep? In several programmes, lack of funds to facilitate referral has frustrated both the family and the CBR workers.
- **Outreach and supervision funds:** CBR is often placed in the social development and health-related rehabilitation in health. Who gives the mandate for health workers to supervise the CBR volunteers and supervisors? Should the supervision always be joint; the social/community development with the rehabilitation team?

Health professionals need to understand the CBR Concept for them to be able look at a person in totality throughout the rehabilitation programme particularly the social economic effects and to appreciate the role of different actors especially the role of community workers in rehabilitative health care. The community workers play a major role in early identification of disabilities, depending on the training they have had they are able to do the general assessment and make appropriate referrals; they do follow up on what has been recommended at the health centres. For example a physiotherapist can train a parent on what to do at home and working together with a CBR worker a lot can be achieved at home. Still, a trained CBR worker has knowledge and skills to make simple assistive devices using locally available resources; in this case the physiotherapist working with the CBR Worker together with the parents can make a number of devices relevant to the needs of a person with disabilities specifically noted a child with CP who may need different devices as he/she progresses along with age. A local artisan, such as a carpenter can be engaged when making wooden devices e.g. special seats and standing or walking frames.

Recommendation

Governments need to consider the importance and need for rehabilitation services at lower health centres. This could be through organising outreaches from regional and district hospitals to lower health Centres which could be at Health Centre IV in the case of Uganda. The services will not only benefit people with disabilities but even old people who need health related rehabilitation whom having the service close to them could save them from becoming disabled due to lack of access to rehabilitation services.

Conclusion

In conclusion, it is important to realise that the provision of quality health care is a human right for all, including people with disabilities. It requires collaborative efforts from all players in health as well as beyond health. There should be a direct link between rehabilitation doctors and other health care workers at all stages including identification, prevention and management. A weak link affects the progress of persons with disabilities including their families, and may impact on other aspects of the disabled person's life, such as education, livelihoods, social and empowerment. Linkages can be strengthened at district level, and this can set a precedent for policy formulation. Ultimately, there is a need to influence the training of health workers and improve staffing norms to ensure that those who are trained are able to provide services to people with disabilities, including those who live in rural areas.

References

- UN (2006). Convention on the Rights of Persons with Disabilities. United Nations, Geneva. (<http://www.un.org/disabilities/convention/conventionfull.shtml><http://www.un.org/disabilities/convention/conventionfull.shtml>, accessed 20 March 2013)
- WHO (2010). Community-based rehabilitation guidelines. World Health Organisation, Geneva
- WHO (2011). World Report on Disability. World Health Organisation, Geneva.
- GUTENBRUNNER C, WARD A B, CHAMBERLAIN M A (2007). White book on Physical and Rehabilitation Medicine in Europe. Journal of Rehabilitation Medicine: official journal of the UEMS European Board of Physical and Rehabilitation Medicine, 45: Suppl 6-47.
- STEINER W A ET AL (2002). Use of the ICF model as a clinical problem-solving tool in physical therapy and rehabilitation medicine. Physical Therapy, 82 vol 11:1098-1107.

CHAPTER 6

The ICF as a Tool to Support CBR Planning and Management



Copyright © Olivier Asselin

Disabled boy in a wheelchair among peers in a classroom in Dakar, Senegal, on Thursday February 4, 2010.

CHAPTER 6

The ICF as a Tool to Support CBR Planning and Management

Ros Madden, Sally Hartley, Elias Mpofu, Ali Baguwemu

Summary

The International Classification of Functioning, Disability and Health (ICF) is an international framework and classification for disability, and recognises disability as a multidimensional experience affected by environmental factors. Here we discuss its relationship to the philosophy of the UN Convention on the Rights of Persons with Disabilities and of the CBR Guidelines including CBR principles. These relationships confirm the suitability of ICF as a technical resource to support CBR planning, implementation and monitoring. In this chapter we illustrate how the ICF can support the four stages of the CBR management cycle as described in the CBR Guidelines. Users are encouraged to use the ICF to suit their circumstances – for varying purposes and at varying levels of detail. Using a common framework helps cross the language boundaries of people and professions, and supports the collection of data and information which also ‘communicate’. Thus we can build a greater and more coherent body of evidence about disability and the needs for and efficacy of relevant services.

Introduction

Planning and management are critical to the success of Community Based Rehabilitation (CBR) programmes, in that resources can be anticipated and secured for best outcomes. CBR seeks to achieve a wide range of positive outcomes for people with disabilities through context sensitive interventions and support systems, with full participation of the community, and for full community inclusion. CBR is a broader notion than community rehabilitation which is about the delivery of rehabilitation services in community settings and not necessarily with the community. The wider scope of community engagement with CBR

makes careful planning and management an absolute necessity, if intended goals are to be realized.

Various types of planning and management rubrics to guide the CBR are possible. The CBR Guidelines offer overall direction (WHO 2010). The ICF also offers a significant resource to guide and underpin planning and management, in that it aligns with the core aspects for which CBR is typically intended: activity and participation in community environments. According to Schneider and Hartley (2006:114):

‘ICF is one tool within a range of tools that can be used in CBR. It can provide relevant information for individual interventions, programme planning, community and policy development, and monitoring and evaluation.’

This chapter expands on the idea of ICF as a tool to support CBR, particularly in the light of developments since 2006, notably the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which was adopted by the UN General Assembly in December 2006; and the launch of the Guidelines for Community-Based Rehabilitation (CBR) in Nigeria (WHO 2010). After a brief discussion relating CBR and the ICF to the UNCRPD, some examples illustrate how the ICF can be used as a tool to support CBR management and monitoring.

Relating CBR and the ICF to the UN Convention

The UNCRPD, the CBR Guidelines and the International Classification for Functioning, Disability and Health (ICF – WHO 2001) are each in their own way, and with differing degrees of formality, key international resources and guides. While they are very different in form, they are based on a common and coherent view of disability and the rights of people with disabilities. They seek to enable disability rights as human rights to equal participation, health and wellbeing. CBR is an all inclusive approach to translate rights into actual lived community experience.

CBR is described as, ‘a strategy within general community development for the rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all people with disabilities’ and promotes the implementation of CBR programmes “...through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and

other services' (WHO 2010, Page 24). The five components of the CBR matrix provide a common framework for programmes: health, education, livelihood, social and empowerment.

The UN Convention is the international normative legal and moral framework setting out the rights of people with disabilities to be able to participate fully in all aspects of society – the same rights and freedoms as for all people. Its purpose is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities ...' The CBR Guidelines specifically ground themselves in the Convention, being influenced by it and aiming to contribute to its implementation (Guidelines pages 11 and 1). They are based on the same principles as the Convention, adding two further principles (see Box 1).

Box 1: Shared principles of CRPD and CBR Guidelines

Principles of the UN CRPD (*see Article 3*):

Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

Non-discrimination

Full and effective participation and inclusion in society

Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

Equality of opportunity

Accessibility

Equality between men and women

Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

CBR Guidelines: the same principles, with two additional (*see CBR Guidelines page 25*):

Empowerment including self-advocacy

Sustainability

The ICF is an international standard framework and classification for functioning and disability, providing the technical infrastructure for recording, communicating and measuring [WHO, 2001].

How do these three frameworks relate to each other?

Overall, the UN Convention legal framework provides the philosophical vision and the call to action to ensure rights are achieved; the CBR Guidelines offer a framework for specific programmes of services to contribute to the Convention's implementation and to the health and well-being of people with disabilities; the ICF provides a technical framework for functioning and disability, consistent with the principles of both the Convention and the CBR Guidelines.

The UNCRPD establishes that people with disabilities have the same rights and freedoms as all people in the community, including the right to participate in all areas of life, the right to live independently in the community, and rights of access to the same services, of the same quality, as all others in the community (e.g. Articles 1, 19, 25). The Convention requires that statistics relating to access to these rights, be collected in appropriate and ethical ways (Article 31).

Effective planning and management of CBR would enhance the quality and utility of the statistics gathered on the types, range and appropriateness of services for the full community inclusion of individuals with disability.

In line with the UN Convention's view of disability, the ICF has a broad scope – across all domains of functioning in daily life (participation, activities, body functions and structures) – and requires an accounting for environmental factors that influence functioning (see Box 2). Annex 6 sets out ethical guidelines for use of the ICF, such as the need for respect and confidentiality and ensuring that people have opportunities for participating in recording functioning [WHO 2001: page 244]:

- “(3) In clinical settings ICF should always be used with the full knowledge, cooperation, and consent of the persons whose levels of functioning are being classified...
- (6) Wherever possible the person whose level of functioning is being classified ... should have the opportunity to participate, and in particular to challenge or affirm the appropriateness of the category being used and the assessment assigned.”

Box 2: Overview of the ICF

The World Health Assembly adopted the International Classification of Functioning, Disability and Health (ICF) as the world standard framework and classification system in 2001 (WHO 2001), complementary to the older classification of diseases (ICD).

Functioning and disability can be experienced as effects on any or all of body functions and structures, activities that people do, and participation in society. Disability results from the interaction of health conditions with the physical, social and attitudinal environment (Figure 1) and personal factors (such as age and sex). The ICF provides definitions, classifications and codes for its major components: body functions and structures, activities and participation, and environmental factors.

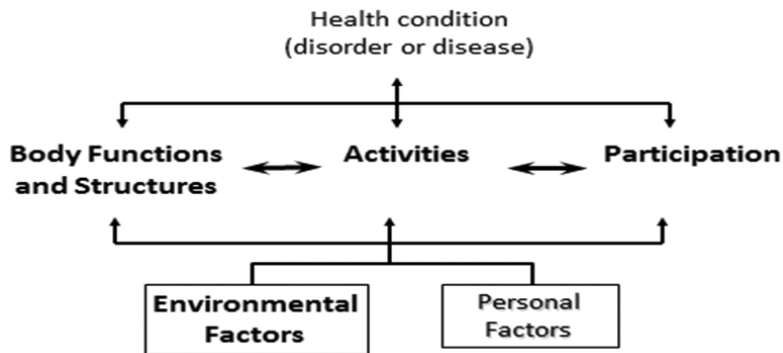


Figure 1: Interactions between the components of ICF (WHO 2001:18)

Experts from many different disciplines and countries, including experts with disabilities, were involved in the drafting and testing of the ICF and it has been widely welcomed and used (Hurst 2003, Jelsma 2009, Cerniauskaite et al 2011, Mpofu and Oakland 2011).

Being constructed as a classification the ICF also provides building blocks for information: infrastructure for measurement and assessment, and for relevant statistics to be designed and gathered, to monitor individual programs. Bickenbach (2011) describes how the ICF can be used to monitor the implementation of the Convention 'both in the shaping of relevant data streams and in the creation of relevant indicators'.

The themes and underlying values of these three different standards and frameworks include:

- Rights to full participation, by all, across all areas of life
- Disability as multi-dimensional and universal – reflecting and respecting the range of human diversity
- The central influence of environment and the broad interpretation of what this means – including the roles and responsibilities of the whole service system and the community
- The need for information – for monitoring, evaluation, accountability
- The importance of involving the person at the centre, along with governments, NGOS, communities, and a wide range of service providers.

Using the ICF to support CBR

ICF is a tool that requires constructive, active and creative use. The ICF demands that we think – about *why* and *what* we record or measure, and *who* measures (Madden et al in prep). It is not a recipe book or a rule book that can simply be followed, but rather a resource. Because it sets out both a framework and a set of classifications, it can be drawn on at different levels of detail, and for different purposes.

Schneider and Hartley (2006) illustrate how the ICF can be used in:

- ‘Planning individual intervention programmes
- Looking at whole community issues
- Monitoring and evaluation of CBR generally
- Motivating policies that promote inclusion of disabled people ‘

These authors give an example of a child with intellectual disability, for whom interventions can be planned, first by describing his body function impairments (e.g. in language function), his activity limitations and participation restrictions (e.g. in learning or communication), as well as the factors in his environment that may need attention (e.g. his physical environment, and the resources available to his family). These major components of the ICF can frame the approach to information gathering or assessment, or simply provide a checklist of information to be considered. At the community level, reduction in the causes of the child’s impairment may be possible, for instance by improvements in antenatal or

obstetric care; these environmental changes or services could also benefit other children in the community. Recording the child's situation before and after an intervention can give valuable information in relation to a number of things; it can:

- draw attention to the child needs,
- indicate the success of the intervention (e.g. in terms of the child's greater participation),
- highlight the effect of changes in the environment.

The information recorded about the child's needs can be combined with similar information for other children, to advocate for change in systems more widely, for instance in maternal health services or in education. Planned CBR activities – to ensure education for children with disabilities, employment for youth and adults with disabilities, and participation of people with disabilities in community activities – can serve as a model for national strategies and policies for development.

The CBR management cycle and use of the ICF

Now that the CBR Guidelines have been published we can see even more clearly how the ICF can be used to support aspects of CBR.

The CBR Guidelines outline a typical management cycle that can be used to develop new programs or strengthen existing ones. The four stages of the cycle are:

1. Situation analysis
2. Planning and design
3. Implementation and monitoring
4. Evaluation (and then back to situation analysis)

The ICF can be used alongside the CBR Guidelines at each stage of this cycle, as a tool to help think about disability and the environment, plan related interventions, and gather information in a common framework, about disability.

Situation analysis

The situation analysis is an important phase, well described in the CBR Guidelines. It entails looking at, 'the current situation in the community for people with

disabilities and their families, and identifies the problems and issues that need to be addressed' (WHO 2010, Page 39) – and involves much more than collecting 'facts and figures'. The ICF can help underpin consideration of the 'facts and figures' but can also provide a framework for a broad analysis of disability in the community and related factors in the environment. During the 'situation analysis' the ICF framework can be used to think about each component of disability in the community – not just impairments (and related health conditions) but also participation by all. This might include considering the education situation for children, economic activity for adults, or participation in the community by all. Consideration of all domains of the ICF's Environmental Factors component might help ensure that factors beyond the physical environment are considered – for instance, community attitudes and accessibility of service systems.

In Uganda, for instance, CBR workers met with disabled people to hear about the issues that were affecting them in the village. They identified the need for medical treatment, aids and appliances, income-generating activities and other social rehabilitation services (Coleridge and Hartley 2010). The ICF could help organize this information, recording the difficulties people were experiencing in activities and participation and relate these difficulties to the services needed. This would nicely supplement the suggestions of Coleridge and Hartley (2010) about using the joint position statement and the guidelines in structuring monitoring and evaluation. Then it would be possible to illustrate that the provision of medical treatment might not only meet the needs for improved health status, but could also affect people's ability to take up the income generating opportunities. The way in which CBR can enhance a person's life opportunities was illustrated in another story in this volume: Madina progressed through surgery, physiotherapy, then to income generation via micro-finance, to education and then to herself teaching in primary school (Coleridge and Hartley 2010).

As well as environmental factors, the disabled person's personal factors – demographic as well as psychological factors – can be important variables enhancing or hindering activity performance and participation. For example, the interaction of a person's age or gender with attitudes in the community environment may affect their participation. A disabled person's psychological factors – such as attitudes towards self and towards others – are often a reflection of attitudes of other people with whom the individual interacts. But sometimes these attitudes originate in part from a person's own perception and cognitive processes, and appropriate psychological counseling may improve the person's

social and physical functioning. Thus disabled persons' personal factors, like other components of ICF, need consideration during the CBR management cycle.

If specific numbers are needed to provide evidence of needs and priorities, the ICF can also provide the building blocks for survey questions. Short and simple ICF-based disability question sets exist that may be useful for community based surveys. For instance, six questions on difficulty with activities have been developed for use in international censuses, based on the ICF (Box 3). Schneider et al (2002) comment on the value of using ICF based questions on difficulties with activities, as a useful way of conducting surveys to determine the need for services.

Box 3: The Work of the Washington Group on Disability Statistics

The Washington Group on Disability Statistics was set up by the United Nations Statistical Commission in 2001 as an international, consultative group of experts to facilitate the measurement of disability and the comparison of data on disability across countries. The Washington Group applies an ICF-based approach to disability and follows the principles and practices of national statistical agencies as defined by the United Nations Statistical Commission. Its questions cover six functional domains or basic actions: seeing, hearing, mobility, cognition, self-care, and communication. The questions asking about difficulties in performing certain activities because of a health problem are as follows.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty with self-care, such as washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating (for example, understanding or being understood by others)?

Each question has four types of response, designed to capture the full spectrum of functioning, from mild to severe: no difficulty, some difficulty, a lot of difficulty and unable to do it at all.

Source: Washington Group on disability statistics. Recommendations for the 2010 Round of Censuses. Viewed 6/2/2012 http://www.cdc.gov/nchs/washington_group/wg_documents.htm

Nine simple questions about support needed with activities and participation have also been found to be of value when examining disability in diverse populations (Anderson and Madden 2011). These questions are used in the Australian national data collection for disability support services and take the form: How often does the person need help or supervision with mobility (or any of the 9 areas of activities and participation in the ICF)? Responses are simply: sometimes, always, never (see Box 4).

Box 4: Simple questions on support needs in ICF Activities and Participation domains

The person can undertake activities or participate in this life area with this level of personal help or supervision (<i>tick one level only</i>)	Unable to do or always needs help/supervision in this life area	Sometimes needs help/supervision in this life area	Does not need help/supervision in this life area
LIFE AREA			
Self care e.g. washing oneself, dressing, eating, toileting			
Mobility e.g. moving around in home and away from home (including getting out of bed or chair, walking, using transport)			
Communication e.g. making oneself understood and understanding others, in own spoken language or with preferred method of communication			
Interpersonal interactions and relationships e.g. making and keeping friends, interacting according to social rules, regulating emotions			
Learning, applying knowledge and general tasks and demands e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, planning or carrying out daily routine			

Domestic life e.g. organising meals, cleaning, shopping, cooking, disposing of garbage, home maintenance			
Education e.g. the actions, behaviours and tasks a person performs at school, college or any educational setting			
Working e.g. actions behaviours and tasks to obtain and retain paid employment (including self employment)			
Community, civic and economic life e.g. recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money			

Source: This table is a slight simplification of questions used in the Australian national data collection for disability services (see AIHW 2009; Anderson and Madden 2011). The Australian collection groups some ICF domains together (e.g. community life and economic life) and subdivides others (e.g. work and education are in 'major life areas' in ICF along with economic life). The domains in the Australian collection are ordered differently from the Activities and Participation chapters in ICF.

Note: Examples within life areas can be modified to suit local context – see ICF itself for full scope of each domain.

The ICF components can likewise help structure the stakeholder analysis recommended by the Guidelines (as part of the situation analysis). Taking a broad view of participation and environmental factors, can ensure that all the organizations in the community that influence disability are included in consultations and this analysis. For instance, using the ICF Environmental Factors component as a checklist would help ensure that organisations such as schools are included as stakeholders, as are organisations that influence community attitudes; such organisations have a significant effect on outcomes for people with disabilities. Thinking systematically about related services or organisations, perhaps women's groups for instance, could also help identify people who may have information or views relevant to planning CBR services. Then the ICF can serve as a framework for organizing views and information, and for the 'problem analysis' conducted in consultation with stakeholders. The framework could help organise the information gained, to assist in identifying common areas of concern and priorities for action, or could serve as a checklist during discussion, for instance to ensure that aspects of the environment had not been ignored. This

information can feed into the ‘problem tree’ and ‘objectives tree’ representation of the main problems and planned actions of the CBR programme (WHO 2010:46).

Planning and design

In the ‘planning and design’ stage of the management cycle, when the focus of the CBR programme is being decided, ICF can be used as a framework or checklist to discuss service design, ‘targets’, or people’s needs. For this purpose, it would probably be useful to refer to the chapters or domains of each component (see e.g. Box 5), or even more detail (from the ICF itself). For instance in the case of the child discussed previously, the CBR programme staff may plan to work in the education sector, with the goal of ensuring the child is able to attend school. Specific objectives could be framed using the ICF, for instance access, regular attendance, inclusion in play, positive relationships with teachers and peers. Again, the ICF as a checklist can help ensure that important aspects of the child’s participation are not neglected, but an overall approach made. This structuring in turn makes it easier to specify the indicators envisaged in the CBR Guidelines – and, insofar as the goals relate directly to the person’s activities, participation and body functions and structures or to environmental factors to be changed, then part of the indicator framework is already structured.

Box 5: Domains of Activities and Participation, and Environmental Factors in the ICF

Body Function: Mental functions Sensory functions and pain Voice and speech functions Functions of the cardiovascular, haematological, immunological and respiratory systems Functions of the digestive, metabolic, endocrine systems Genitourinary and reproductive functions Neuromusculoskeletal and movement-related functions Functions of the skin and related structures	Activities and Participation: Learning and applying knowledge General tasks and demands Communication Mobility Self care Domestic life Interpersonal interactions and relationships Major life areas Community, social and civic life
----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Body Structure: Structure of the nervous system The eye, ear and related structures Structures involved in voice and speech Structure of the cardiovascular, immunological and respiratory Systems Structures related to the digestive, metabolic and endocrine systems Structure related to genitourinary and reproductive systems Structures related to movement Skin and related structures	Environmental Factors: Products and technology Natural environment and human-made changes to environment Support and relationships Attitudes Services, systems and policies
-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Implementation and monitoring

During the third stage of the suggested CBR management cycle – implementation and monitoring – many actions are undertaken where the ICF is not a key tool. By this stage CBR managers will know what areas of the CBR matrix they are working in, and what areas of disability, environment and related service systems they are focusing on. That is, the CBR matrix and the ICF may have helped in the first two stages of analysis and planning, but activities such as obtaining resources and recruiting people require more generic management activities. Nevertheless, training and human resource development could include familiarisation with the ICF insofar as it has been used in the planning stages and hence is a framework informing the services structure and priorities, and structuring the information to be gathered.

If monitoring information is to be collected, then the ICF is a useful framework to underpin those parts of information systems that relate to people's functioning, disability and environment – one of the key purposes for which the ICF was designed. The process of designing information systems and using the ICF has been described as a process of thinking about why, what and how we record or measure, and who measures (Madden 2011; Madden et al in prep). We need to know exactly what the information will be used for, and who by, in order to specify what the key information items are. For instance, if a key indicator of a programme's success is children's increased participation in play, and monitoring is a key way of gauging progress, then we need simple ways of 'measuring' participation in play. For instance, we might indicate how often a child goes out to play with other children outside the family, or joins in games at school. Some

of the key results observed from a CBR programme in Egypt were indicated by a mother who said: 'During the camps organized by the CBR project I see how my children interact with the non-disabled ones and how they are able to integrate and take care of themselves' (Coleridge and Hartley 2010). Such key outcomes can be monitored using the framework of the ICF (see Box 4). And if the use of the ICF framework begins with the situation analysis and continues through the planning stage, then thinking about the third stage, to construct monitoring systems, is easier and clearer.

Again, consultation with all stakeholders is the only way to guarantee success in the information design process – both in identifying the key information and in finding practical ways of recording it. The person about whom the information is recorded should have a say in what is recorded and in stating their own views about priorities for action. Usually it is important to record the minimum amount of information, as every time information is recorded there is a cost, in terms of staff time, person time and materials (paper, forms, computers).

Evaluation

'The final stage of the management cycle, evaluation, involves an assessment of the current or completed CBR programme. It helps determine whether the outcomes outlined in the programme plan (see Stage 2: Planning and design) have been met and how the situation on which they were based (see Stage 1: Situation analysis) has changed.' (WHO 2010, page 60). Change in functioning may be a program goal and hence an indicator of success – whether in terms of improved body functions, activities or participation – or of more facilitating environments. Good basic monitoring systems, well designed, can feed in very well to evaluation.

Reporting on the information collected is a critical step in the management cycle. Ongoing monitoring reports allow the CBR worker and manager to reflect on progress and to adjust what they are doing. More public reporting allows stakeholders to see what is happening (and of course funders and government are among the interested audience) this is a key part of accountability. The CBR guidelines emphasise the importance of sharing findings and taking action – and this is the whole motivation for gathering information (WHO 2010, page 64).

The ICF is proving a useful tool in some new research being undertaken in the Asian region. The World Report on Disability identified a need to strengthen the evidence base for CBR (WHO and World Bank 2011) and a collaborative project is

being undertaken with the aim of creating a prototype CBR monitoring toolkit or 'menu' and associated guidelines (Madden et al 2011). The toolkit is to be practical, flexible and usable in low resource settings, encapsulate the multidimensional nature of CBR and disability, and produce data useful for analysis at district and regional level.

The project is focusing chiefly on monitoring (rather than evaluation) as monitoring tends to have a more internal focus, and provides ongoing information that enables managers and staff to identify and check for progress, changes or problems (for the person or the program). Moreover, a successful monitoring system can make an evaluation unnecessary, can reduce the amount of information required from an evaluation, or can help structure an evaluation. It is a local information system designed, managed and used by CBR managers and stakeholders. In short, it supports empowerment of local managers and stakeholders, rather than relying on occasional, more externally focused evaluations.

Literature reviews to inform this development are being undertaken, to examine the tools used in either monitoring or evaluation, the information items gathered in such studies and the relationship they bear to the CBR matrix and the ICF.

In parallel, collaborative research on information needs and possibilities began in 2011, with partners in Vietnam, Lao PDR, the Philippines and the University of Sydney. An early prototype for testing in country is being developed based on these two parallel research streams. The ICF has so far proved useful in the logical ordering of many of the outcome items relating to people, their functioning, and the relevant environmental factors.

Moreover, early thinking by the CBR managers points to a number of possible uses of such a menu, including: designing information collection at village level, or database (central); monitoring progress in the village/community; monitoring service use and progress by people with disabilities; identifying and monitoring the influence of the environment on participation; enhancing knowledge and skills of staff (e.g. using the menu as a planning and awareness raising checklist). This general method could be of value in other regions of the world, including Africa.

Conclusion

The ICF can be used alongside the CBR Guidelines at each stage of the management cycle, as a tool to help gather information, in a common framework,

about disability, people's needs, outcomes and the environmental changes that CBR managers and workers may wish to consider. Its use at each stage – from the situation analysis, and the planning stages, to implementation, monitoring and evaluation – helps ensure clarity and consistency among stakeholders in thinking about disability and related factors, and in creating coherent programmes capable of being monitored and evaluated, for the benefit of people's participation in society.

Based on this brief analysis, and its growing use in a range of countries and settings, the ICF is worth considering as a framework and checklist for planning and community discussion, and as a classification and checklist for efficient information gathering – a potential tool for use in CBR and in its management and monitoring.

It is a challenge but also an advantage that the ICF does not provide a formula or strict set of rules for its use. Its use requires thought and selection. But this also means that it provides flexibility – it can be used freely to suit different uses and circumstances – as a tool not a master.

Stakeholders including people with disabilities, must be involved in decisions about information and ICF use, just as they are in other aspects of CBR management and monitoring. This is required by the UNCRPD, the CBR Guidelines and by the ICF itself.

The Convention, the CBR Guidelines and the ICF are all tools which facilitate 'linking CBR, disability and rehabilitation', and this linkage is needed if rehabilitation is to address the needs of disabled people and their families.

References

- ANDERSON P, MADDEN R (2011). Design and quality of ICF-compatible data items for national disability support services. *Disability and Rehabilitation*, 2011; 33(9):758-769
- AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE (2009). Disability support services 2007–08: national data on services provided under the Commonwealth State/Territory Disability Agreement. Disability series. Cat. no. DIS 56. Canberra: AIHW.
- BICKENBACH J E (2011). Monitoring the United Nations Convention on the Rights of Persons with Disabilities: data and the International Classification of Functioning, Disability and Health. *BMC Public Health*. 2011; 11(Suppl 4): S8. Published online 2011 May 31. doi: 10.1186/1471-2458-11-S4-S8
- CERNIAUSKAITE M, QUINTAS R, BOLDT C ET AL (2011). Systematic literature review on ICF from 2001 to 2009: its use, implementation and operationalisation *Disabil Rehabil*. 2011;33(4):281-309.
- COLERIDGE A, HARTLEY S (Eds) (2010). CBR stories from Africa: what can they teach us? University of East Anglia. Available online at <http://www.afri-can.org/CBR%20Information/CBR%20Stories%20from%20Africa.pdf>

- HURST R (2003). The international disability rights movement and the ICF. *Disabil Rehabil.* 2003;25: 572-6.
- ILO, UNESCO, WHO (2004). Community Based Rehabilitation: A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities (Joint Position Paper). Geneva, (www.who.int/disabilities/publications/cbr/en/index.html, accessed 18 June 2010).
- JELSMA J (2009). Use of the International Classification of Functioning, Disability and Health: A literature survey. *J Rehabil Med*; 41: 1-12
- MADDEN R (2011). Recording functioning and disability: why, what, how and who? Presentation at University of Sydney symposium Think before you measure. June 2011 http://sydney.edu.au/health_sciences/health_systems_global_populations/think_before_you_measure/
- MADDEN R ET AL (in prep). Basic questions before measuring functioning and disability
- MADDEN R, LUKERSMITH S, DUNE T ET AL (2011). Collaborative development of a menu and guidelines for monitoring CBR. Presented at The World Report on Disability: Implications For Asia And The Pacific. University of Sydney symposium 5-6 December 2011
- MPOFU E, OAKLAND T (Eds) (2010). *Rehabilitation and Health Assessment: Applying ICF guidelines.* Springer Publishing Company NY
- SCHNEIDER M, LOEB M, MIREMBE J ET AL (2002). In Hartley (Ed) *Community-Based Rehabilitation (CBR): a Participatory Strategy in Africa 2002.* University College London
- SCHNEIDER M, HARTLEY S (2006). In Hartley (Ed) *Community-Based Rehabilitation (CBR) A part of community development.* University College London
- STUCKI G, CIEZA A (2008). The International Classification of Functioning, Disability and Health (ICF) in physical and rehabilitation medicine. *European journal of physical & rehabilitation medicine.* [Editorial]. 2008 Sep;44(3):299-302.
- UNITED NATIONS (2006). *The UN Convention on the Rights of Persons with Disabilities*
- WASHINGTON GROUP ON DISABILITY STATISTICS. Recommendations for the 2010 Round of Censuses. Viewed 6/2/2012 http://www.cdc.gov/nchs/washington_group/wg_documents.htm
- WHO (2001). *International Classification of Functioning, Disability and Health.* Geneva: WHO
- WHO (2010). *Community-based rehabilitation: CBR guidelines.* Geneva: WHO
- WHO, WORLD BANK (2011). *World Report on Disability.* Geneva: WHO

CHAPTER 7

Evidence Base for CBR



Copyright © Olivier Asselin
Ghana amputee football team.

CHAPTER 7

Evidence Base for CBR

Sunday Udoh, Joseph Gona, Carol Maholo

Summary

The chapter focuses on the evidence base for Community Based Rehabilitation (CBR) and draws mainly from the literature review conducted by Finkenflugel et al (2005). This study shows that despite an increasing number of publications on CBR, the evidence base for CBR over the last three decades still remains weak. It further demonstrates that most of the publications show little coherence and key aspects such as participation and sustainability are insufficiently covered. This chapter explores the challenges in conducting CBR research; it identifies ways in which disability research can be done with and by, rather than mainly 'on' people with disabilities and rounds up with some recommendations for improving research in CBR.

Introduction

The concept of CBR

Community Based Rehabilitation (CBR) is a strategy for rehabilitation, equalization of opportunities, poverty reduction and social integration of people with disabilities (ILO, UNESCO, WHO 2004). It is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services (ILO, UNESCO, WHO 2001).

In 1969, WHO defined 'Rehabilitation' for people with disabilities as 'the combined and coordinated use of medical, social, educational and vocational measures for training or retraining the individual to the highest possible level of functional ability.' It is the first step towards enhancing the quality of life of people with disabilities through a multi-sectoral effort. Access to rehabilitation services is perceived to enhance opportunities for poverty reduction; enabling people to meet their basic needs and access equal rights.

CBR is carried out in the community using local resources, involving people with disabilities, their family members and the community, so that they help to reduce costs and learn the needs that people with disabilities have to effectively help them overcome their needs to pursue development. The programme involves activities that help people with disabilities to either regain lost potentials or acquire potentials which were never developed, using locally available resources which are cost effective, acceptable and sustainable.

Importance of research in CBR

The overall aim of CBR is to achieve community-based inclusive development where people with disabilities and their family members are part of all the developmental initiatives with equal rights and opportunities like others. It also facilitates access to services for people with disabilities especially those who are poor and live in a difficult situation or in rural areas. To achieve these aims, CBR practitioners/ implementers/promoters need to access up to date information, share experiences, carry out research activities, enhance their capacity and disseminate their knowledge and experiences with all stakeholders.

CBR has many benefits for beneficiaries and service providers, particularly in remote and rural practice settings. For communities, CBR increases accessibility of rehabilitation and therapy services for people with disabilities by increasing service provision, especially for those living in rural and remote areas. Additionally, the community development orientation of CBR builds on community capacity both at individual and community level. At the individual level, CBR models facilitate capacity building for people with disabilities and their families to foster independence, enhance participation and subsequent improvement in well-being. It also empowers communities and develops leadership for effective implementation and monitoring. However, all this can never be realized without adequate information to inform key decisions. Information to this effect is best attained using participatory approaches to promote evidence-based practice.

What counts as evidence-based practice in CBR?

Few researchers would disagree with the proposition that CBR policies and practices should be grounded in evidence. *Evidence*, for the purpose of this paper, refers to the knowledge that connects research to practice. Over the years, an increasing emphasis on evidence has led to a movement for evidence-based

practice (EBP). Emerging first in the health care industry, EBP has since swept into a number of other professional fields, including CBR.

In the field of CBR, EBP involves using the best available evidence - integrated with clinical expertise and the values and experiences of people with disabilities and other stakeholders - to guide decisions about CBR interventions and practices.

Since its debut in 1976, issues about the documentation, evaluation and review of CBR interventions have been at the heart of the discourse around CBR. Researchers have been concerned about the number and quality of studies on CBR that had been published. According to Mitchell (1999), *"Little quality research on CBR has been placed in the mainstream of scientific literature"* Also, Thomas & Thomas (1999) opined that, *"In spite of the recognitions of the need for research in this field, community-based rehabilitation has grown on experiential accounts rather than with scientific research in the last decade"*. By 2002 Wirz & Thomas (2002) concluded: *"CBR has not developed sufficient published literature about planning, implementation, and evaluation in the same way as other areas of service delivery such as primary health care, community development or income generation"* and just recently, Miles (2003) pointed at *"the modest amount of CBR research in refereed journals"*. He then stated that, *"CBR knowledge is still thin, scattered, mostly unsifted, unreliable, unrecorded or unpublished"*.

In taking these comments seriously, Finkenflugel et al (2005) decided to conduct one of the most extensive literature searches to find answers to questions regarding how many and what type of studies have been actually published, and which aspects of CBR have been covered after about 3 decades of experience with the concept? This chapter examines this evidence.

Identifying the evidence

Finkenflugel et al (2005) found papers by searching PubMed2, PsycINFO, Source, CIRRIE, and Rehabdata. The search included, in different combinations, the key words: 'CBR', 'disability', 'rehabilitation', and 'community'. The search was extended with the use of (electronic) bibliographies and by scrutinizing articles on relevant references. Additionally, the electronic databases were searched again using the names of (leading) authors (Helander, Miles, O'Toole, Thorburn etc.). Also, authors and organisations were contacted directly to enable them to supplement the search results.

The search was done between November 2002 and March 2003 and the following inclusion criteria were adopted:

- Only articles with 'Community-based rehabilitation' or 'CBR' in the title, key words, abstract, introduction, or discussion have been included.
- Studies relating to CBR in developed countries were excluded. are not included.
- The time period from 1976 to 2002 has been chosen for this study.
- Only articles in English were included.
- Only Journals and articles that were either indexed by the Index Medicus (IM) or the Social Sciences Citation Index (SCI), or listed in PubMed were included.

Classification of articles

In addition to the inclusion criteria set out above, the articles were classified by the year of publication, country or region, type of article and key elements of CBR.

Year of publication

The review covered 25 years of CBR, from 1978 to 2002.

Country or region

The reviewers grouped the articles into six regions according to a classification used by the World Bank (undated): (a) East Asia and Pacific, (b) Europe and Central Asia, (c) Latin America and the Caribbean, (d) Middle East and North Africa, (e) South Asia, and (f) Sub-Saharan Africa.

Type of article

A classification of 'type of article' was made based on the methodology used in the article. Five different types of articles were distinguished. These include Intervention papers; Descriptive papers; Case reports; Review papers and Theory papers. The classification is based on (Helewa & Walker, 2000).

Key elements

Every article was classified by the aspects presented in Table 1. Only a single entry per article was allowed by the reviewers. In situations where two categories per article were applicable, the reviewers scored the articles according to their aim of study.

Table 1: Showing Key aspects of CBR

Heading	Subjects included
Screening	Disability surveys, prevalence studies, screening instruments, assessments, etc.
Knowledge	Knowledge, awareness, attitudes, behaviour, traditional beliefs, traditional healers.
Local resources	Use of local resources (funding, technology), cost effectiveness.
Participation	Integration, inclusion, participation, mainstreaming, accessibility.
Implementation	Development of services, implementation of projects, working with other organisations, ownership, disability rights
Stakeholders	Stakeholders, community involvement, manpower planning, training.
Case reports	Articles describing a particular CBR project, an approach to a specific problem or aspects of a CBR project.
Evaluation	Follow up studies, project evaluation, comparing different types of rehabilitation.

Analysis of the evidence for CBR

Evidence from the quantity of articles published on CBR

A growing number of published articles point to an increasingly rich source of information available for guiding decisions in any discipline. Finkenflugel et al. (2005) found only 128 articles which met the inclusion criteria, translating to an average of 8 articles on CBR published per year over the review period. In addition, it was observed that CBR articles were increasingly being published in indexed journals and most of these come from a little over 35 different developing countries.

Further analysis by the reviewers showed that about Sub-Saharan Africa, South Asia, and East Asia and Pacific accounted for about 34%, 27% and 22% of these articles, respectively. An analysis of the contributions of individual countries in the Sub Saharan African region revealed that most of the articles came from South Africa, Botswana, and Zimbabwe (with nine, nine, and eight articles respectively). Thus, although it would appear that CBR research in developing countries has increased dramatically in recent years, the reviewers found that in most African countries where CBR projects are taking place, not much research is done.

Evidence from the quality and type of articles published on CBR:

The work by Finkenflugel et al (2005) also explored the quality of evidence of CBR by analyzing the quality of the articles. The reviewers based the classification of the articles on (Helewa & Walker, 2000) as shown in Table 2.

Table 2: Showing classification of CBR articles

Type of Article	Description
Intervention studies	Articles reporting on studies assessing the effect of an intervention for a specific group (e.g. a training programme has been implemented), studies comparing outcomes of interest of different groups of which at least one group has been subject to a specific intervention, and single case (n=1) studies. To be included, articles should enclose a description of the research design, the intervention, the research methods, and the results.
Descriptive studies	Articles describing outcomes of interest (e.g. income, ability to walk, educational needs, use of services) of a selected population at a defined moment (without an intervention being carried out) are included here. It includes Screenings as well as papers that report on the testing of instruments.
Case reports	Articles describing a particular CBR project, an approach to a specific problem or aspects of a CBR project.
Review papers	Articles based on earlier published work, which give an overview of knowledge in a specific area.

In this study, 'Theory papers' were found to be the most common type of articles published on CBR and contribute to more than 40% of all articles. 'Descriptive studies' accounted for around 30% of the articles, while 'Intervention studies' or effect studies accounted for only 8%. They therefore concluded that the use of a control group in combination with assessments before and after the intervention, are not common in studying interventions in CBR. Almost all of the studies described are pre-experimental studies and should be interpreted with care (Finkenflugel et al., 2005).

Generally speaking evidence generated from intervention studies, including Randomised Control Trials are usually considered to be Level 1 evidence. The fact that only 8% of studies in CBR studies are intervention studies suggests that the body of evidence in CBR is still limited. This shortage of Level 1 intervention studies in CBR is due in large part to the nature and scope of the field.

In both research and practice, CBR is an exceptionally wide, multidisciplinary field involving biological, psychological, social, economic, legal, and environmental factors related to disability. The field's mission entails the commitment to help people with disabilities "perform activities of their choice" and "to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities" (Federal Register, 2006). This vast scope of concern includes social integration, employment, independent living, health, and enabling technology. Although basic scientific standards and methods can be applied to CBR, multiple standards and methods are needed to discern the best evidence for the wide and heterogeneous problems and interventions addressed in CBR research and practice.

Evidence for Key components of CBR

In the light of the evolution of the CBR into a broader multi-sectoral development strategy, a matrix was developed in 2004 to provide a common framework for CBR programmes. The framework consists of five key components – the health, education, livelihood, social and empowerment component. There is evidence that CBR is effective in bringing about positive change in these areas, however such evidence still remains limited (WHO, 2010).

With respect to the health component, Velema et al. (2008) in their study, demonstrated that CBR programmes are effective in improving communication and mobility of people with disabilities. Also, in the area of livelihood development, Velema et al. (2008) and DeKlerk T., (2008), have shown that the income of people with disabilities and their families can be improved through CBR livelihood projects. With regards to education, CBR has facilitated the adjustment and integration of people with disabilities (Mannan & Turnbull, 2007). For the social and empowerment components, research has equally shown that CBR interventions can promote a positive community attitude towards persons with disabilities and enhance social inclusion and integration (Mitchell, 1999).

Why has the issue of research been a challenge for CBR practitioners?

Basically, community-based rehabilitation (CBR) was established with a strong emphasis on service delivery and not research. The approach was geared towards the provision of services to people with disabilities where none were available.

Under such emphasis, research may have been considered a waste of precious resources needed for service implementation or not necessary at all.

The ideology behind CBR has been practical response to the needs of people with disabilities (Kuipers, 1998). This ideology on practice rather than theory, inquiry and analysis has not led to the establishment of a strong research base. This commitment to practice in CBR has led to its extraordinary spread, but has not been the basis of a strong research foundation (Miles, 1989).

The nature of questions in CBR projects do not easily fit into traditional research. CBR is not excessively concerned with constricted clinical rehabilitation questions, but with wider issues involving models of service delivery, community participation, empowerment and improvement of social conditions of persons with disabilities. These broader social issues can be enquired through exploratory approaches rather than experimental ones. Such exploration and conceptualisation may not be suitable in research frameworks, posing a big challenge to CBR practitioners.

Experience in CBR theory and practice suggests that the place and role of research within CBR appears to be somewhat unclear, and in some cases problematic. Research literature in rehabilitation has shown that much of the published work is mostly quantitative and experimental in nature. This means majority of the research involves setting up of formal experiments, often in structural settings and comparisons made against predetermined levels through statistical analysis. While this is considered important in getting reliable evidence, it is suggested that this approach has not been highly appropriate for the current stage of the development of CBR. CBR is an evolving entity. This evolving nature of CBR has not been clearly conceptualised and described (Kuipers, 1998), hence does not fit well in traditional research.

There is a prevailing view that in order to conduct good rehabilitation research within the traditional framework, the researcher requires considerable technical, research design and statistical proficiency, or at least access to experts who have these skills. It is believed that these advanced levels of technical expertise requirements could have scared CBR practitioners away from doing research.

It can also be argued that the prevailing research framework in rehabilitation is highly associated with the western countries. This experimental approach to knowledge may be quite foreign to many non-western countries, and may

therefore be able to have been ignored by CBR practitioners in developing countries. Traditional research approaches tend to appear to be impractical for the CBR worker in the field (Walker, 1993). The clear distinction between practical service realities and the research mindset may lead CBR practitioners to view the pursuit of research as being not relevant.

The subject matter of traditional research and types of methods used may be seen as inappropriate for the key issues confronting CBR. These methods tend to falter in community settings. They fail to accommodate important social factors such as importance of connectedness between people, and the place of social and community processes (Price, 1990; Riger, 1994). Similarly, traditional research methods offer limited control to participants (Barlow & Harrison, 1996). In an environment in which empowerment is increasingly viewed as central to CBR, the use of such methods may be perceived as not appropriate to maximising empowerment.

A suggested alternative to traditional research in CBR practice could be action research. This is an approach for fostering collective action in a social setup within a research framework. It is not a highly technical approach, but it is a logical way of systematically integrating practice with research. The main principles are change and understanding. Central to this approach is the belief that our action, and changes in our action, will be enhanced by research; likewise, that research will be enhanced by integrating it into practice. This integration is achieved through a spiral process in which action and critical reflection alternate (Dick, 1999).

A core principle in action research is that action and research can both be enhanced through participation. This means involving people at the action level, by providing information on their action, and in planning the changes that are indicated, and at the research level by ensuring that key stakeholders are involved in conducting, analysing and interpreting the research. Action Research is conducive to people investigating their own issues, formulating their own accounts of these issues and devising plans to deal with the identified problems (Stringer, 1996). A practical example is an action research conducted in Kilifi, Kenya, where disability stake holders participated in the identification of potential gaps in the initiation of a CBR programme (Gona et al, in preparation).

Action research mirrors the typical logic that is used by health and disability workers as they solve problems and respond to people's needs (Hart & Bond, 1995). Concepts of assessing need, developing a rehabilitation response and

reviewing progress is quite familiar to CBR practitioners. However, this process requires more disciplined cooperation of many stakeholders, clear and consistent documentation and careful planning and follow-up. If clear and detailed documentation is not kept, the capacity to replicate is lost and the possibility of learning systematically from the previous experience is also lost.

As may be evident, action research departs from some of the core notions of conventional research. Action researchers hold that research results will be most useful when they arise from a repeated incremental cycle. Action researchers recognise the values context of research and see that judgements regarding the value of an outcome or conclusion are best made by the participants who will be most affected by it.

Including persons with disabilities in CBR research

CBR research should ideally be community-based with collaboration between community groups and researchers, for the purpose of creating new knowledge or understanding about a practical community issue to facilitate change. Being beneficiaries of CBR, people with disabilities, family and community members should ideally generate issues or concerns and participate in all aspects of the research process. It should therefore be community-based research; “collaborative, participatory, empowering, systematic and transformative” (Hills & Mullett, 2000).

Generally, people with disabilities are dissatisfied with traditional methods of disability research, which are seen as exclusionary and based on the idea of an expert researcher doing his/her research on disability and on people with disabilities. Such exclusionary methods lead to research findings which do not fully reflect the actual experiences and needs of persons with disabilities. Some of the key considerations for inclusion of persons with disabilities in research is discussed and models that researchers can use to include people with disabilities in their research are hereby outlined.

There are some key considerations which should be applied to any inclusive approach to disability research. These are:

Planning for inclusion

While the fact that a person has a disability does not automatically mean that they will require any specific assistance or support to become included in research, the

best way to identify what methods and supports for inclusion may be required is to simply ask those you wish to include. Planning for any specific types of support or assistance for inclusion in research should be the first part of any inclusive project. Individuals with specific types of disability who are amongst the research target population, or groups representing them, should be consulted in the planning phase to identify what kind of needs should be addressed. This will enable researchers to identify and respond to the specific needs of the people they want to include in their research.

Making the research process accessible

Researchers planning for inclusive research need to ensure that the process is accessible to the people they want to include. This includes ensuring that venues, communication, information and transport are accessible where required.

Using appropriate language

Disability etiquette addresses what type of language is appropriate for use when writing about, describing or meeting people with disabilities. It also addresses what terms should and shouldn't be used when conducting or reporting research.

Disability etiquette in a research context can also include directly addressing a person with a disability, rather than a carer or Personal Assistant in meeting situations. This can be particularly important when, for example, including people with communication difficulties as respondents in interviews. It may be necessary to include an interpreter to facilitate communication in such a situation. However, it remains important to directly address the respondent as much as possible and not the interpreter.

Being disability-aware

It is important for researchers to ensure that they, and any of their research staff, have a sufficient level of disability awareness when undertaking disability research and including people with disabilities. Disability/Equality awareness for researchers can involve: understanding what is meant by *disability* and how people with different types of impairment are disabled; an understanding of the social, economic, political and cultural issues and concerns which affect people with disabilities; acknowledgement of the rights of people with disabilities,

within the broader concept of equality for all members of society; and the use of appropriate language that is acceptable to people with disabilities.

Models of Inclusion

The diverse nature of research means that some ways of including people with disabilities will be more suited to some projects than others, depending on the methodology employed and on the scope of the research. Some projects may also involve different ways of including people with disabilities at different stages of the research process. Some of the models of inclusion which researchers can consider are:

Participatory approaches to research

Participatory research is the most inclusive model of disability research that has been identified. This is because the research done is conducted by people with disabilities who are representative of the target population of the project – i.e. the researchers are people who are, or have been, directly affected by the issues at the centre of the research question and aims. As stated earlier, one model of participatory research which has been conducted successfully in recent years is *Action Research* (Stringer, 1996). Another model, *Participatory Learning and Action* (PLA), has been identified from other fields of social research as having possibilities for being adapted for disability research (Kane & O'Reilly-de Brun, 2001).

Steering and advisory committees

Another model of including people with disabilities in research is as members of either a research steering or advisory committee. In this capacity, people with disabilities who are appointed to either type of group will give advice, input and feedback at various stages of the research process. The level of influence which such groups have can depend on the level of input and additional expertise the researchers require, or how willing they are to accept the group's input and advice so that their research benefits from the knowledge and expertise that the group has of the research topic(s). By definition, a research *steering committee* will have more of an influence and say over the research, whereas an *advisory committee* will provide advice which the researcher can consider in light of their own experience and expertise, and make decisions about the research themselves. The

terms of reference and power of committees should be established at the outset. Both types of committee act as a resource to provide ideas and direction in the planning stage and feedback at intervals throughout the research process, with the researcher carrying out the research tasks in between each feedback interval.

Consultation and planning group

Another model of ensuring that people with disabilities, and their views and concerns, are included in research is through the use of consultation and planning groups. Prior to starting a research project, a researcher identifies the key issues of importance and concern to the target population through a consultation or planning phase. This can be approached with a clean slate, whereby the researcher asks the group to identify a key topic of concern on which to focus the research. It can also be used in a situation where the researcher brings ideas for their research to the group to establish their relevance to the target population and to receive further ideas on the specific direction and focus for the research. Either approach will give the researcher an insight into what topics are relevant to the target population and where the focus for the research should be. This approach can also be used effectively for organisations who are planning a strategic research programme over a period of time. It will help the organisation to identify projects which are of greatest relevance and concern to people with disabilities.

Employing researchers with disabilities

The consultation process involved in establishing these guidelines has also identified the value and use of researchers and research organisations employing other researchers with disabilities to work on their projects. The main benefit of this to research was highlighted where researchers with disabilities similar to those of the target population were employed to undertake fieldwork which involved meeting respondents. In an element of research in which building rapport with respondents is very important, some respondents may feel more empathy and understanding from an interviewer with a similar type of impairment as they themselves have. It has been found that respondents can be more open and frank with researchers they feel can empathise with their situation (Alderson, 1995; Ward, 1997).

Employing researchers with disabilities similar to those of the research target population can also be of value in terms of utilising disabled people's experience

and expertise to inform the content of the research, and in terms of directly challenging social and economic exclusion. It can also be a way of ensuring that researchers employed can demonstrate an awareness of some of the fundamental research issues around disabling barriers, which should be allied to practical experience of research methods - although this might be a secondary requirement as methods can more easily be taught (Zarb, 1997).

Respondents in research

Many researchers' experience of including members of the target population in their research consists of inclusion as respondents. This model of inclusion is also important for disability research and the inclusion of people with disabilities. It also has added significance for disability research due to the fact that some researchers might assume that certain people with disabilities are unable to contribute to research as respondents on account of an impairment. It is incumbent on researchers to make every effort to include people with disabilities as respondents in their research where that research requires ascertaining the views of people with disabilities. Furthermore, researchers should plan to include people with disabilities as direct respondents whenever possible. Researchers may encounter difficulties in this regards where the respondents are people with communication or learning difficulties. However, in these circumstances there are measures that researchers can take to maximise this type of inclusion for all people with disabilities, including people with communication difficulties or learning disabilities.

Conclusion

The field of CBR faces the challenge of identifying and applying evidence to its practices. Thirty years after its debut, the evidence base for CBR is still weak. Majority of articles published about CBR are 'theory papers'. Although these have a distinct function in revealing underlying assumptions and processes, their use is limited unless complemented by in-depth case reports, descriptive studies, or intervention studies.

Because of the inherent complexity of CBR, no one research study will be able to establish evidence for CBR. Instead of trying to establish a general knowledge and evidence base for CBR, it is probably more fruitful to ascertain evidence on specific aspects of CBR, and to study these in more controlled and experimental settings.

The standards and methods used to select evidence should address research quality, the needs and values of people with disabilities, and applicability to practice. These factors complement one another, and each of them must be considered when using research evidence to guide decisions affecting people with disabilities and the many issues they face in society.

Finally, evidence for CBR should be built with the involvement and participation of persons with disabilities and on the basis of practical experiences with CBR projects. Various models of participatory research are recommended, particularly Action Research.

References

- ALDERSON P (1995) *Listening to children: Children, Ethics and Social Research*, London: Barnardos
- BARLOW J, HARRISON K (1996). Focusing on empowerment: Facilitating self-help in young people with arthritis through a disability organisation. *Disability and society*; vol. 11 (4), 539-551
- DEKLERK T (2008). Funding for self-employment of people with disabilities. Grants, loans, revolving funds or linkages with microfinance programmes. *Leprosy Review*, 79(1), 92-109.
- DICK B (1999). Action Research and evaluation on line. Internet instruction course. <http://www.seu.edu.au/schools/sawd/areol/areol-home.html>.
- FEDERAL REGISTER (February 15, 2006) Vol. 71, Number 31, pp. 8165–8200. Notice of final long range plan for fiscal years 2005–2009 (71 FR 8166). Retrieved from the Federal Register Online via GPO Access: <http://edocket.access.gpo.gov/2006/pdf/06-1255.pdf>
- FINKENFLUGEL H, WOLFFERS I, HUISMAN R (2005). The Evidence Base for Community-based Rehabilitation: a Literature Review. *International Journal of Rehabilitation Research*.
- GONA JK., ODERA-MUNG'ALA V, NEWTON C ET AL (In preparation). Using local perceptions to inform rehabilitation service development in Kilifi, Kenya. *Intended journal: Disability and rehabilitation*
- HART E, BOND M (1995). *Action research for health and social care - A guide to practice*. Buckingham: Open University Press.
- JAYNES J. (1982) (1976).
- HELEWA A, WALKER J M (2000). *Critical Evaluation of Research in Physical Rehabilitation - Towards Evidence-based Practice*. Philadelphia, USA: W.B. Saunders Company.
- HILLS M, MULLETT J (2000). *Community-Based Research: Collaborative Action for Health and Social Change*. Victoria, B.C.: Community Health Promotion Coalition, University of Victoria.
- ILO, UNESCO, & WHO. (2004) *Community Based Rehabilitation: A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities* (Joint Paper 2004). Geneva, Switzerland. Available at: who.int/disabilities/publications/cbr/en/index.html, accessed December 2011.
- KANE E, O'REILLY-DE BRÛN M (2001). *Doing your own research*, Marion Boyars: London
- KUIPERS P (1998). *Community based rehabilitation (CBR) as Engagement: Context, parameters and potentials*. Unpublished PhD thesis. Brisbane, Queensland: Griffith University
- MANNAN H, TURNBULL A (2007). Quality of life as an outcome measure for future evaluations. *Asia Pacific Disability Rehabilitation Journal*, 18(1), 29-45.

- MILES M (1989). Information-based Rehabilitation for Third World Disability. *Social Science & Medicine*, 28(3), 207-210.
- MILES M (2003). CBR Works Best the Way Local People See It and Build It. *Asia Pacific Disability Rehabilitation Journal*, 14(1), 86-98.
- MITCHELL R (1999b). The Research Base of Community-based Rehabilitation. *Disability and Rehabilitation*, 21(10-11), 459-468.
- PRICE R H (1990). Whither participation and empowerment? *American Journal of Community Psychology*. Vol. 18 (1), 163-167
- RIGER S (1994). What's wrong with empowerment? *American Journal of Community Psychology*. Vol. 21 (3), 279-292
- STRINGER E T (1996). *Action research: A handbook for practitioners*. Thousand Oaks, CA.: Sage
- THOMAS M, THOMAS M J (1999). A Discussion on the Shifts and Changes in Community-based Rehabilitation in the Last Decade. *Neurorehabilitation and Neural Repair*, 13(3), 185-189.
- VELEMA J P, EBENSO B, FUZIKAWA P L (2008). Evidence for the effectiveness of rehabilitation in the community programmes. *Leprosy Review*, (79):65-82
- WARD L (1997b). *Seen and heard: Involving disabled children and young people in research and development projects*, York: York Publishing Services
- WHO (1988). *Report: Regional Working Group on Applied Research on Community-based Rehabilitation*. Manila: Regional Office for the Western Pacific of the World Health Organization.
- WHO. (2010) *Community Based Rehabilitation Guidelines. Towards Community-based Inclusive Development*. World Health Organization, Geneva.
- WIRZ S L, THOMAS M (2002). Evaluation of Community-based Rehabilitation Programmes: A Search for Appropriate Indicators. *International Journal of Rehabilitation Research*, 25,163-171.
- ZARB G (1997). *Researching Disabling Barriers in Doing Disability Research*, Barnes and Mercer (Eds.) Leeds: The Disability Press.

Acknowledgement

All the contents of this book were the results of the discussions that took place during the 4th CBR Africa regional conference, “Linking CBR, Disability and Rehabilitation”, held on October 26th -29th, 2010 in Abuja, Nigeria. The conference was organised as a joint initiative of civil society, governments, and UN agencies. It brought together leading CBR professionals and practitioners from different parts of the world who gathered to share many useful disability experiences.

Acknowledgements go to all the sponsors of the conference; without their assistance the conference would not have been a reality. Particular thanks go to C.P Trust, Christoffel Blinden Mission (CBM), Norwegian Association of the Disabled (NAD), The International Labour Organisation (ILO) and the government of Nigeria, particularly the Federal Ministry of Women Affairs and Social Development. Every contribution is sincerely recognised and appreciated.

Special appreciation goes to the members of the organising committee and their respective organisations, key Ministries of the Government of Nigeria, Disabled Persons’ Organisations in Nigeria and CBR Africa Network, who worked over a year to prepare both the contents and logistics for the conference. Particular mention must be made of Daniel Tsengu, for all the work he did in organising the conference. He was instrumental in forming the Nigerian committee and linking the committee with the CAN Executive. The committee worked tirelessly to ensure that every aspect of administration would go smoothly and to guarantee that all participants should gain the most from the conference and their stay in Abuja.

The conference opening remarks were delivered by the Nigerian First Lady, Dame Patience Goodluck Jonathan. It was attended by 387 participants from 52 different countries from the African continent and other regions. There was a marked increase in representation from the French, Arabic and Spanish speaking countries with their numbers being 16, 5 and 2 respectively. Sincere thanks to all the speakers and the participants for their willingness to share ideas and experiences and their participation in the plenary and concurrent sessions.

Members of the National Organising Committee

1. Ms. Joan Okune: CAN Executive Director
2. Ms. Siphokazi Gcaza: CAN Chairperson
3. Mr. Fidelis T Iyor: NKST Rehabilitation Hospital, Mkar
4. Mr. Daniel Tsengu: Christian Blind Mission, Abuja
5. Mr. Idris Mohammed: Federation Ministry of Women Affairs and Social Development
6. Mr. Michael A Idah: Netherlands Leprosy Relief, Jos
7. Dr. Sunday O. Udo : The Leprosy Mission – Nigeria
8. Mrs. Tive Diogba: German Leprosy Relief Association, Enugu
9. Mr. Musa Goyol: Dark & Light Blind Care, Jos
10. Ms. Lucy Upah: Joint National Association of Persons with Disabilities
11. Mr. Ibukun Alesinloye: National Centre for Women Development, Abuja
12. Ms. Safiya Sanda - Sight Savers, Nigeria Country Office
13. Ms. Jennifer Abagye
14. Rev. Sr. Gloria Aniebonam

Appendix 1

List of participating organisations

Ministries

Federal Ministry of Education, Nigeria

Federal Ministry of Health, Nigeria

Federal Ministry of Women Affairs and Social Development, Nigeria

Ministry of Gender, Children and Community, Malawi

Ministry of Gender, Labour and Social Development, Uganda

Ministry of Health and Social Services, Namibia

Ministry of Health, Afghanistan

Ministry of Health, Gabon

Ministry of Health, Malawi

Ministry of Health and Social Services, Namibia

Ministry of Health, Niger

Ministry of Health, Swaziland

Ministry of Health, Uganda

Ministry of Health, Zimbabwe

Ministry of Labour, Malawi

Ministry of Persons with Disabilities and the Elderly, Malawi

Ministry of Social Services, Nigeria

Ministry of Social Welfare and Community Development, Nigeria

Ministry of Social Welfare, Youth and Sport, Nigeria

Government Institutions

Benue State Rehabilitation

Dunukofia Area Council Anambra State

Hoima Local Government, Uganda

Kaduna State CBR Program

Kaduna State Rehabilitation Board

Leprosy Centre Uzuakoli, Welfare Department, Abia State
Local Government Staff Pension Board
Local Government Service Commission, Nigeria
Nasarawa State Rehabilitation Board
National Orthopaedic Hospital, Igbobi, Yaba, Lagos
Office of the Governor Sec Ibadan
Physical Handicap Association of Nigeria Plateau State
Social welfare Department, Oyo State
State Emergency Management Agency, Kano - Nigeria
St. Catherine's TBL/PHC, IWARO-OKA, Ondo State, Nigeria

National organisations

Association for the Physically Disabled of Kenya
Blind People's Association, India
Ghana Blind Union
Malawi Council for the Handicapped
National Association of the Blind, Nigeria
National Development Fund for Persons with Disabilities, Kenya
National Emergency Management Agency (NEMA), Abuja -Nigeria
National Emergency Management, Nigeria
National Union of Disabled Persons of Uganda (NUDIPU)
Nigeria Association of the Blind
Programme National RBC, Benin
Rwanda Union of the Blind
South Africa National Council for the Blind
Union Nationale des Associations et Institutions de et pour Personnes handicapées du Cameroun (UNAPHAC)
Zambia Agency for Persons with Disabilities (ZAPD)
Zambia Federation of Disability Organisations (ZAFOD)

Non-Governmental Organisations

Acceleration Therapy Limited, Lagos -Nigeria

Action Aid Partnership Against Poverty, Kwara State -Nigeria
Action for Disability and Development International, Uganda
American Leprosy Mission, Brazil
American Leprosy Mission, Democratic Republic of Congo
Asia-Pacific Development Centre on Disability (APCD), India
Associaizione Italiana Amici di Raoul Follereau (AIFO)
Blinding Hope For special Learners
C.P. Charitable Trust
CBR Africa Network (CAN)
CBR Prevention of Childhood Disability, Ghana
Centre Handicapes en Avant, Burkina Faso
Coptic Evangelical Organisation for Social Services, Egypt
Challenge Your Disability Initiative (CYDI)
Cheshire Homes Society of Zambia
Childhood Disability, Egypt
Childhood Disability, Education & Protection, Egypt
Christian Blind Mission (CBM)
Community Based Rehabilitation Alliance (COMBRA)
Dark and Light Blind Care, Nigeria
Daughters of Charity, Nigeria
Daughters of Charity, St. Catherine's House, Delta State
Disability Support Project
DOM SPARK, Kenya
Elim Christian Vocational Training Centre (CVTC), Benue State Nigeria
Ethiopian National Association of Persons Affected by
Hansen's Disease (ENAPAHD)
Ethiopian National Association of Persons Affected by Leprosy
Evangelical Reformed Church of Christ, Nigeria
F.A.D.P.D, Guinea Bissau
Fédération Togolaise des Associations de Personnes Handicapées
(FETAPH), Togo

Feed the Children, Malawi
Foundation for Special Needs Education, UK
Gabriella Children's Rehabilitation Centre (GCRC), Tanzania
German Leprosy & Tb Relief Association
Ghana Association of the Blind
Global Partnership for Disability and Development (GPDD)
Handicap International (HI)
Heeren Loo, The Netherlands
Helping Hands for Women and Youth Support, Plateau State, Nigeria
Ideal Development and Empowerment Agency- Bauchi State Chapter, Nigeria
Independent living for people with disabilities (ILP)
International Labour Organisation (ILO)
Jedidja –Kimon, Guinea Bissau
Joint National Association of Persons with Disabilities (JONAPWD),Nigeria
Khoula Hospital, Oman
Kuhenza For The Children, Kenya
Lewisham HealthCare NHS Trust, United Kingdom
Liftup Care for the Needy, Abuja -Nigeria
Light for the World, Austria
Liliane Foundation
Medical Aid for Palestinians
Mobility India
National Mine Action Centre (NMAC), Sudan
National Council for Persons with Disabilities, Kenya
Netherlands Leprosy Relief
NKST Rehabilitation Hospital, Nigeria
Norwegian Association of the Disabled (NAD)
L' Organisation Catholique pour le Développement et la Solidarité
(OCADES-CARITAS), Burkina Faso
Opportunity Zambia (Norwegian Disability Consortium)
Organised and Useful Rehabilitation Services (OURS) , Uganda

People Affected with Leprosy, Nigeria
Plateau Association for the Deaf, Plateau
Presbyterian C.B.R. Garu
Programme SANDEMA, Ghana
Programmes des Incapacités et Traumatismes Prevention et Readaptation
a Base Communautaire au Togo (PITR/PNRBC), Togo
Projet de Réadaptation à Base Communautaire aux Aveugles et Autres Personnes
Handicapées du Niger (PRAHN)
Rehabilitation a Assise Communautaire des Handicapés (RACH) Gagnoa
Côte d'Ivoire
Rehab Centre for Disabled, Old and Tramps Anambra
Rehabilitation International
Secretariat of the African Decade of Persons with Disabilities
Service de Formation de Rehabilitation des Aveugles et autres
Handicapés (SEFRAH), Togo
Services for People with Disabilities FCT, Abuja
Seti Centre, Egypt
Sightsavers
Sisters of St Louis Oka-Akoko, Nigeria
Stichting Liliane Fonds, The Netherlands
Stiftelsen for industriell og teknisk forskning (SINTEF), Norway
Sudan Evangelical Mission (SEM)
Simon Wellington Botwey (SWEB) Foundation, Ghana
The Ethiopian Centre for Disability and Development
The Ethiopian Centre for Disability and Development
The Leprosy Mission International,
The Salvation Army
Uganda Society for Disabled Children (USDC)
Vision 2020 Support Program, Nigeria
Vision Community Based Rehabilitation Association, Ethiopia
West Essex Community Health Services, UK
World Blind Union

World Federation of Occupational Therapists

World Health Organisation (WHO)

Write Out Loud, UK

Zabre CBR Project

Universities and Institutions

Center for Disability and Rehabilitation Studies- KNUST, Ghana

Centre for Global Health & School of Psychology Trinity College Dublin

Education Development Centre, USA

Institute of Child Health

Kenya Medical Research Institute (KEMRI)

Kyambogo University

New York University

St. Joseph's Remedial Training Centre, Nigeria

Stellenbosch University, South Africa

Université Catholique du Gabon, Congo DRC

University of Australia

University of Cape Town

University of East Anglia

University of Jos, Nigeria

University of Leeds

University of Winneba

Vicentian Fathers, School for the Deaf & Children with Special Needs

Anambra

Appendix 2

Key resolutions from the 4th CBR African Network Conference

During the Conference, eight participants¹ kindly agreed to act as reporters to identify key recommendations from discussions. They came up with a list of suggestions, which were edited with the help of the plenary assembly in the concluding session of the conference. In order to enable all participants to take part and have a say, these recommendations were translated into French and Portuguese languages.

English:

- **CBR Guidelines:** The guidelines provide a framework for development of CBR and should be used in a way that fits the local context
- **CBR Matrix:** No walls should be built around the boxes of the CBR Matrix but CBR practitioners should be encouraged to reach out to and partner with stakeholders involved in other components/ sectors
- **Research:** Research networks should be set up in the region to promote evidence- based good practices and build up stronger evidence for CBR
- **Training:** CBR needs to be included in mainstream training of workers across development sectors, such as agriculture, education, law
- **Training:** People with disabilities should be at the centre of any training initiative
- **Families:** Families need to be at the heart of CBR planning and practice
- **People with disabilities:** The expertise of people with disabilities is the core of any CBR programme
- **Children with disabilities:** Children with disabilities should be supported to advocate for themselves
- **Policies:** Disability should be included in the mainstream development agenda through overarching development frameworks such as the Millennium Development Goals, Poverty Reduction Strategy Papers and UN Development Assistance Framework

1 Linda Lehman (American Leprosy Mission), Rozenn Botokro (Handicap International), Harry Finkenflugel (Institute for Health Policy and Management), Mary Wickenden (University College London), Alice Nganwa (Ways of Inclusive Development), Karen Bunning (University of East Anglia), Hasheem Mannan (Trinity College Dublin), Nathalie Jessup (World Health Organization).

Recommandations issues de la conférence en Français:

- **Guides RBC:** Les Guides RBC fournissent un cadre pour le développement de la RBC et doivent être utilisés d'une manière adaptée aux contextes locaux;
- **Matrice RBC:** Il ne faut pas construire de murs autour des cases de la matrice RBC mais au contraire inciter les acteurs de la RBC à rechercher et collaborer avec les acteurs impliqués dans les autres composantes et secteurs que le leur;
- **Recherche:** Des réseaux de recherche doivent être développés dans la région afin de promouvoir les bonnes pratiques fondées sur les preuves et de développer une base de connaissances pour la RBC
- **Formation:** La RBC doit être intégrée dans les formations générales des professionnels de tous les secteurs, par exemple l'agriculture, l'éducation, la justice
- **Formation:** Les personnes handicapées doivent être impliquées au centre de toutes les initiatives de formation
- **Familles:** Les familles doivent être au centre de la planification des actions de RBC et de leur mise en pratique
- **Personnes handicapées:** L'expertise des personnes handicapées doit être le cœur de toute programme de RBC
- **Enfants handicapés:** Les enfants handicapés doivent être appuyés à défendre leur cause
- **Politiques:** La question du handicap doit être incluse dans les priorités générales du développement, notamment à travers des cadres globaux tels que les Objectifs du Millénaire pour le Développement, les Documents Stratégiques de Réduction de la Pauvreté et les Cadres des Nations Unies pour l'Assistance au Développement.

Recomendações da conferência em Português :

- **Manuais de RBC:** Os manuais são diretrizes para o desenvolvimento da RBC e devem ser utilizados de forma adaptada ao contexto local.
- **Matriz de RBC:** Não se deve construir paredes em volta das áreas da matriz de RBC, mas ao contrário estimular os atores da RBC a procurar e colaborar com atores envolvidos em outras áreas e setores.
- **Pesquisar:** redes de pesquisa devem ser desenvolvidas na região para promover boas práticas baseadas em comprovações e para desenvolver uma base de conhecimentos sobre RBC.
- **Treinamento:** A RBC deve ser incluída em treinamentos para os profissionais de todos os setores, tais como agricultura, educação, justiça, etc.
- **Treinamento:** As pessoas com deficiência devem ser envolvidas na base de todas as atividades de formação.
- **Famílias:** As famílias devem estar no centro do planejamento das ações de RBC e na sua implementação.

- **Pessoas com deficiência:** O conhecimento próprio das pessoas com deficiência deve estar na base de qualquer programa de RBC.
- **Crianças com deficiência:** As crianças com deficiência devem ser apoiadas na defesa das suas questões.
- **Políticas:** A questão da deficiência deve ser incluída nas prioridades gerais do desenvolvimento, notadamente em documentos gerais tais como os Objetivos de Desenvolvimento do Milênio, os documentos estratégicos de redução da pobreza e os programas das Nações Unidas para assistência ao desenvolvimento.

Afterword

Recent and upcoming developments in CBR

Priscille Geiser, Grace Musoke

From Abuja to Manila, from Manila to Agra

This book attempted to account for the presentations and discussions held in Abuja, Nigeria during the **4th CBR Africa Conference** organized by the CBR Africa Network (CAN) under the theme, “Linking CBR, Disability and Rehabilitation”. Between this conference and the late release of this book (for which the authors and editors apologize), CBR has continued to evolve and adapt to different contexts, to think out the best possible strategies to improve the lives of people with disabilities across the world.

The release of the **CBR Guidelines** in 2010, has created a momentum around this strategy. Prior to this, the entry into force of the **UN Convention on the Rights of Persons with Disabilities** (UNCRPD) in 2008, stirred new commitments and opportunities for States, development stakeholders and Disabled People’s Organizations (DPOs) to engage in the promotion and enactment of rights of people with disabilities, with the vision of an inclusive society where all can enjoy their rights equally.

Since Abuja where the Guidelines were launched, new synergies have emerged between stakeholders involved in the promotion of disability rights and the enforcement of the UNCRPD on the one hand, and development stakeholders involved in CBR programme design, implementation and monitoring, on the other. The **CBR Asia Pacific Conference organized in Manila**, Philippines in November 2011, accounted for changes in CBR language and practices, with increased concerns for CBR to be a strategy towards Community-Based Inclusive Development and an effective contribution to realizing human rights.

In November 2012, the first ever **CBR Global Congress was organized in Agra**, India, under the theme, “CBR: a key to realizing the UNCRPD”. This congress was yet another step towards rights-based, inclusive approaches to CBR. Although much effort is still required, positive steps are taken towards an

increased participation of people with disabilities and their representative organizations in CBR, towards the development and structuring of CBR networks that are active in promoting CBR strategies, tools and methods, and towards continued efforts to bring CBR as part and parcel of mainstream development efforts.

During this Global Congress, the International Disability and Development Consortium (IDDC), co-author of the CBR Guidelines, released two important documents aimed at promoting CBR as an effective strategy to realize the UNCRPD (available on IDDC website: www.iddcconsortium.net):

- CBR Guidelines as a tool for Community-Based Inclusive Development
- Community-Based Rehabilitation and the UN Convention on the Rights of Persons with Disabilities.

CBR Global Network

The first CBR Global Congress was also the occasion to launch the CBR Global Network, which has the following vision and mission:



CBR Global Network Vision

"Inclusive and empowered communities"

CBR Global Network Mission

- Promoting the concept of Community-based Inclusive Development (CBID) in line with the CBR Guidelines and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and human rights through global, regional, sub-regional and national CBR networks and other partners;
- Ensuring CBR as an effective strategy to realize the CRPD and related national and international laws and legislations;
- Applying the principles of the CRPD into daily life of men and women with disabilities, children with disabilities and their families, especially those with severe/multiple disabilities;
- Developing an alliance with other disadvantaged groups to reduce poverty, and to seek social justice and equity in society;

- Working with CBR partners and other stakeholders to develop mutual capacity;
- Partnering with other stakeholders to achieve the vision of the CBR Global Network; and
- Working with Disabled People's Organizations (DPOs) to ensure the empowerment of persons with disabilities and their participation in all decisions related to their lives.

CBR Global Network Executive Committee

The first formal meeting since the inauguration of the CBR GN Executive Committee took place in Bangkok on 1st and 2nd July 2013.

Announcing the next CBR Africa Conference

With the creation of the CBR Global Network, the pace has been set to organize CBR regional conferences every four years. The next conference will be organized by the CBR Americas Network from 22nd to 25th October 2013 in Medellin, Colombia.

The CBR Africa Network is happy to announce the **5th CBR Africa Conference to be organized in Kenya, in November 2014**. CAN looks forward to welcoming many participants from the widest range of African as well as other countries to share knowledge and experiences and walk the next step towards more effective, inclusive, rights-based CBR.



Community Based Rehabilitation (CBR) Africa Network (CAN)



Sponsored by
CP Charitable Trust, UK
2013

