

# **CBR AS PART OF COMMUNITY DEVELOPMENT**

## **A POVERTY REDUCTION STRATEGY**

**Editor**  
**Sally Hartley**

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# FOREWORD

FROM THE GOVERNMENT OF MALAWI

Malawi was honoured and privileged to host the 2nd Africa Regional Conference on CBR on behalf of the CBR Africa Network that was held at Kalikuti Hotel in Lilongwe from the 31st August to the 3rd September 2004. It was a delight to host so many participants from across Africa and Europe whom I trust enjoyed the unique warmth and hospitality of Malawi, the Warm Heart of Africa. I would, therefore, like to thank the organisers for choosing Malawi as the venue for this international conference. To us, this was a reflection of the trust and goodwill that the country has earned in the international community.

It was gratifying to note the response and attendance of the Conference which brought together so many players working with or for people with disabilities and CBR from a number of countries in Africa and beyond. Delegates came together in the spirit of cooperation and partnership to share ideas and experiences on how to promote Community-Based Rehabilitation; and to examine the evidence that CBR is an integral part of community development in Africa.

There is no doubt in my mind that the conference participants believe and support the vital role of people with disabilities in community development. In Malawi, as indeed in any African country, we cannot expect to reduce poverty or achieve our socio-economic development goals without the inclusion or participation of persons with disabilities. Our major challenge, therefore, as a disability sector is to ensure that all other sectors share a similar view and are so aware of disability issues that the inclusion of persons with disabilities in development forums, policies and programmes becomes second nature and lobbying government, international partners and policy makers becomes a thing of the past.

Although most readers will find the book irresistible, let me urge you all to use this book primarily as an encouragement and inspiration to ourselves working in the disability sector and learn from the shared experiences so that we can continue to empower the lives of persons with disabilities in our countries. Secondly, this book should be used as an advocacy tool to change the mindset of our politicians, governments and other policy makers to mainstream disability in all areas of community development. It is my fervent hope that this book will open the door for local and international forums to actively involve people with disabilities when they meet to discuss important social and economic issues concerning our nations.

While all the development issues raised in this book are equally important, I would like to stress the importance of research in CBR as part of community development. "Inclusive" research offers us a gateway into development forums and onto development agendas. With valid and reliable evidence, disability issues cannot be ignored and can only lead to positive development for people with disabilities and our nations.

Finally, let us all make use of the CBR Africa Network website and the directory at the back of this book to continue to share our research, experiences and knowledge so that disability is mainstreamed in all sectors and in every African nation.

**Elias U. Ngongondo**

Secretary for Social Development and Persons with Disabilities  
Government of Malawi

# FOREWORD

## FROM THE NORWEGIAN ASSOCIATION OF DISABLED (NAD)

The perception of community based rehabilitation (CBR) has changed substantially since its inception more than two decades ago. The initial small projects were developed in isolation with a kind of personal view of what CBR was supposed to be. Further, in the past the term *rehabilitation* reflected a medical and diagnostic approach which ignored the imperfections and deficiencies of the surrounding society and environment.

Globalisation in terms of increased opportunities of sharing knowledge and experiences, as well as the strong involvement of disabled people has changed this, and today CBR increasingly tends to bear the same meaning all over the world. The current terminology recognises the necessity of addressing both the individual needs such as rehabilitation and technical aids, as well as the shortcomings of the society and its various obstacles and barriers for participation.

The global recognition of a more holistic approach to rehabilitation can largely be attributed to initiatives which bring key stakeholders in the field of CBR to seminars and workshops on a regional and global basis. For example the two CAN conferences held in Uganda 2001 and in Malawi in 2004, with participants from more than 20 different countries, have brought about valuable opportunities to learn from one another and expanded our ability to respond to the rights and the needs of persons with disabilities in their community.

In the late eighties NAD made a strategic shift in its development assistance to disabled persons, from institutional to community based rehabilitation maintaining a strong representation from the local governments. At the same time NADs support to disabled persons organisations (DPO) has had equally high priority. This twin track

approach; strengthening the *duty bearers* on the one hand and the *rights holders* on the other; aims to strengthen their respective roles, responsibilities and performance in the society, as well as the communication and interaction between the two. It is therefore not a coincidence that NAD has supported the two CAN conferences in Uganda and Malawi, since our organisation also supports their two governments in developing national community based rehabilitation programmes.

A prerequisite for NAD's support to these conferences has been that all the presentations, deliberations and discussions during the workshops should be captured and translated into a book to be shared with a wider audience. We do therefore sincerely hope that this book will be widely distributed and read by senior government officials, NGO managers and community development workers. Most importantly we hope that it will trigger the interest of disabled persons' organisations and encourage them to take an active role in the planning and implementation of community based rehabilitation programmes throughout the African continent.

**Lars Odegard**

Secretary General The Norwegian Association of  
Disabled - NAD

# FOREWORD

**FROM ICH, U.K.**

It is a great pleasure to be invited to provide the foreword for this book which provides clear statements as to how CBR must be seen as part of other mainstream services and activities and can no longer be viewed as an add-on service only if there is a budget available. The book demonstrates how far CBR AFRICA NETWORK (CAN) has progressed over the past 4 years, Shaya Asindua in the first chapter outlines the growth of CAN and is proud to acknowledge its role in promoting the largely African authorship of the majority of the chapters in this book. It shows that practitioners from throughout the African continent are now able to share their experiences with readers throughout the world.

The book extends some of the papers given at the conference and addresses not only of how CBR should be, but also gives examples of how CBR can be integrated into different services including health, economic, education, social and cultural sectors. Peter Coleridge in the second chapter addresses the issue of how CBR can address the all important issue of poverty reduction for persons with disability and their families. In this chapter he gives a thoughtful overview of factors, which have inhibited the economic progress of persons with disability and challenges the World Bank's view in 1999 (before the appointment of Judy Heuman) that persons with disability are economically inactive.

There then follow four interesting chapters illustrating how CBR can be integrated into first social cultural and political development, secondly into the economic development of a community, thirdly into community health development and finally how CBR should be perceived as part of the inclusive education movement.

The under recognised issue of the impact of the HIV/AIDS pandemic upon persons with disability and the way in which the (relatively) new ICF classification system from WHO can be used to assist CBR activities

# Contributors

are then presented in in the next two chapters. The great strength of the ICF chapter is that it gives several illustrative examples which will be useful to practitioners.

It is unfortunate that the authors of some chapters fail to relate the ideas they promulgate to the published literature. This is especially important where chapter authors are trying to change attitudes of readers who are not closely involved with CBR such as the issue of CBR and HIV/AIDS. This is a book primarily about CBR in Africa but should be useful to readers working in CBR and community development from South Asia, South East Asia, Central Asia and elsewhere, all of whom have slightly different interpretations of CBR but these African interpretations may also fit into community development regimes in their settings

The three final chapters stress the need for exchange of information. One gives an excellent summary of sources of information about CBR that must be of value to any programme planner. Another gives a directory of disability services in Malawi. The chapter on CBR research as part of community development reviews 25 years of research in CBR specifically seeking the evidence base for this work It notes the need for more writing and recording of good practice and says "*without such work CBR development will be slow and many programmes will continue to function in ways which others have already discarded*".

The participants of the Lilongwe conference, the chapter authors of this book and the editor Sally Hartley have all produced a book, which addresses the challenge raised in the quote above.

## **Sheila Wirz**

Professor of Disability and Development  
Institute of Child Health  
University College London

## **Torild Almnes**

Torild has put in more than 20 years in Social Services in Oslo, Norway, most of the time as a director, and has more than 7 years of experience in African and Asian countries. She has been appointed to numerous governmental and private committees and boards. She has lectured at universities, national and international conferences and workshops. Her leadership abilities, motivation and inspirational skills are well known. She is now in Malawi as Senior Programme Adviser to the Government on disability issues, with special emphasis on developing a new CBR model for the country. She also assists FEDOMA, the umbrella organisation for DPOs and its 7 member organisations. She is on contract with the Norwegian Association for the Disabled.

## **Shaya Asindua**

Shaya has over twenty years of experience in working in disability and development, at both community and policy levels. She has been the key in developing and adapting the CBR concept as a meaningful tool for development work and empowering disabled persons in Africa. Shaya works for Leonard Cheshire International as the East and North African Regional Programme Manager. She is presently the Chairperson of the CBR Africa Network.

## **Svein Brodtkorb**

Svein is a Senior Adviser to the Norwegian Association of Disabled. He spent 4 years (1991-1995) in Uganda, as advisor to the national CBR programme during the early stages of the programme. Since 1995, he has been based in the NAD Head Office in Norway, with particular

responsibility for following up CBR programmes and organisational development among DPOs in Uganda, Malawi and Lesotho.

### **Alick H.P. Chavuta**

Alick Chavuta is currently working at Montfort College of Special Needs Education, Malawi, as a senior lecturer in special needs education. He is the head of the Learning Difficulties Programme and has vast experience in special needs education. His research interests include inclusive education, education of children with learning difficulties and coping strategies for parents of children with disabilities. Alick has a Master's degree in Community Disability Studies in Developing Countries from the University College, London.

### **Peter Coleridge**

Peter has worked in disability and development, for more than 25 years in the Middle East, Afghanistan and East Africa. He is the author of "Disability, Liberation, and Development" (Oxfam 1994) and numerous papers on disability and development. He is currently engaged in an ILO research project, on skills development and access to work for disabled people in developing countries.

### **Lisa Davidson**

Lisa originally went to Namibia as a volunteer to work on a TB and malaria programme in 1996. Soon after arrival, it became apparent that any work regarding TB and malaria needed also to address HIV and AIDS, and very quickly this became the main focal point of her work. Three years ago, she started working for VSO, supporting their HIV and AIDS programmes. Part of this job included supporting volunteers working in other sectors such as education, secure livelihoods and disability to mainstream HIV and AIDS. In 2003 she was involved in a national conference on Disability, HIV and AIDS and the programme she is presently working on, grew out of it.

### **Servious Dube**

Servious has been working for over twenty years in health, community development and disability within government and NGOs, at implementation and senior management levels. This has been in both his home country, Zimbabwe, and as an expatriate development worker in other African countries. He is now working for Leonard Cheshire International (UK) as a Senior Programme Manager for Africa, based in London. He has also worked for Save the Children UK, job sharing on the disability adviser's position. He was involved in research work from 1999 to 2002, at the Institute of Child Health, University College London as an Associate Fellow. Together with Professor Sheila Wirz, he investigated the possibility of designing a low cost hearing screen for identifying permanent hearing loss in young children in low income countries.

### **Harry Finkenfliigel**

Harry was involved in the CBR pilot projects in Zimbabwe (1988-1991), and has since then been committed to the development of the CBR concept. He has published several articles and edited two books on CBR including, "Empowered to differ, stakeholders' influences in CBR" (2004). As a researcher at the Institute of Health Policy and Management of the Erasmus University of Rotterdam, the Netherlands, he has committed himself to research into conceptual models, competencies of stakeholders and effectiveness of community care programmes in the Netherlands and Sub-Saharan Africa.

### **Sally Hartley**

Sally has worked with and for disabled people in many African countries over a period of 30 years. She was a Senior Research Fellow at the Institute of Child Health, London University till 2005. Her research has focused on community approaches to improving the quality of life of disabled people in low-income countries. Sally is the Executive

Director of CAN and from 2006, she has taken up a position as Professor of Communication and Health at the University of East AngHa, UK.

### **Marko Kerac**

Marko is a medical doctor who completed basic specialist training in paediatrics in the UK. His interest in disability was inspired by a childhood friend as well as a 'Community Child Health' job working in inner city London. From 2003-4, he spent a year at the Malawi College of Medicine, Blantyre, working as a paediatric registrar and lecturer. Having been captivated by "The Warm Heart of Africa", he is going back in January 2006, this time for 2-4 years, doing a PhD on 'CTC '(Community-based Therapeutic Care) for severely malnourished children. Links and friendships, made whilst compiling the directory, are a maj or factor behind the plans to return.

### **Chapal Khasnabis**

Chapal Khasnabis graduated in Prosthetics and Orthotics Engineering from the All India Institute of Physical Medicine and Rehabilitation, Mumbai, India in 1979. He then joined the National Institute for the Orthopaedically Handicapped, under the Ministry of Social Welfare. After 15 years in government, he started a highly successful NGO named Mobility India. Mr Khasnabis is currently a Technical Officer in the Disability and Rehabilitation team in the VIP department of WHO, Geneva.. His responsibilities include the promotion of community based rehabilitation and assistive devices. He uses his 25 years of work experience in government and NGOs, to ensure that rehabilitation services reach the majority of people who need them, particularly the poor and women.

### **Edward Kisolo Kimuli**

Edward Kimuli is presently the Deputy Vice Chancellor of the new University of Kyambogo in Kampala, Uganda. He was previously the Director of The Uganda National Institute of Special Education (UNISE) and the Chairperson of the committee, which planned and hosted the first CBR Africa Network conference, 'CBR as a Participatory Strategy in Africa, in 2001.'

### **Mitchell Loeb**

Mitchell works for SINTEF Health Research. He has a B.Sc. (Biology) and M.Sc. (Epidemiology) with 25 years of experience in epidemiological research methodology and the analysis of statistical research data. Relevant work experience includes research in developing countries/emerging democracies, including environmental epidemiology in Kenya, Poland and Romania, studies of living conditions among people with disabilities in Namibia, Zimbabwe, Malawi, Zambia and South Africa, and quantitative data collection and analysis on disability in Indonesia.

### **Stefan Lorezkowski**

Stefan is working in Central Asia where he supports the development of a regional programme with a focus on inclusive development, for Handicap International. Earlier, he worked for the "Source" Information Resource Centre at the Institute of Child Health, London, as the Disability Information Officer. He was in charge of making disability relevant information, more readily available.



### **Alister Munthali**

Alister has an M.A. and Ph.D. (Medical Anthropology). His research thesis was entitled "Change and Continuity in Perceptions about Childhood Illnesses in Northern Malawi." His current position is Research Fellow at the Centre for Social Research, Zomba, Malawi. Since January 1996. Dr. Munthali has conducted a number of studies mainly in the field of medical anthropology, with special interest in children - including vaccinations, and health and illness in African societies.

### **Fredrick Blesius Venus Mzoma**

Fredrick is a polio survivor, born in 1960. He went to mainstream schools for primary, secondary and university education and graduated from the University of Malawi in 1983, with a Bachelor of Arts degree. He worked for the government and retired at Permanent Secretary level. He now works on contract for the government, assisting with the setting up of a new directorate to oversee public procurement. Fred has been in the disability movement since the early eighties and was one of the founding members of Disabled Peoples Association in Malawi. As its Executive Chairman, in 1998, he successfully lobbied for the rights of persons with disability which led to the president creating a Ministry to specifically take charge of persons with disabilities. He was appointed its first Permanent Secretary.

### **Benon Christopher Ndaziboneye**

Benon has been a very active member of the National Union of Disabled Persons in Uganda (NUDIPU) and in this capacity, he has made remarkable contributions in the area of co-ordinating organisations and programmes for disabled persons in Uganda. He has worked for Action on Disability and Development (ADD) and for the CBR Africa Network (CAN) also in Uganda.

### **Alice Baingana Nganwa**

Dr. Nganwa is a medical doctor working in Uganda as the Director of Injury Control Centre, Uganda. She previously worked for the Ministry of Health, Headquarters in Uganda, where she established the Disability Prevention and Rehabilitation Section. While in the Ministry she guided the development of the health disability policy, policy for prevention of blindness, deafness and injury. She is on the Uganda National CBR committee and works with WHO on new CBR guidelines. Dr. Nganwa has been involved in research, training and programme development in disability in Uganda, Lesotho and Southern Sudan.

### **Orpa Ogot**

Orpa is the Inclusive Education Liaison Officer for Leonard Cheshire International, East and North Africa Region. Her particular responsibility lies with the Oriang Cheshire Inclusive Education Project, Kenya. She has a B.Ed (Special Education). She previously worked as Inspector of schools in charge of special education programmes in Nyanza Province, as a teacher of special education for visually impaired children in regular school. Her current career focus is to influence government policy on inclusive education. In the future she hopes to do this through research, on the inclusion of children with disabilities into educations in the early years.

### **Margie Schneider**

Margie is a Chief Research Manager in the Child, Youth and Family Development Research Programme, at the Health Services Research Council (HSRC) South Africa. She initially trained as a Speech Therapist and Audiologist, but since 1995, has been involved in research on disability broadly. Her areas of research interest include disability assessment and measurement, disability in relation to exclusion and poverty, public health and disability, and community based rehabilitation (CBR). Research projects include, the first national baseline survey on disability

in South Africa, social security and disability. While working at WHO, Margie worked on the revision of the International Classification of Functioning, Disability and Health (ICF). Her publications have been mainly in the area of the disability and more specifically the role of the environment in disability.

### **Daniel Vershima Tsengu**

Daniel works for Christoffel Blindenmission International (CBMI) as the National Assistant Coordinator. He has an MSc in Community Disability Studies, UCL, London University. As a disabled person himself he is particularly interested in the contribution that disabled people can make to their own destiny and in the economic aspects of community interventions.

# Acronyms Used

ABEK	Alternative Basic Education for Karamoja, Uganda
ADD	Action on Disability and Development
APDK	Association for Physically Disabled, Kenya
BOSEP	Build Own Small Enterprise Project, Bangladesh
CAN	CBR Africa Network
CBR	Community based Rehabilitation
CDA	Community development assistant
CICH	Centre for International Child Health, UK
COMBRA	The Community Based Rehabilitation Alliance, Uganda
CSO	Civil Society Organisations
DPI	Disabled People's International
DPO	Disabled People's Organisations
EARS	Educational Assessment and Resource Services, Uganda
EFA	Education For All
FEDOMA	The Federation of Disability Organisations in Malawi
HSRC	Health Services Research Council
ICT	Information and Communication Technologies
IDDC	International Disability and Development Consortium
IE	Inclusive Education
IGA	Income Generation Activities
IGNOU	Indira Gandhi National Open University, India
ILO	International Labour Organisation
IMF	International Monetary Fund
INGOS	International Non-Governmental Organisations
LQ	Leonard Cheshire International
LNGOS	Local Non-Governmental Organisations
MACOHA	Malawi Council of the Handicapped
MDG	Millenium Development Goals
MIEP	Malawi Integrated Education Programme

# Editorial

*Sally Hartley*

MLRR	Ministry of Lands, Rehabilitation and Resettlement, Namibia
MPBOU	Madhya Pradesh Bhoj Open University, India
NAD	Norwegian Association of the Disabled
NFPDN	National Federation of People with Disabilities in Namibia
NGO	Non-Government Organisation
NUDIPU	National Union of Disabled Persons of Uganda
NUWODU	National Union of Women with Disabilities of Uganda
PAP	Poverty Alleviation Programmes
PHC	Primary Health Care
PRSP	Poverty Reduction Strategy Paper
PWD	People with Disabilities
RAISA	Regional AIDS Initiative in Southern Africa
PJ	Rehabilitation International
SAFOD	Southern Africa Federation of Disabled People
SARPV	Social Assistance and Rehabilitation for the Physically Vulnerable, Bangladesh
SCL	Spinal Cord Lesion
SDC	School Disability Committee, Kenya
TALC	Teaching Aids at Low Cost
TPA	Three Pillars Approach
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNISE	Uganda National Institute of Special Education
USDC	Uganda Society for Disabled Children
WB	World Bank
WHO	World Health Organisation
VSO	Voluntary Services Overseas
WF	Vesicular - Vaginal Fistula

## INTRODUCTION

This book has developed from presentations and discussions that took place in Malawi at a conference entitled, "CBR as part of Community Development". Some of the chapters remain an exact replication of the presentations that took place, whilst others have been strengthened by additional information from discussions or relevant literature. In addition some chapters have been added that were not presented at the conference at all. As such this publication is a reflection and development from the original conference, one that is much richer and has much more to offer, than a straightforward conference proceedings document.

The choice of "CBR as part of Community Development" originates from the observation that the WHO/ILO/UNESCO (1994) definition of CBR states that "CBR is part of Community Development". The book examines how this key concept is played out in practice and what challenges and opportunities it presents to the stakeholders of CBR programmes in Africa. Stakeholders here include disabled people themselves, planners, trainers, implementers and researchers of CBR.

In 2004, at about the same time as the Malawi conference, WHO/ILO/UNESCO amended and re-ratified this Joint Position Paper (WHO/ILO/UNESCO, 2004). The amendments were relatively minor and CBR remained defined as "*a strategy within general community development*". One key change however, related to the recognition of poverty as both a major determinant and an outcome of disability. This resulted in the inclusion of "poverty reduction" as a key element of the recommended CBR strategy. The decision by the UN agencies to include poverty in the definition of CBR is a major step in highlighting the importance of addressing poverty as part of CBR and provides another

strong link with community development. The chapters in this book provide plenty of evidence to support the UN decision, and this is particularly well reviewed by Peter Coleridge in Chapter 2. The arguments presented underpin one of the main key messages of the conference, that **CBR must address poverty because it is the major need of people with disabilities.**

At the last CBR conference in Uganda, key tasks and players were identified for future activities, meetings were held and a new organisation was born. This organisation was named the "CBR AFRICA NETWORK" (CAN) and part of its portfolio was the organisation of the conference in Malawi and the publication of this book. Chapter 1 by Shaya Asindua, the Chairperson of CAN, outlines the activities that have taken place in relation to the tasks that were identified. The Malawi meeting ratified this initiative in one of its key messages and agreed that **"Sharing information is crucial to the development of CBR."** This is perhaps the key message of CAN itself. Many people are doing good work but others never hear about it and the wheel is re-invented every-time. An excellent example of what can be done by individual countries as a first step towards tackling this can be found in Chapter 10 which describes an initiative in Malawi for collecting and sharing information about CBR related activities. Recognising the need for information sharing at all levels of operation is also crucial. Different mechanisms for sharing information may be required to achieve this. Books and journal articles may be a good medium for academics, but radio and drama may be the best way for rural community dissemination.

CAN is working to address all these approaches and has made impressive progress. Its outputs clearly demonstrate determination to harness the strength of participatory approaches in Africa. These approaches are very much in line with the "African worldview" of a holistic and integrated way of looking at the family and the universe. They challenge the "Euro-centric worldview," which follows a more scientific paradigm and often looks at the whole in the separateness of the parts. This holistic approach

has enabled CAN and its stakeholders to begin to develop structures that nurture information sharing between all the people involved in addressing the problems faced by disabled people.

One of the main outputs from the Uganda conference was the identification of 10 key ingredients for CBR in Africa. These can be found in the book "CBR as a Participatory Strategy in Africa" or on the CAN web page [www.afri-can.org](http://www.afri-can.org) Reflection on these ingredients over the intervening years and comparison with the Joint Position Paper on CBR (1994) and (2004), show many more similarities than differences. It has been obvious from the discussions and meetings of CAN that there is a great need to express the underlying concepts of CBR in an African way, one that resonates with disabled people and service providers on the continent. Interestingly the major difference between the key ingredients for Africa and the Joint Position Paper is the omission of "rehabilitation" as a key dimension in the African CBR ingredients. Two of the contributing reasons for this are firstly that the needs of disabled people in Africa relate strongly to the change required from the physical, political and social environment. Secondly the interpretation of 'rehabilitation' is a narrow one.

The traditional interpretation of the term "rehabilitation" focuses on changing the individual with the disability to "fit in" or to "normalize" his/her functioning. This reflects a medical/individual model approach, which as a single strategy has been found to be most unsatisfactory, not only to disabled people themselves, but also to many service providers. On the other hand, the social model demands that the change be made by society and the environment. As a direct alternative or substitute to the medical model it may still have some weaknesses. As Cole (1996) says *"The 'medical' and 'social' models are both partial understandings of the experience of disability. In both cases persons are seen as passive victims of biology or society."* p. 14.

In a comprehensive holistic approach the possibility that rehabilitation might offer a more positive contribution is sometimes overlooked..

Maximising an individual's potential to perform activities related to daily-living, participation and inclusion, may be potentially important mechanisms within CBR for achieving the goal of an improved quality of life. Chapter 4 highlights this point in relation to the realities of economic empowerment and the need for disabled people to take responsibility for their own development and integration into society. Man can only liberate himself, he cannot be liberated by others. Maximising full potential through a rehabilitation process could be seen as part of this process. This observation and argument led to another key message of the conference, that **"CBR should promote rights but also it should promote responsibilities."**

The African groups are not alone in their difficulties with including 'rehabilitation' as a useful 'ingredient'. The 'R' of CBR has been the source of many discussions and debates summarised by Miles (1996). However representatives from the world CBR community in Helsinki (WHO 2003) agreed that, to change the name of CBR at this stage (two decades after its inception) would not be productive. A more constructive way forward is the realisation that the rehabilitation process can apply to the community as well as the individual and that CBR has an important role to play in "rehabilitating the community". Social integration, inclusion and awareness raising are, in reality, strategies for "rehabilitating the community". This perception does much to vindicate the use of "rehabilitation" within the title of CBR, and is discussed in Chapter 2 with many examples from different African countries of how this has already been done.

If this argument still remains illusive to the reader, there are many other "R" words that might reflect good practice and important dimensions of the CBR ideology, such as, "Rights" "Responsibility" "Regular contact" "Regard" "Reflection" "Resilience" "Relations" "Rejuvenation" and "Resolution". It would appear that rehabilitation of both the individual and the community have an important role to play in a comprehensive (rather than a medical OR social OR rights) approach.

## WHAT THIS BOOK OFFERS

This book provides 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 a clear view of the "state of the art" of CBR in many parts of their continent. They provide examples of their own CBR experiences and case studies of their programmes, the problems they faced and how they were overcome. 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.

The 12 key messages from this conference are listed in Appendix 3, and give readers the opportunity to evaluate their own activities against these messages. For example they might ask themselves: does our CBR programme address poverty? If so how? If not, how could it address this problem in a practical way? To what extent is our CBR programme pro-active? How could this be improved? How do we include disabled people in the planning and implementation of our programmes? Do we make special provision and effort to include deaf people? If not, how can we improve this? etc., etc.

The book also offers discussion questions in Appendix 2 that could be used for conferences or workshops, or as a basis for discussions in CBR training programmes. They can be used to develop a more in-depth understanding of the situation in which people are working and help them to develop their own solutions to the problems that they are facing.

Finally, at the end of each chapter, the book provides a source of references to the academic literature. In addition, Chapter 11 provides a list of useful web sites and unpublished documents can also be found. This information can be used by practitioners all over Africa to access more information about services and support for people with disabilities.

### WHAT THIS BOOK CANNOT OFFER

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

### WHO SHOULD READ THIS BOOK?

The groups of people who will find the content of this book useful are those who are interested and involved in the development of healthy equitable communities. This includes communities who seek to provide an environment that enables people with impairments and their families to maximise their own potential, to improve their quality of life and have the same opportunities and responsibilities as people who do not have impairments. Such people may be part of a family who have a disabled member or belong to the general community. They may be a member of an established professional group or a profession that is just emerging. These professional groups may be medically, socially or technically based; at an individual level they may be able-bodied or have a bodily impairment, they might be parents of children who have an impairment, or be members of a disabled people's organisation; or they may be politicians or personnel from funding agencies. They may be academics, trainers or programme managers.

### WHAT ARE THE KEY MESSAGES OF THIS BOOK?

Three of the key messages have already been mentioned and are recorded in bold in the text above. They relate to poverty reduction being a major ingredient of CBR; the importance of sharing information, and disabled people themselves taking responsibility for their own development.

The observation that "**The Millennium goals cannot be achieved if they do not include disabled people**" (particularly the goals concerning the eradication of poverty and the provision of education for all) is a real breakthrough in terms of putting disabled people and their families on the world agenda. However it is disturbing that the response to these goals are so slow in terms of implementation. For example disability is hardly mentioned in the UNESCO 2004 report on Inclusive Education. Interesting examples of the issues around this are found in Chapters 2, 3, 4 and 6.

Chapter 9 addresses in some detail the absence of experimental (as opposed to experiential) evidence, on the efficacy (or otherwise) of CBR. This, it argues, is not only crucial to the future development of CBR but also something that CBR programmes themselves can make a major contribution towards in terms of making sure that research is grounded in reality. It was agreed that "**The priority of CBR research needs to address local resources and participation.**" The absence of such data is a major concern, and undermines the credibility of CBR with service users, governments and funding agencies. CBR programmes are the best possible organisations to collect and provide this evidence. This is a real challenge to the readers of this book.

In the previous section we discussed the possible representational meaning of the "R" in CBR. Ndaziboneye, Nyathi and Mzoma in Chapter 3 use the same approach to explore alternative concepts which could be represented by the 'C' in CBR. They use this to highlight some of the limitations which have been experienced in the implementation of the CBR programmes such as "confusion" or "confinement" based rehabilitation. Many other practitioners also felt that "**CBR should be more pro-active, and promote its activities aggressively to get other services in place,**" especially in relation to mainstreaming for education (Chapter 5), economic empowerment (Chapter 4), and for HIV/AIDS support and health (Chapters 6 and 7). The tendency for CBR programmes to be "re-active", and just "respond" to the problems that are presented is discussed. As a result CBR workers have become skilled at "problem solving" and "crisis management". There is a need for them to tackle the root causes of the problems, such as taking initiatives to get other agencies involved.

One of the problems facing CBR stakeholders is how they can participate in the CBR process. In the past and still to some extent today, this uncertainty was experienced by disabled people themselves. The CBR strategy said they were to be involved. Further, they were to be key players, but what could they do? What exactly was their role? The disabled rights movement showed the way and now this is much clearer. Disabled people are recognised as the best people to raise awareness and set priorities. This is always apparent at any meeting where the messages conveyed by disabled people are so valuable and powerful in the political and professional arena. Now it is perhaps the turn of the health professionals to feel unsure about **their** role. At the WHO/CBR meeting in Helsinki, many professional felt dis-empowered by the "rights" approach and wondered what their role was in a rights-based model of CBR. Of course the answer lies in appreciating the need for a comprehensive or universal model of disability and of CBR, which involves ALL stakeholders in a process that addresses medical, social, educational and equality dimensions of disablement. These observations and discussions led to the key message **"CBR is for us all."** This is sometimes a very difficult concept to operationalise, but the International Classification of Functioning and disability (ICF) is possibly one framework that might assist in this process. This is examined in Chapter 8.

The development of CBR programmes based on local culture has been a feature of its history, often producing different varieties of CBR and initially leading to confusion over its definition and implementation. However it is recognised that some aspects of all cultures may be negatively disposed towards people with disabilities and that CBR needs to play a role in changing these negative elements (see Chapter 4). Recognising that **"Aspects of culture that are negative cannot be changed overnight"**, as pointed out by Ndaziboneye, Nyathi and Mzoma in Chapter 3, this means giving information again and again in different ways. The technique is clearly demonstrated by big businesses such as Coca Cola.

A very active and contributing member of the Malawi conference was Ms. Gloria Kampondeni from Montfort Teachers College in Malawi. Gloria is a deaf teacher of the deaf and reminded the participants on many occasions of how often deaf people are excluded from CBR initiative and activities. She raised the members' awareness about the extent to which people with hearing difficulties are missed out. She challenged the gathering to examine their activities in relation to this factor and see how they could resurrect it. Two particular examples arose around the need for HIV information (Chapter 7) and their exclusion from research projects in Malawi (Chapter 9). The conclusion was that **"CBR should make sure that deaf people are not being missed out."**

The need for CBR programmes to collaborate with teachers, to contribute to their training and to have an input to tertiary education are discussed in Chapter 5 and the relationship between this and economic empowerment of disabled people in Chapter 4 led to one of the final key messages that **"CBR should promote education at ALL levels if people with disabilities are to have economic empowerment."** This was also seen to relate to the need for CBR programmes to take initiatives and to be proactive. Programmes might ask themselves, how can they collaborate with teachers and contribute to their education?

The problems that arise from difficulties in communication across the African continent were the subject of much discussion in the plenary sessions. These difficulties have created many barriers to the development of CBR programmes and on understanding the issues around having an impairment and the effect of this on the individual, their family and community. Good communication was observed to be seriously confounded in the first instance by the incredible number of different languages in each of the African countries (for example Nigeria has 521 and Kenya 61). This makes it difficult to develop countrywide programmes or produce local materials for information sharing, let alone communicate effectively across the continent. In the second instance there were serious problems with defining key terms such as impairment or disability. CBR words and concepts were not always translatable into local languages. It was concluded that **"CBR needs to communicate its concepts in**

**language that can be understood."** It was observed that using English as a lingua franca and initiatives such as the ICF were only able to touch a very small part of this considerable problem.

The final key message related once more to CBR support for people with HIV and AIDS which was seen at the last conference as a key ingredient of CBR activities in Africa. Chapter 7 gives an example of how **CBR must (and can) address HIV/AIDS issues** in Namibia. In so doing it provides a good example of how CBR activities relate to community development and how disabled people can and should be included into mainstream activities of community development.

## IN CONCLUSION

This book has much to offer the reader in terms of information but also as a catalyst for stimulating debate at national level and as an evaluation tool for individual programmes. The next CBR conference in this series will be held in South Africa towards the end of 2007. It will address **CBR and the Millennium Development Goals**. Readers can check the CAN website [www.afri-can.org](http://www.afri-can.org) for up-to-date information. We look forward to seeing you there!

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## CHAPTER 1

# Community-based Rehabilitation Africa Network (CAN)

*Shaya Asindua*

## SUMMARY

*This chapter outlines the development of the CBR Africa Network (CAN). It describes its mission, aims, objectives and related activities over the past three years.*

## BACKGROUND

The first African Regional Conference on CBR was held at the Uganda National Institute of Special Education (UNISE), Kampala in 2001. This conference was the final output of a linkage between UNISE and the Centre for International Child Health, (CICH) University College of London, which was designed to facilitate and support the development of CBR training in Uganda. The theme of the Conference was "CBR, A Participatory Strategy in Africa." Participants from 14 countries attended the workshop, which was supported by the Norwegian Development Agency (NAD) and the CP Charitable Trust, UK.

This highly successful conference enabled the participants to extensively discuss CBR, ranging from its history and underlying concepts, to its practical application in the various countries and communities. This helped to generate a more mutual and holistic understanding of CBR and its



implementation in Africa. The conference proceedings, reflecting the presentations and discussions, were documented and published as a book, 'CBR A Participatory Strategy in Africa'. The CBR book was distributed to all those who participated in the conference and made available on the internet through the websites of ICH, EENET, GLADNET and SOURCE (See Chapter 10 for details on how to contact these agencies). The book was also made available for purchase through Teaching Aids at Low Cost (TALC). This book became a useful resource to many in CBR. In hindsight more copies could have been made available in Braille.

Four action points were identified at the Kampala conference, which later formed the initial tasks for the interim CBR Africa Network (CAN) committee.

1. Initiate the formation of National CBR Associations
2. Improve capacity for sharing information about good CBR practice
3. Review CBR training programmes in order to promote their synchronisation
4. Organise regular (every three years) CBR conferences in Africa, starting with one in 2004

For each action point, individuals were identified to carry them forward. These individuals formed the basis of the Interim Committee of CAN.

The team included participants from Kenya, Uganda, Tanzania, Zimbabwe and UK. As a member of the committee (Executive Director), Dr. Sally Hartley was able to use her good connections in the UK to secure a grant from the CP Trust UK for four years, to support the establishment and development of the network.

At its first meeting in June 2002 in Kampala, Uganda, the Steering Committee adopted the name "CBR Africa Network" (CAN), and proposed that the Secretariat be based in Uganda, for which the position of co-ordinator was later advertised and recruitments made.

At this meeting and a subsequent meeting, which took place in Nairobi Kenya, towards the end of 2002, the task for the steering committee was to define the mission and objectives and logo of CAN.

### **CAN MISSION STATEMENT**

To promote access to appropriate information on disability and development for all people in Africa.

### **CAN SPECIFIC OBJECTIVES ARE TO**

- Collect and collate information about community-based disability services from all African countries
- Facilitate the development of record keeping and writing skills' culture for the purpose of documenting community initiatives and good practice

Facilitate the capacity of CBR workers, to communicate their experiences between themselves and with other practitioners

Make information on CBR services accessible in electronic (Internet, audio and video) and other media (print, pictorial and Braille)

- Organise regular forums, including regional conferences, to promote CBR as a developing field and advance the inclusion and empowerment of persons with disabilities in the community

### **WHAT ARE THE ACHIEVEMENTS OF CAN IN 3 YEARS?**

#### **The establishment of the secretariat**

A secretariat for CAN was established in Uganda. A registration process is underway in order to register CAN as a non-governmental organisation (NGO) in Uganda. The secretariat has two staff members; the coordinator and the driver. It has office equipment such as computers, Internet services, photocopiers and a vehicle. The secretariat has been given free office space at the Uganda National Institute of Special

Education (UNISE) which is now part of Kyambogo University, from where it operates. A constitution is at the final draft stage.

### **SURVEY**

One of the initial activities was to conduct a survey to establish the extent of CBR work in Africa, the amount and type of information available, as a basis for developing and getting people and organisations to sign up as members. The response has been poor. This form is now available on the website. About 100 people have responded.

### **WRITING WORKSHOP**

In July 2003, a writing workshop bringing together 15 participants from Kenya and Uganda was held in Kenya and facilitated by Dr. Julie Carter and Dr. Sally Hartley, from ICH London. The workshop intended to include participants from Tanzania, but they failed to send any delegates. Another workshop was held in Tanzania in October 2004 with fifteen participants from Kenya, Botswana and Tanzania.

The objective of these workshops is primarily to develop the writing capacity of CBR implementers, in order for them to be able to document their experiences for sharing. They also intend to address the training of trainers so that some individuals will be enabled to pass on their skills to others at national level. As mentioned earlier, the difficulty of documenting and sharing experiences about CBR, was identified as a major barrier to the development of CBR in Africa.

The outcome of these writing workshops was a number of articles that were published in local newspapers, organisational newsletters and small booklets that are presently undergoing review. Many of these can be found on the CAN website: [www.afri-can.org](http://www.afri-can.org)

### **Some of the topics were:**

- Poverty: a challenge to CBR workers in Bwaise, Uganda
- Practitioners' knowledge and skills in the use of group dynamics in CBR
- Checking affirmative action to stop sexual abuse of a disabled child in Uganda
- Advocacy for policy change in Kenya; among others

### **TRAINING REVIEW**

Another key issue raised at the 2001 conference was the variety of training programmes on CBR in several African countries, with little or no linkages between them. This was observed to breed confusion and often unhealthy competition. The committee identified Uganda as one country where a number of training programmes existed with limited levels of collaboration and synchronisation, so it was agreed to begin this task by reviewing the programmes in Uganda. Three institutions are involved in providing formal training in CBR and related activities ranging from a certificate level, to a two - year Masters' degree programme.

Five organisations of disabled persons participated in this evaluation programme along with personnel in the Ministries of Health and Gender, Labour and Social Development. The major shortcoming of the evaluation was that it was unable to get substantive information on the Makerere University Master's Course on CBR.

Nevertheless, the key recommendations from the evaluation were:

The courses should be synchronised to allow for an upgrading system where participants can move from one level to another. At the moment the training content and levels are very similar

The Community-based Rehabilitation Alliance (COMBRA), which offers a six - week certificate course, should seek recognition by

the appropriate examination body, as a large number of CBR implemented do take this course

- COMBRA should also maintain its flexibility and training for grassroots workers, as well as up-grading its course to diploma level
- UNISE should continue training for CBR managers, but should improve on the practical aspects of the courses that it offers
- CBR should be included in the curriculum of other courses like health and education
- UNISE and COMBRA should begin distance-learning courses in CBR

The Berkeley Trust UK, specifically funded this evaluation and we are deeply grateful to them for this support.

### **CBR ASSOCIATIONS / STRENGTHENING COUNTRY NETWORKS**

As an African Regional Network, the success of CAN will be seen by the presence of strong national associations and networks, in which CBR implementers will have regular opportunities for face-to-face exchange of ideas and experiences. Unfortunately, feedback to the secretariat on the progress of this initiative has been limited. Uganda is the only country that reported having regular CBR stakeholders' meetings, while Kenya made recent attempts to recruit more members to the network.

CAN is aware that informal networks already exist in many other countries and we would not wish to see the forming of new associations by CAN, as jeopardizing these natural efforts. At the same time, we are also concerned that national meetings may not address the grassroots levels and their needs. We suggest that readers might like to discuss how to form CBR associations and communicate their ideas to CAN.

### **WEBSITE**

A website was developed for CAN in 2003 under the website page of [www.afri-can.org](http://www.afri-can.org). This site gives background information about CAN, lists its executive members and how to contact them as well as supplying reports and documentation generated by CAN.

### **STRATEGIC PLAN**

The network coordinator with support from the steering committee, has embarked on the development of a 5-year strategic plan for CAN. For 2006-2010, this document will be used to generate further funding and guide the future activities of CAN.

### **COMMITTEE MEETINGS**

The steering committee has had 4 meetings; efforts have been made to have different members within East Africa to host the meetings. These meetings have been very fruitful and have been key to the development of the network.

### **FINANCIAL SUPPORT**

We have received financial support from various organisations including; the CP Trust whose support has enabled the establishment and development of the secretariat; Berkeley Trust funded the assessment of the training programme in Uganda and also contributed towards the organisation of this conference; while NAD and the International Labour organisation (ILO), have supported the organisation of the conference and facilitated the participation of some participants.

### **FUTURE**

Future activities include finalizing the current development related to pending issues such as the registration, constitution and strategic plan, which will provide the way forward for future activities of the network.

Thanks go to the steering committee for the achievements made in making CAN a reality (a list can be found at the end of the book). I would also like to thank the team in Malawi, Rachel Plackett and her organising committee for furthering the objectives of CAN by organising the 2<sup>nd</sup> African Regional Conference on CBR. Special thanks go to all those organisations/ agencies/ companies and individuals who provided financial support to enable this book to become a reality.

Lastly, I hope that more people will register and become active members of CAN, and strengthen the spine of the network.

# CBR as Part of Community Development and Poverty Reduction

*Peter Coleridge*

## SUMMARY

*This chapter reviews the major shifts in thinking about disability, that have occurred over the past ten years or so. It examines how CBR fits in with these changes. The discussion considers the current debate about poverty, development and human rights. Collectively, there has been a huge shift in consciousness about disability, from individual need, to universal rights. It notes that the first step in tackling poverty is to give a voice and the opportunity of full participation, to those who are most affected by the poverty. Unless disabled people have a voice, they will continue to be marginalised, misunderstood and excluded from poverty reduction strategies. CBR is identified as primarily a process of community, as well as individual, development, and is therefore an essential part of poverty reduction strategies. The chapter concludes with some of the ways in which CBR can become more effective as part of the strategy to reduce poverty*

## INTRODUCTION

The underlying theme of this chapter is to review the major shifts in thinking about disability that have occurred over the past ten years or so, and to examine how CBR fits in with the changes that have occurred. The chapter will address three main questions, namely, what is the current global strategy for reducing poverty? What role does CBR have in this strategy? How can we make that role more effective? As we will see, this debate is directly relevant to strategies for reducing poverty.

### WHAT IS THE CURRENT GLOBAL STRATEGY FOR REDUCING POVERTY?

There are a number of key global initiatives, which set out the terms of the debate about development and poverty. I will focus on the two most relevant ones: The Millennium Development Goals (UN 2000), and the PRSP, the Poverty Reduction Strategy Paper approach (World Bank 1999).

The Millennium Development Goals have the following aims:

1. Eradicate extreme poverty and hunger
2. Achieve universal primary education
3. Promote gender equality and empower women
4. Reduce child mortality
5. Improve maternal health
6. Combat HIV/AIDS, malaria and other diseases
7. Ensure environmental sustainability
8. Develop a global partnership for development

These are ambitious, and it must be admitted, rather vague goals, but nobody could possibly disagree with them. We can make two points about these goals in the context of disability and community development. First, they need detailed, well-planned, participatory programmes if they

are to be achieved; second, they cannot be achieved if some people are excluded, including and especially disabled people.

While they do not intend to exclude anyone, the reality, is that exclusion happens not primarily as a result of prejudice but as a result of ignorance of the reality of certain groups of people, and that is especially true of disabled people. Our main task in influencing such a grand plan, is to combat ignorance about the situation and the potential of disabled people.

A major mechanism for reaching these goals is the PRSP approach, a concept launched by the World Bank in 1999, and now a feature of the planning processes in many developing countries, including and especially ones in this region of Africa.

This approach is designed to create a process of participatory planning within countries, in contrast to the top-down, externally imposed planning of Structural Adjustment policies used by the IMF in the eighties and early nineties, which are seen to have created as many problems as they tried to solve.

The hallmark of the PRSP approach is participation by all stakeholders, including and especially poor people themselves. Participation of the poor is sought at all stages of the PRSP process: formulation, implementation, monitoring, and evaluation.

The adoption of the PRSP approach represents a momentous and historic shift in attitudes by the World Bank and IMF towards the true democratisation of development. It is a recognition that top-down, externally imposed ideas do not work, and that if change is to be lasting and sustainable, the ordinary people must have their say in what kind of change is required, and how it should be carried out; they should also be actively involved in the process of change.

However, there is a serious problem of ignorance when it comes to disabled people. The World Bank's Sourcebook (WB 1999) to the PRSP process is out of date as far as disabled people are concerned, and has

not reflected the huge shifts in thinking about disability, that have been made in the past ten years or so. The Sourcebook places disabled people, along with children, old people and the chronically sick, in the basket marked 'not able to be economically active, in need of special care and welfare.' Disabled people, in the eyes of the World Bank Sourcebook, are not participants in development; they are objects of charity.

Why did the World Bank not get the message? Had it not been listening when it wrote the Sourcebook? This Sourcebook was written in 1999, and fortunately things have changed since then. In the last two years, the World Bank has gone through something of a revolution in disability. On the personal initiative of the World Bank President, James Wolferson, they appointed an extremely able disabled activist Judy Heumann, as principal adviser, and the Bank has now adopted a policy of mainstreaming disability in all its programmes. But when the Guide was written in 1999, this was not the case.

The fact that the World Bank got it so wrong about disability is indicative of a key factor we need to focus on. That is, disabled people tend to be trapped in a vicious circle of voicelessness. They were not until very recently, listened to in major organisations like the World Bank, so they got missed out of its discussions, and it got the wrong end of the stick.

In the same way, with some notable exceptions like Uganda and Malawi, disabled people are not generally included in PRSP discussions, and so disability gets missed out of country poverty reduction strategies.

### **BEING POOR MEANS BEING VOICELESS**

The first point that we have to make about disabled people and poverty reduction, is that part of the definition of being poor is being voiceless. Once we do something about disabled people having a voice, we have already taken an important step in reducing their poverty.

This point was well understood by the disability movement in Africa, which lobbied the African Union to declare the African Decade of Disabled Persons in 1999. Their view was that the United Nations Decade of Disabled Persons (1983-1992), had achieved some successes, but mainly in the north. Disabled people in Africa had not really benefited, even though the eighties saw the formation of many Disabled People's Organisations (DPOs) in Africa, in particular, SAFOD (the Southern Africa Federation of Disabled People). It was SAFOD that was one of the driving forces behind the idea of an African Decade. They wanted expressly to address the issue of voicelessness of disabled people in poverty reduction planning.

We are now four years into the African Decade, and so far, only a few African countries have developed policies and launched programmes specifically targeted at disabled people. Malawi is one of them, and the fact that Malawi is hosting this conference is a further indication of its commitment. There clearly needs to be a great deal more effort by disabled people and their allies, like those involved in CBR, to get the voice of disabled people heard.

There is, as it happens, an important opportunity to increase the way in which the collective voice of disabled people is heard in the formulation of the UN Convention on the Rights of Persons with Disabilities, currently in progress. It was always argued in the past, that other UN conventions, such as the UN Covenant on Economic, Social and Cultural Rights and the UN Covenant on Civil and Political Rights, not to mention the Universal Declaration of Human Rights itself, automatically include the rights of disabled people, and that if we are talking about mainstreaming, then there is no need for a separate convention on the rights of disabled people. But this argument was finally defeated by experience: disabled people cannot be buried in the general category of 'vulnerable groups', because their situation is particular. And if they are so buried, we end up with the result demonstrated in the World Bank PRSP Sourcebook, where their situation is simply misunderstood.

## THE GLOBAL DEBATE ABOUT DISABILITY

What has driven the need to formulate the UN Convention on the Rights of Persons with Disabilities is a sea change in the debate about disability globally. This debate can be characterised by the following shifts:

*"Policy and programmes in favour of persons with disabilities are no longer viewed as a means to rehabilitate and adapt the disabled individual to society, but to adapt society to the needs of the disabled individual."*

*"The concept of rehabilitation has given way to the concept of creating an enabling environment; the concept of social assistance to the one of respect of a society for the rights of her minorities."*

*"More recently, the minority concept has been embedded into the more inclusive one of social diversity, of a society for all."*

*"Even though this revolution has occurred in minds and in policies, the profound changes it implies are often not understood. Obsolete concepts like "sheltered workshops" or "centres for the handicapped" still enjoy widespread public acceptance."*

In other words, there has been a revolutionary shift in thinking from the individual medical model, in which the disabled person is required to fit in with the norms of an able-bodied society, to the social model, in which society must adapt to the needs and rights of disabled people.

But although this revolutionary shift in thinking has taken place in the minds of those who attend conferences like the Malawi conference, it takes a long time for such a revolution to have a practical impact on services and opportunities.

### **WHO IS INVOLVED IN THE GLOBAL DISABILITY DEBATE?**

It is important to chart the way ideas are shared and how they develop. It is therefore worth spending a moment to outline the actors in the whole drama. Who is involved in the debate about disability, and who is involved in the debate about CBR?

Four broad but distinct groups can be identified:

1. DPOs
2. People in and around CBR programmes
3. Rehabilitation institutions and professionals
4. Specific efforts to assist landmine and war victims

These have been in the past and continue to be to some extent, fairly separate entities, with their own ideas and agenda. But there are encouraging signs that they realise that they have a common purpose. They all have their valuable contribution to make to the debate about disability and development, and they are increasingly listening to each other.

There is of course a fifth group made up of the UN, donor governments, donor agencies, the World Bank and so on, who collectively are a lot more powerful than any of the other four.

DPOs used to be rather dismissive of CBR, seeing it as a continuation of the old individual medical model in a different form. But they are now beginning to realise that CBR programmes can be an important way for disabled people to attain their rights by increasing community knowledge of their needs and aspirations.

CBR practitioners used to regard DPOs as all right, if they kept to their side of the tracks, which was advocacy, and did not interfere in actual programmes. But increasingly, CBR practitioners recognise that disabled people must not only have a voice, but be full participants in the planning of their programmes, and this means joining forces with DPOs, supporting them, and making them allies in their CBR programmes.

Rehabilitation institutions and professionals used to be dismissive of both DPOs and CBR, but they too, are beginning to realise that isolated institutions do not work if they are not connected to families and communities, and if disabled people do not have a say in their own

rehabilitation. Leonard Cheshire International (LCI), for example, used to be entirely institution based, but now 80% of those it serves in its programmes, are outside institutions.

**The Ottawa treaty** to ban landmines was passed in 1994. This was brought about not by governments waking up to their responsibility, but by NGOs joining forces to make the case against landmines. Their point was that these remain in the ground long after hostilities have ended, and kill or maim thousands of innocent people for many years. On these grounds alone, mines should be banned.

The Ottawa treaty was a landmark victory for the power of NGOs to influence international policy. They found their voice, and it was heard. While that treaty is about landmines and not about disabled people, it does mention the need for attention to be paid to people disabled by mines and war, and this one clause has brought both major funding and another whole body of enthusiastic allies to the disability scene. Agencies involved with war and mine victims tended to be dominated by the individual medical model, but they are getting more drawn into the global shift in consciousness on disability. Most of these organisations now do not differentiate between war injured and other disabled people in the services they offer, and are becoming increasingly aware of the need to move beyond medical rehabilitation to the quality of life of disabled people after rehabilitation. This leads them to think about rights, and specifically about economic empowerment.

**The fifth group, the UN and international donors**, has already been touched upon in the example of the World Bank. Because they control funding, they are extremely powerful, and must remain the principal target of lobbying and advocacy, by the other four groups in the disability debate.

Of course, the picture is not all rosy. Competing and conflicting agendas remain to some extent, between these groups. Like the World Bank in 1999, some do not always get the message. But on the whole, the general trend is positive.

More than 20 years earlier, in 1981, the World Congress of RI was held in Winnipeg, Canada. At that Congress all the disabled people present left the main conference chamber in protest at the fact that it was the professionals who were speaking on their behalf. So they left the main conference chamber and set up their own Congress in an adjacent hall. This was the beginning of Disabled People's International (DPI).

It was the issue of voice and voicelessness again: disabled people can have all the rehabilitation in the world, but unless they also have a voice and can be in charge of their own development, they are still excluded from mainstream society and treated as second class citizens.

Things are now changing. At the 20th RI congress this year in Oslo, both professionals and disabled people from DPI and other advocacy groups met together in complete harmony, with an agenda that was mainly about rights. Most of the speakers were disabled people. This was strikingly indicative of how far we have all come, in recognising that there is indeed only one main agenda in disability, and that is about rights and how to make them a reality.

This is why CBR is so important, and why it has a role to play in poverty alleviation directly.

## **WHAT ROLE DOES CBR HAVE IN THE STRATEGY TO REDUCE POVERTY?**

### **Development is about rights**

The general development debate is now mainly rights based. It is recognised that poverty is not simply a lack of money; it is a denial of fundamental rights to the decent things of life: health, education, dignity, choice, opportunity. To be poor means that one is denied these fundamental rights. If everybody had all these rights there would be no poverty, even though there would still be disparities of wealth. The debate is therefore, about both rights and the realisation of rights through equal access to services and opportunities.



The commonly accepted definition of CBR now, is that it is a strategy within community development for the equalisation of opportunities for people with disabilities. This is the key to its role and its importance in the debate about development and poverty.

The question for CBR, is whether it can contribute to the overall development of a community, not just to improvement in the function of individual disabled people.

The reason why the welfare approach to disability is so wrong, is that it does not recognise the crucial importance of both individual development and community development. If someone is the object of charity, they are stuck in an imposed role from which they cannot escape. Disabled people, like everyone else, need choice and opportunity. That is what development is: to grow, to be enriched by experience, to see and take opportunities, to blossom.

This is true of both the individual and also the community. Like individuals, communities are not static, but dynamic, in a constant state of change and flux. They can blossom, and they can wither. There is no such thing as an island community, locked into some idyllic form of cosy human society. Communities develop through the interplay between internal and external influences.

The issue of disability is a very important element in the way communities grow and develop. If persons with disabilities are included, communities are immeasurably enriched. If they are excluded, communities are impoverished.

### **CBR AS COMMUNITY DEVELOPMENT**

An external evaluation of one CBR programme illustrates this point. This programme is not in Africa, but in Palestine. The reason I have chosen it, is because the general situation in Palestine is as unpromising for community development as it could be. It is a situation where fundamental rights are denied to an entire population, where a whole people are being systematically disempowered politically. But underneath

this dreadful situation people are trying to get on with their lives and build a community.

The national CBR programme has been an important element in that process of building a community. It has made a demonstrable difference not only to the lives of individual disabled people, but also to the lives of their communities. It is a powerful demonstration that, even if the overall situation is extremely discouraging, the impact of a CBR programme can be enormously heartening, well beyond the issue of disability itself.

The evaluation was done by an external academic body from Norway, (Eide 2001). It looked at the impact of the programme on three levels:

- the individual disabled person
- his/her family, and
- the community in which they live

At the individual level, the evaluation found that there had been, overall, a change from passivity, dependence, sometimes abuse and neglect, to a situation where the disabled person is enabled to utilise his/her potential and to contribute to the family and community.

At the family level, the programme has meant improved family relations and a considerable improvement for many women, who tend to be the primary carers. For women especially, it has led to a way out of isolation, and the release of human resources within the community, especially for the care of disabled children.

On the community level, there are strong indications that significant changes have occurred: disability issues that were previously neglected have come to the forefront, kindergartens and schools have become more receptive to children with disabilities, disabled people are accepted as participants in community life, both socially and politically, and communities have indeed acquired a deeper understanding of what community building means.

The point about these findings, is that once disabled people are fully included, the entire community is enriched.

In my own experience, when disabled children are included in regular schools, if this is done well, the atmosphere in the whole school changes. The inclusion of disabled people opens up a different kind of understanding, not just about disability but about human life.

### **HOW CAN WE MAKE THAT ROLE MORE EFFECTIVE?**

#### **What are the terms of the debate?**

CBR has now been around under that name since 1976, when the three magic words "Community Based Rehabilitation" were first coined by WHO. But of course families and communities in Africa had been practising the concept in some form for centuries. What started in 1976 was a debate about how to make rehabilitation more effective, especially in poor rural communities with few resources. Over the nearly thirty years since then, the debate about its effectiveness has raged to and fro, and continues to this day. Some people involved in this debate go as far as to say that if CBR cannot provide better evidence of being an effective approach, policymakers and funding agencies might no longer be interested, and CBR will fade out.

Personally, I believe that such a proposition is based on the wrong premise, because it seems to be comparing CBR with other forms of individual rehabilitation such as institution based. But CBR cannot be equated with other forms of rehabilitation because it is not simply about the rehabilitation of individual disabled people. It is first and foremost about inclusion, breaking barriers, and changing attitudes. In other words, it is about community development, as well as individual development. If a particular CBR programme is not about community development in this sense, then it has missed the point, and may indeed be no improvement on the institutional model.

So the question is not whether there is any evidence that CBR works, or does not work. We have enough evidence to say that it can be an effective agent for change in communities in relation to disability and wider issues. It can change the lives of individual disabled people, of their families and especially mothers, and of their immediate communities.

I do not think that CBR is seriously in danger of losing donor commitment. What are the alternatives? No one has thought of a better way to reach especially rural communities. I do not think anyone is seriously suggesting that we scrap CBR and go back to a reliance only on institution-based rehabilitation, which in Africa anyway was always completely inadequate to cover the numbers of disabled people requiring services.

The question is not whether CBR is effective. It is, when the concept is properly grasped, how it can be more effective as a vehicle for community development, for rights, and therefore for the reduction of poverty.

How CBR can be more effective as a vehicle for community development is the subject of this book, which will consider CBR under the following headings:

### **CBR AS PART OF SOCIAL, CULTURAL AND POLITICAL DEVELOPMENT**

The issue is representation. The question is: how can CBR contribute to the representation of disabled people in their local communities, socially, culturally and politically? The major reason for disabled people's poverty, lack of rights, and disempowerment, and the major reason for ignorance and prejudice towards them, is voicelessness, which means lack of representation.

This is where an alliance between CBR programmes and DPOs is so important. They must be mutually reinforcing.

## **CBR AS PART OF (COMMUNITY) HEALTH DEVELOPMENT**

It has been noted, that among most of those who work full time in the disability sector, whilst the thinking has shifted dramatically from the individual medical model to the social model, this shift has not yet become evident in general services. This is especially true of health services.

The problem is that we all tend to perceive the world through the spectacles of our professional training. Doctors have been trained to cure people, so they see permanent impairment as a failure. Hospitals all over the world still treat patients as statistical items. The message to patients is: 'The doctor knows best. Keep quiet and take the medicine.' Some doctors still see themselves as in charge not only of people's health, but also of the quality of their lives. There is a keen debate now in Europe, about whether doctors should have the final say in when to turn off a life-support machine of someone they deem no longer to have an adequate quality of life. There is an assumption, that if someone cannot communicate, their quality of life is not worth preserving.

So there is still a long way to go to change attitudes in the medical profession about disability.

Nevertheless, CBR programmes must build alliances with the health services. Prevention of impairments is an extremely important part of CBR, and health services are vital to prevention. Operations for glaucoma, cataracts, club feet, cleft palates, and contractures are vital, and more cost effective in the long run, from a strictly economic point of view, than allowing these impairments to remain untreated. Proper peri-natal care is essential to reduce the incidence of, for example, cerebral palsy. The number of spinally injured people in Africa who survive more than a few months, is very low. Better medical care, and simple knowledge transmitted to families and communities about preventing pressure sores and internal infections, would enable them to live almost normal life spans.

Of course, we need both the medical provision and the community work. Both are vital. But in our enthusiasm for community development, we do well to remember the importance of what doctors can offer.

## **CBR AS ECONOMIC EMPOWERMENT**

As already noted, to place disabled people in a basket marked, 'not able to be a economically productive' is a grave misunderstanding of disabled people's needs, hopes and aspirations, and a violation of their right to development.

To quote from Disability and Poverty Reduction Strategies, a discussion paper written by the ILO in 2002:

*"The majority of people with disabilities are potentially autonomous. Adequate support measures are sufficient to neutralise the impairment so that it does not constitute a disability. If the mobility problems of a physically disabled person are resolved by adequate transport and accessibility, there will in principle be no difference between this person and any other non-disabled person. The same holds true for a person with communication problems. Consequently, this person, in principle, does not need any social assistance or protection. He/she only needs the guarantee that opportunities are equal. The logic of the approach to disability has completely changed. "*

It is important to consider the cost of NOT enabling disabled people to be economically active. The presence of a disabled person in a family affects the whole family, especially of course, if it is the main breadwinner who is disabled. If they are not economically active, the whole family suffers the consequences. In countries with comprehensive welfare systems, this means handing out welfare, but these countries recognise that that approach is unsustainable. It is far cheaper to get disabled people into employment, than to hand out welfare, even if that means spending money on modifying the workplace.

To quote the ILO paper again:

*"The objective should be to reduce poverty of persons with disabilities by "unlocking their economic potential", and not by handing out welfare. Costs in terms of accessibility, technical devices, and workplace accommodations are to be seen as investments and not as unproductive social welfare expenditure. "*

We must, in addition, focus on the principle of decent work, which is the watchword of the ILO. Disabled people do not need any old job. They have the same need for personal fulfilment through creative and constructive work as everybody else. They should not be confined to menial and stereotyped tasks like basket making. They should have the same opportunities as others to develop their talents, and to pursue careers which are both demanding and enriching.

So the question addressed in this book, which needs to be taken up in discussions, is: how can these principles of equal opportunities and decent work be made a reality? They are accepted in principle, but they are very rarely a reality.

### **CBR AS PART OF EDUCATION AND TRAINING DEVELOPMENT**

Of course economic empowerment is directly linked to education and training. To quote the ILO discussion paper again:

*"Exclusions are linked together, accumulate and get worse. How could a disabled child that did not go to school because there was no adequate transport, no accessible school building, no place in the classroom adjusted to their needs, no special schools, no training and jobs for special teachers, no inclusive education, no special education service at the ministry of education, a child that later in life did not get any vocational training because they did not get a sufficient basic education - how could anyone imagine that this child, once grown up, would get a job? He or she has accumulated too much exclusion. "*

This is probably the hardest part of the process of community development to address, in relation to disabled people. In African schools, where there are sometimes one hundred children in a classroom without desks, let alone textbooks, what hope is there for including disabled children?

However, the overall gloomy picture need not be a reason for not starting somewhere. Parents of mobility impaired children need to insist on their children being admitted and find creative solutions to mobility problems and transport, such as the use of donkeys. CBR is fundamentally a problem solving approach, solving individual problems for a wider communal gain. If an individual head teacher is convinced about inclusion, he or she will do it. Conviction comes through demonstration.

So the suggestion is not to wait for the entire Ministry of Education to make inclusive education a policy. We can start doing it piecemeal where it is possible and demonstrate that it can be done, and then use that experience to lobby for policy reform.

Lobbying is important. Education for All is the global objective and slogan. All means all, not just the lucky ones who can make it to school and back again. PRSP programmes place a great deal of emphasis on education. As a well-known leader has recently said, 'There are only three things which really matter in a country's development: Education, education, and education.'

CBR practitioners and DPOs need to work hard on this. They need to get familiar with the PRSP process and to claim their space at the table. Instead complaining, the need of the hour is to participate, to be proactive, to become informed and knowledgeable, and to get involved.

### **CBR AND HIV/AIDS**

In many countries in Africa, many more people are affected by HIV/AIDS than by disability. There is much to learn in both directions. CBR programmes need to be fully visible in the whole HIV/AIDS effort. HIV/AIDS programmes can learn from CBR about how to train

community workers, and CBR programmes can learn from HIV/AIDS programmes about their preventive processes. AIDS awareness needs to be included in CBR programmes. CBR programmes need to pay particular attention to the education of deaf people in AIDS awareness, who do not naturally pick things up from the radio or other aural sources.

The suggestion for CBR programmes is to get involved in AIDS, to join the AIDS debate, and to network with AIDS programmes.

### **RESEARCH ON CBR AS PART OF COMMUNITY DEVELOPMENT**

A common complaint in the discussion about CBR is that there is a poor record of proper scientific articles about CBR, giving objective evidence for its successes and failures. Too often, a CBR programme is donor driven, and reporting tends to be geared to the donor's expectations, and for that reason uncritical. There is a powerful need for reflective writing about CBR by the people engaged in it, in which they reflect candidly on their successes and failures, and open the donor's eyes to the process as well as the product.

The process is indeed more important than the product, and the process has to start by people involved in CBR being open-minded, objective and self-critical. One of the best ways to get constructive criticism into a CBR programme is by involving disabled people in its evaluation and review. This can be both formal and informal. Linkages with DPOs for conducting or joining a formal evaluation, collection of informal views of individual disabled people, encouraging local CBR committees to include disabled people, who can bring a fresh perspective, can be of help.

This kind of documentation will then be of far more use to researchers looking for objective evidence, and will lead to a better standard of scientific writing about CBR. It is encouraging to see that steps are already being taken in parts of Africa, to encourage such writing, for example by CBR Africa Network (CAN) in running writing workshops for people involved in CBR programmes.

The challenge is to make reflective writing, which is both objective and self-critical, an integral and essential part of each programme. Reporting should not become simply a chore and an afterthought just to keep donors happy. Disabled people should be made an integral part of the evaluative and research process.

There is also an urgent need for people involved in CBR to network. It is very easy for people to work in isolation. But reading and contributing articles to professional journals, attending conferences, using the internet to discuss and spread ideas, are all enormously important, and room for these activities needs to be factored into programme budgets.

### **CONCLUSION**

We have considered the current debate about poverty and development, and seen that it is focused on rights.

We have noted that the first step in tackling poverty, is to give a voice and full participation in change to those who are most affected by poverty.

We have seen that unless disabled people have a voice, they will continue to be marginalised, misunderstood and excluded from poverty reduction strategies.

We have noted the different stakeholders on the disability scene, and seen that collectively, there has been a huge shift in consciousness and attitudes about disability, from individual need to universal rights.

We have identified that CBR is primarily a process of community, as well as individual, development, and is therefore, an essential part of poverty reduction strategies.

And, we have identified some of the ways and areas in which CBR can become more effective as part of the strategy to reduce poverty.

It is easy to be discouraged in our day-to-day work, when we feel that so much is loaded against us, especially in Africa. But, by looking at how

ideas have changed, we can take heart and find, that looking back, much has been achieved. Individuals can make a difference; NGOs can make a difference; world bodies do (eventually) listen; policy can be changed.

We can make a difference, and we are making a difference. We have to keep faith, and never be tempted to give up. As Edmund Burke said: "For evil to triumph it is sufficient for good men to do nothing."

Walt Whitman, an American poet who was well ahead of his time in an understanding of where true wisdom lies, wrote:

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*The earth does not argue,  
Is not pathetic, has no arrangements,  
Does not scream, haste, persuade,  
threaten, promise,  
Makes no discriminations, has no  
conceivable failures,  
Closes nothing, refuses nothing,  
shuts none out.*

**Walt Whitman: 'A song of the rolling earth.'**

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There is the world, and there is the earth. The earth is what God created. The world is what man has done with it. It is the earth which makes no discriminations, has no conceivable failures, closes nothing, refuses nothing, shuts none out. And we need to go back to the earth to find our way in how we construct our world.

Let us listen to the earth, the rolling earth, the deep rich soil of Africa, and hear its message of no discriminations, no conceivable failures; which closes nothing, refuses nothing, and which shuts none out.

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# CBR as Part of Social, Cultural and Political Development

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## SUMMARY

*By definition, CBR should be part of social, cultural and political development, but in reality, there is a tendency for it to bask in the merit of its own invention. CBR programmes need to look carefully at their effectiveness in terms of relevance and responsiveness to the current challenges. These challenges relate to effective rehabilitation, inclusion, social integration and equal rights for persons with disabilities. Examination of CBR practice in Africa shows that major difficulties arise from a number of issues. These include the inclination of CBR programmes to focus their activities on individuals with impairments, limited involvement of the community in CBR planning and development, under-estimating the effect of culture and what is required to change this and finally, the limited engagement, participation and commitment of Governments. This chapter examines the actual situation in Africa, identifies the gaps, highlights the factors aggravating the problems and recommends possible mechanisms for including CBR into mainstream social, cultural and political development. The chapter concludes that unless CBR becomes part of mainstream social, cultural and political development, it will fail in its task. At the same time social, political and cultural development will also be negatively affected.*

## INTRODUCTION

By definition (WHO, ILO, UNESCO, 1994), CBR is a strategy within community development, yet there is substantial evidence that CBR activities often operate independently in the community as parallel projects to other mainstream social development<sup>1</sup> projects. As a result, social development implementers refer persons with disabilities to CBR projects to receive services they could have ordinarily received, from any existing mainstream service providers. This is especially true, where CBR is being implemented by NGOs or by disabled people's organisations that run CBR projects in small localities.

These small organisations employ their own personnel; some of them even build some infrastructure such as clinics, community offices, orthopaedic workshops, vocational centres and schools in those communities. These can be successful only for a while when initial resources are still available and when their coverage remains limited. This state raises challenges for sustainability, affordability, coverage and inclusive development. Building separate CBR infrastructure is too costly to sustain in the long run and makes it harder to expand to wider coverage.

These realities are a reminder that we should not bask in the invention of community-based rehabilitation, without looking at its effectiveness, relevance and responsiveness to the current challenges. Let us use this opportunity to reflect, reorient and map out strategies that will improve on coverage and effectiveness.

1. A social problem is a condition that affects a population of people in such a manner that it keeps them in a state of vulnerability, powerlessness, poverty, isolation and other areas of disadvantage. In this case, disability in its diversity is an important social problem. Social development is therefore a combination of deliberate initiatives undertaken to deal with such problems. Social development process aims at eliminating social problems by equipping the target population with capacities to deal with such problems; access resources, develop power to make wealth, access useful information to make important decisions and overcome constant vulnerability.

## FACTORS AFFECTING THE INCLUSION OF CBR IN MAINSTREAM DEVELOPMENT

### Focus on the individual

Despite the talk of a holistic approach in CBR, its implementation often remains focused on the situation of an individual. As such, there have been suggestions for changing the name to "individual based rehabilitation". This temptation has been triggered by the fact that very often CBR implementers concentrate on the individual and forget that it is the individual's environment that disables the person. So what is this environment that CBR aims to deal with? It may include the following challenges:

1. Lack of assistive devices such as wheelchairs and crutches
2. Inaccessible roads, buildings, etc
3. Lack of Braille material and equipment
4. Lack of hearing appliances
5. The use of compulsory oral teaching for deaf children
6. Poor educational facilities
7. Lack of occupational teaching for children with mental disabilities
8. Negative attitudes towards disabled people
9. Lack of policies
10. Lack of commitment to good governance

Number 10 is a key environmental barrier that perpetuates the disabling conditions. Many world regimes are busy authorising massive expenditures on weapons and wars, that in the end only leave people more disabled physically, economically, socially and psychologically. Most of our people in so many nations have become poorer with a pathetic state and status, due to disabling governance policies and processes that our governments follow. Even in countries like Malawi where governments have tried to move positively, one notes that the world institutions like World Bank and International Monetary Fund (IMF) as well as the elites

in our societies, do not come clearly to support such initiatives. Disability issues are not highlighted as tenets or pre-requisites for assessing issues of both governance and poverty reduction strategies, although it is a fact that people with disabilities are among the poorest of the poor. This attitude and approach to disability is the major cause for the poor showing of the African decade implementation. The lack of government commitment to the cause of disability is now clearly showing in the slowness by which the decade is being implemented.

It is clear from this that disability is not just a medical or individual issue, but also one with many social determinants. The temptation to re-name CBR as individual based rehabilitation needs to be resisted. Such a name would be based on "bad practice", knowing, as we do, that the main aims of CBR are not only to rehabilitate and empower the individual, but also to eliminate the social and physical environmental barriers and to build communities' capacity to address disability needs and promote equalization of opportunities.

### Limited involvement of the community

Looking at the definition of CBR in comparison with what is actually implemented, one is tempted to reflect on the question, **Is it "community" or "confusion" based rehabilitation?** Confusion because the definition emphasises the importance of the community while in its conceptualisation and planning, no 'communities' seem to feature.

CBR is more often planned and executed with the community featuring only as an arena. The emphasis is that this process must take place in a community but it bears no elements of community participation in the conceptualisation and planning phases. Additionally, although the directive is that communities should be involved in planning CBR programmes, there are many examples of CBR projects, where this is not the case and yet participation at this stage is crucial for ownership and sustainable processes.

So this might lead us to another question, **Is it "community" or "confinement" based rehabilitation?** Confinement here must not be



confused with confinement as applied by critics of institutional based rehabilitation, but confinement here is applied as a process where the planners deliberately set a cut-off point in CBR, where they execute a CBR programme with defined targets that they have planned and monitor accordingly and once achieved, the CBR programme comes to an end. What is often neglected, is the understanding that CBR is a process that affects a person's life and as long as that life breathes, the effects and impact of a CBR programme are forever triggered. If this is not properly followed up, a lot of other side-effects are bound to emerge in the lives affected. The planners in this case, can be said to be processing CBR within the confines of their plan at the expense of the beneficiary, who will bear the effects of their planned process probably for the rest of his or her life.

Looking at CBR as "confusion based rehabilitation" and "confinement based rehabilitation", serves to raise very serious issues. It alerts us to the practice of CBR planners to talk about community involvement as embedded in the CBR philosophy, but in reality, not to involve the community in its planning and implementation. Such a situation hinders CBR's inclusion in the mainstream community or social development. It seems to indicate that the proprietors of CBR themselves undermine the process, perhaps in a misguided effort to protect their own territory.

Also, when the community features only as an arena for programmes and not an active participant, it becomes a passive recipient of a service that has been planned by other people. This situation makes it difficult for the CBR programme to be owned by the community and therefore will have very little influence on their social, cultural or political development processes. As a result, the projects are difficult to sustain, they tend to be short lived. They only run as long as the initiating agency stays.

### **The role of political action**

Can CBR succeed without government intervention? We are compelled to say NO. Central government and local authorities (where such power has been delegated) should develop legislation and policies, that will ensure

that certain activities are done in the interests of disabled people. Without enforceable policies, it is unlikely that attitudes will change. We all know the power of the law when it comes to enforcing change or compliance. Appeals and persuasion in the absence of the law can achieve very little.

It is so easy for our African parliaments to pass a law that authorises the purchase of weapons, than a law that advances the rights of disadvantaged groups. For CBR to succeed, there should be a political will and political action.

EVEN in Uganda, where there is considerable good political environment and good legislation on disability, there still exists a high level of exclusion of disabled people in social development action.

In one instance, when National Union of Disabled Persons of Uganda (NUDIPU) an umbrella organisation of DPOS in Uganda, contacted an agency to include disabled people in their wide range of community development projects, the project manager responded, *"we can only include them, if it will not exert any costs on our planned resources."*

In a separate incident, a community development officer was challenged to include disabled people in a functional adult literacy project she was heading. She responded, *"The funds for this programme come from Central government with such strict guidelines that we cannot risk diverting them."* When she was asked where disabled members of her community would then obtain the services she - was providing, she suggested that it would only be possible if the government could gazette additional funds for disabled learners. Both these messages categorically imply that disabled people cannot benefit from the development initiatives provided by specialised social development programmes. This kind of attitude could only be changed if CBR programmes are started with an intent to be part of the overall social, cultural and political fabric.

International development partners who fund social development, have an important role to play in including disability, and subsequently CBR, in the social development activities they support, in Africa. A deliberate

policy in this case can affect a tremendous response. Conditionalities to include disabled people as one of the prerequisites for development-cooperation, can be a powerful tool to cause implementers to effect inclusion. Some examples of this have started to emerge. For example, Oxfam GB in Uganda, made a conditionality that any partner organisation they are funding, must have a comprehensive framework in which persons with disabilities are effectively included in their programmes.

The American government has also issued a directive that every programme supported with funds from the American Government, must create mechanisms for including disabled people. Meanwhile, the European Union has also come up with guidance for the inclusion of disabled people. If these policies are adhered to and properly monitored, they will cause substantial change towards inclusive development and CBR programmes will be able to take advantage.

What has disadvantaged CBR projects in the long run, is that in most cases they come from either a separate national department, or are funded by an international fonder, or are funded and implemented by a foreign organisation. This results in other existing mainstream projects seeing them as separate, parallel programmes. In our view, CBR projects should not position themselves as independent institutions that provide all services to persons with disabilities (PWDS). Instead, they should be as much as possible, appended to existing programmes that have a comparative advantage in terms of capacity to influence and mobilise others.

### **The effect of culture and an advocacy role for CBR**

In this context, CBR has the important role of influencing and assisting the mainstream providers to take on the aspects of CBR, which are relevant to their own work, for example, income-generating projects, inclusive practices in schools.

For CBR to be part of social, cultural and political development, it has got to have advocacy as a big component. Cultures of people take time to build and as such, take time to change. Therefore, CBR cannot change the negative cultural beliefs on disability overnight. A few sensitisation

workshops at the beginning of the projects cannot influence a substantial socio-cultural and political change. Changing a culture of people, needs sustained and consistent sensitisation of all development actors throughout the project cycle.

Cultural development refers to the developments within societal values, traditions, languages, responses to crises, religious orientations, recreation, formal and informal celebrations of important events, treatment of celebrities, rewarding achievements, management of such social relations as marriage, inheritance, succession of cultural leaders, conflict resolution and other aspects of life as they affect the welfare of individuals. In this context, we need to ask ourselves these questions: In the above aspects of life, how is disability viewed? Is it seen as an important issue? Is it deliberately attended to, in all these developments? How can these be influenced for the better?

### **STRATEGIES FOR INCLUDING CBR IN MAINSTREAM DEVELOPMENT**

1. The mechanisms for inclusion should start right from the initial project design. At this level, all the appropriate structures, both government and non-governmental organisations (NGOS), should be involved. They should be carefully identified and their roles properly documented within the project framework. It is important to note that the roles here have got to be **real** and not only for window dressing.
2. The project should seek to build the capacities of the partner agencies to implement some aspects of the projects. For example a project run by the Uganda Society for Disabled Children (USDC), is first to support hospitals to establish physiotherapy units in order to enable the CBR programme. Subsequently, the government took on these structures and employed the appropriate staff in these hospitals.
3. A CBR project should aim to facilitate the mainstream service providers to develop some CBR elements in their programmes. This enables development agencies doing general services within social

development to deliberately target persons with disability. For instance, an adult functional literacy programme that takes place in the community needs to have provisions for PWDS as well. This has several advantages. It relieves the overwhelming burden of just a few actors and helps other agencies to see that disabled people are members of the community.

## CONCLUSION

For CBR to achieve its goals of equalisation of opportunities for disabled people and their full inclusion in all the development process, it has got to be built into the mainstream socio-cultural and development processes. This will help to address the major CBR challenges of effectiveness, affordability, sustainability and coverage. This is possible if the CBR implementers are committed to this. They must be careful not to hold on to CBR programmes as special territory, for this does not reflect the underlying philosophy.

The original goal of CBR was to provide capacity of community development, to address the rehabilitation needs of persons with disabilities within their environment (community.) It is supposed to be an integrated strategy, to address the needs of PWDS within the overall community development process. For this goal to be achieved, CBR has got to be embedded in all aspects of the social development action, interwoven into the culture of people, backed by political action like appropriate legislation and policy making. This goal yet has to be realised in most places where CBR has been implemented in Africa.

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## CHAPTER 4

# CBR and Economic Empowerment of Persons with Disabilities

*Daniel Vershima Tsengu, Svein Brodtkorb, Torild Almnes*

## SUMMARY

*This chapter attempts to define CBR and the empowerment of persons with disabilities. It gives justification as to why persons with disabilities need to be empowered. It outlines several ways in which persons with disabilities can be empowered through CBR, referring to examples in use by many CBR programmes and other related programmes in Asia and Africa. It emphasises the importance of sensitising the community including the labour market, to increase recognition of the capabilities of PWDS and enhance their participation in the general economic life of the society. This chapter also outlines how to ensure sustainability of economic empowerment activities. The chapter concludes that the economic empowerment of PWDS cannot be achieved without their active participation in the whole process.*

## INTRODUCTION

WHO, UNESCO, ILO, (1994), define CBR as a "strategy within general community development for rehabilitation, equalisation of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined effort of persons with disabilities, and the appropriate health, education, vocational and social services."

CBR promotes not only the rights of persons with disabilities, but also seeks to create an environment where they can have equal opportunities with their "able-bodied" counterparts, and are allowed to participate fully in all activities of the society. As such, the role of CBR in the empowerment of PWDs is very essential.

## DEFINITION OF EMPOWERMENT

Helander (1993), defined empowerment as *"an on-going process, which enables an individual to fulfil and be accountable for his or her duties and responsibilities and protect his or her rights in the society. Part of the process is to provide people with the resources, opportunities, knowledge and skill needed to increase their capacity to determine their own future and fully participate in community life."*

Empowerment of persons with disabilities therefore, refers to giving them a variety of opportunities to discover themselves, understand their environment, be aware of their rights and take control of their lives and partake in important decisions that lead to their destiny.

## WHY THERE IS NEED FOR ECONOMIC EMPOWERMENT OF PWDS

WHO, UNESCO, ILO (2004) observe that, *"there is a strong correlation between disability and poverty. Poverty leads to increased disability and disability, in turn leads to increased poverty."* In the year 2000, UN Member States set the Millennium Development

Goals, wherein eradication of poverty was top on the list. The effect of poverty on people with disabilities is unbelievably huge and devastating. According to Department for International Development (DFID) (2000), 50% of disabilities are preventable and directly linked to poverty. Narayan and Petesch (2002), observe that *"poverty violates the fundamental human rights of PWDs, depriving them of the basic necessities of life including, health, education, safe water, food, shelter and clothing including means of livelihood."*

Experience suggests that the majority of persons with disabilities are unemployed, and often denied employment opportunities even when they have met necessary requirements. Consequently, they have no stable income and have to depend on the mercy of family members, well-wishers and charity groups for handouts to sustain their livelihood. International instruments, like the Convention on Human Rights and Rights of the Child; ILO Convention No. 159 on national policy for employment of persons with disabilities, and the UN Standard Rules on Equalisation of Opportunities for persons with disabilities, are practically ignored by most governments in Africa. As such, PWDs continue to suffer increased *"discrimination", "marginalisation" and "oppression"* (Onota, 2003; Akintaro, 2004) from the so-called able-bodied opportunists. Dazie, (1980) and Omubene, (2002) argue, that such manifestations of negative societal attitudes suffered by PWDs creates *"animosity, engenders resentment, and stifles initiative and creativity"*.

Findings from a recent study on the "Impact of Services for People with Spinal Cord Lesion (SCL) on Economic Participation" reveal that, PWDs suffer various forms of barriers including; access to employment, obtaining appropriate work, retaining work, receiving appropriate wages, discriminating attitude, appropriate skills, lack of educational qualification, inaccessible environment and transport systems etc. (Momin, 2004). These attitudinal and environmental barriers tend to limit their ability to participate effectively in economic activities. PWDs have great potential that could be tapped and harnessed for community development, given appropriate opportunities, attitude, and approach. This challenge lies with

Community Based Rehabilitation (CBR) programmes as grassroots service providers and change agents. We agree with Coleridge (1993) Rifkin and Pridmore (2001), that it is high time that the "powerless " be "liberated" and "given the opportunities to gain experience and confidence needed to influence the decisions that affect their own daily lives "; to discover and choose the path leading to their destinies, take control of their lives and make their contribution towards the development of their communities.

### **STRATEGIES FOR ENSURING ECONOMIC EMPOWERMENT OF PWDS**

There are three main ways to achieve economic empowerment of PWDs through CBR. They are as briefly discussed below.

#### **Providing Education Opportunities**

Education is a powerful tool for economic empowerment of people with disabilities. Rifkin and Pridmore (2001), support this fact when they state that, "*information (education) is power; people who lack information lack power and lack choices about how to improve their lives or control what happens to them...* " Through educational programmes (either formal or informal), PWDs can gain knowledge and skills needed to perform functions, tasks or carry out some socio-economic activities for personal and community development.

Education for empowerment should start from pre-school to adulthood. CBR programmes should not underestimate the importance of pre-school skills, like; speech, sign language, sorting/measuring, orientation and mobility, use of tools, daily living skills etc. taught to children at pre-school stage. By teaching such skills, we are already preparing them for future life. Early pre-vocational skills training increases self-confidence, raises self-esteem and perfection, which enhances effective task performance during future working life. In Nigeria, like many African countries, there are a limited number of inclusive schools offering special education and training in vocational skills. The few existing ones do not

have appropriate curricula that provide for the special needs of PWDs. Curricula for special and vocational training schools should also take into account activities that would prepare for effective transition of PWDs from school to working life. This view was widely shared by many contributors to an e-discussion on Employment of Disabled Youths, sponsored by the World Bank. CBR programmes and relevant government services need to support PWDs in schools with necessary assistive devices, like hearing aids, talking calculators, mobility aids etc, provide learning materials/equipment, as well as encourage disability-friendly school environments (e.g., accessibility etc.) to facilitate learning.

Empowerment through education cannot be achieved only by training PWDs alone; it is also important to build capacity of the rehabilitation professionals working with them. The Indian Rehabilitation Council in collaboration with Indira Gandhi National Open University (IGNOU) and Madhya Pradesh Bhoj Open University (MPBOU) has introduced distance education programmes in 25 prominent training institutions and 67 study centres respectively, across the country. Courses offered include; Speech Therapy, Hearing Aid and Ear Mould technology, Special Education, Vocational Counselling etc. This helps in updating and enhancing the knowledge/skills of professional rehabilitation workers, thus increasing the level of empowerment of the PWDs whom are working with (Singh 2004). Long and short term formal training are also going on in countries like Uganda, Malawi, Zimbabwe and Nigeria etc.

In Nigeria, Christoffel Blindenmission International (CBMI) runs a National Training Programme for CBR fieldworkers. This is a short-term training initiative where workshops are conducted on various rehabilitation subjects including management of economic integration programmes. An average of 8 workshops is conducted each year. Target trainees include: CBR fieldworkers, special education teachers, parents of PWDs, and government rehabilitation workers etc. This type of short-term training contributes tremendously to the economic empowerment of PWDs. However, to determine the effectiveness of these training

programmes, CBR needs to increase evaluation of impact of services provided by staff who benefit from trainings; especially how the negative attitudes are changed and the economic status of PWDs is improved.

At the community level, CBR can facilitate economic empowerment of PWDs, by arranging for pre-vocational training in various vocations, using relevant services within the local community preferably, under apprenticeship arrangements. An analysis of questionnaires administered in some of the CBMI supported projects engaged in vocational training in Bangalore, India, reveal that, majority of CBR Vocational Training Officers *"fitted trainees into preconceived vocational training programmes that are out of date and for which there are no job opportunities"* instead of involving them/their families in decision making process (Breisacher 2002). In-service training for PWDs under open employment gives them full qualification for favourable competition with able-bodied persons, and can also help them in retaining their jobs, thereby stabilising their income.

### **Providing Employment Opportunities**

Article 23(1) of Universal Declaration of Rights by UN states that: *"everyone has the right to work, to free choice of employment, to just and favourable conditions or work and to protection against unemployment"* (UN, 1948). On the contrary, ILO estimates that the *"unemployment rate among PWDs in the developing world is an overwhelming problem - up to 80% in some countries"* (ILO, 2003). Caswell (2003), observes that: even though *"there exists legislation for quota system favouring employment of PWDs, unfortunately, this legislation is either under utilized or not enforced"*.

Many PWDs are well educated and have brilliant ideas to contribute towards development of their communities and indeed their nation, through public service; but generally they are not allowed the opportunity to do so due to their disability. It is ridiculous for governments in Africa

to think they can achieve any meaningful development in all aspects of human endeavour, without involving persons with disabilities in the planning and implementation process. If PWDs have to be involved, then they must be fully represented by way of employment in all government ministries and offices. Most governments and some NGOs in Africa do, to some extent, provide sheltered employment for PWDs. Although this arrangement caters for their special needs, it encourages social exclusion, increases stigma and denies them their right to equal employment opportunities as enjoyed by other able-bodied persons.

The private sector, which is likely to control about 50% of job opportunities in most African countries, is ignorant of capabilities and possibilities of PWDs. During an evaluation of a CBR project's activities in Benue state, Nigeria, a restaurant owner was asked if she would employ a disabled person, and her response was automatic and unmistakable, NO. Asked why, she said; *"they can't do anything right; besides, they will bring bad luck to my business"*. Unfortunately, 80% of private business owners in this district shared her opinion! This negative attitude of the public towards PWDs is one of the biggest challenges for CBR programmes to deal with. On the other hand, PWDs on their part have to work hard to turn this picture around, through hard work and credible performance in any given job opportunity.

CBR should facilitate employment of persons with disabilities in leadership positions to enable them to advantage of such opportunities to develop themselves and use their initiatives in handling their responsibilities. Employers should also allow PWDs under employment, to join in labour unions to enable them express their views and feelings concerning general problems and issues affecting their lives. CBR programmes can encourage open employment of PWDs through creating awareness on the need for equal opportunities for PWDs, educating the public on their capabilities and encouraging DPOs to get involved in the political process, by forming pressure groups capable of influencing government policies.

### Self-Directed Employment

Albright, (1993), observes that, *"self directed employment is an option that is of increasing interest to people with disabilities both in economically developed and developing countries. "* This could be a strong tool for economic empowerment of persons with disabilities; not only because they take the initiative, but also because they play a leading role in their structural set up and day-to-day decision making and management process. Self-directed employment includes running small business enterprises, and working in cooperatives controlled by disabled persons. Nyerere, J., the president of Tanzania, supports self-directed effort as effective tool, for empowerment and development, when he said:

*"Man can only liberate himself or develop himself. He cannot be liberated or developed by another. For man makes himself. It is his ability to act deliberately, for self determined purpose, which distinguishes him from animals. The expansion of his own consciousness, and therefore of his power over himself, his environment, and his society, must therefore ultimately be what we mean by development".*

Toit (1991), cites the Self-Help Association of Paraplegics, (SHAP) in Soweto, Republic of South Africa, as one of the good examples of self-directed efforts to empower, develop, and create employment opportunities for young persons with physical disabilities. SHAP operates a factory, which employs 130 disabled people working on a sub-contract basis, doing packaging and assembly work, repairing sophisticated mechanical and electronic devices, such as cameras and calculators etc. This association wins the admiration and support of government and indigenous companies in their fundraising efforts for self-support.

Another good example of self-directed effort worthy of mention is the that made by the Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV) initiative in Chakoria, Bangladesh. Founded in 1989, by Mr. Shahidul, who is physically disabled, SARPV runs a Skill

Development and Credit programme called, BUILD OWN SMALL ENTREPRISE PROJECT (BOSEP), to empower and support poor disabled persons in the district, who want to be successful entrepreneurs but are lacking relevant skills and funds to realise their dreams. Although Caritas-Netherlands and UN ESCAP largely fund SAPRV, its ability to integrate its activities to suit the culture and needs of the people in this area makes it original. Business skills are taught to members and loans provided to groups of disabled members *after successful graduation*. Members of the association are encouraged to work together with family members and other able-bodied persons in the community in carrying out respective economic activities (Alan, 1997). In Mombasa, Kenya, the APDK (Association for the Physically Disabled, Kenya) project runs a community based employment creation programme where 360 micro-enterprises have been established, of which 80% are running successfully. CBR programmes should encourage similar initiatives in other African countries, to enhance economic empowerment of PWDs.

### Providing Opportunities for Financial Resources

In an attempt to empower people with disabilities economically, it is not adequate for CBR programmes to stop at *"teaching them how to fish"* without arming them with the necessary equipment that they need to use in *"catching the fish"*. PWDs who have successfully graduated from vocational training and have not been able to secure wage-earning jobs need to be supported to set up workshops or suitable income generation activities (IGAs), in order to earn a living.

In Nigeria, Services for People with Disabilities gave loans to 40 persons in 2003, under its Revolving Loan Fund. Loans ranged from 1000N (7 USD) to 50,000N (370 USD). Loans are determined by the client's disability condition, nature of the business and economic situation of the PWD/family, among other requirements. PWDs whose IGAs require substantial capital are given part grant and part loan. Findings from a world survey conducted by CBMI to determine the success and failure of vocational training and livelihood programmes confirm that, PWDs supported with both grant and loans, are likely to succeed better than

those who only have access to loans (Caswell, 2003). Experience with supervising the economic integration scheme in Nigeria shows, that it does not necessarily take large sums of money to make a difference in the lives of majority of PWDs living in the rural areas. Sources of funds for support of PWDs willing to start IGAs could come from the government's Poverty Alleviation Programmes (PAPs), community banks, philanthropists, local non-governmental organisations (LNGOs), international non-governmental organisations (INGOs), members of the community, disabled peoples families etc.

Case studies of various of various economic integration projects in Africa, Asia and Latin America show, that it may be an illusion to conclude that they are successful based on records of high loan recovery rates. This is because majority of PWDs go hungry for a long time in order to meet loan repayment deadlines. Some have to literally borrow from neighbours to pay back loans! Therefore, the goal of CBR programmes in creating opportunities for PWDs to access funds for business purposes should not only be to recover loans given, but also to answer the question: what difference has credit made, on the lives of PWDs who receive them? As much as PWDs have to fulfil their loan contract agreements, they also have a right to live.

PWDs also need technical support from CBR programmes in order to succeed with their IGAs. Areas of support include; elaborate business plan, teach basic bookkeeping, monitor progress, evaluate execution process and advise on areas that need to be improved upon. PWDs should also be encouraged to cultivate the habit of saving, either with the programmes or with local community banks. This provides relief in time of any hiccup, helps in case of expansion and raises the status of PWDs (Malcolm, 1996).

In realisation of the importance of economic integration programmes for the empowerment of PWDs, and the challenges that exist in running them, CBMI recommends the training of specialist supervisors for all CBMI-supported CBR programmes. The invaluable support of such supervisors can enhance the effective management of the programmes.

## **ENSURING SUSTAINABILITY OF IGAS TOWARDS ECONOMIC EMPOWERMENT OF PWDs**

The ability of PWDs to earn a living for themselves, rather than depending on others for a living, is a cornerstone for their economic empowerment. It is important that PWDs have a sustained economic power, in order to meet their essential needs and contribute towards community development.

### **HOW TO MAKE IGAS SUSTAINABLE**

Integrate CBR economic integration activities into government poverty reduction and other related programmes

Encourage establishment of cooperative societies through DPOs

Increase financial support for economic integration activities through CBR

Increase public awareness on capabilities and possibilities of PWDs

Encourage capacity building of PWDs involved in IGAs and CBR workers in this area

Encourage utilisation of locally existing related services e.g. community banks, vocational training centres, etc

- Encourage innovations. New ideas about IGAs can motivate local support and patronage

Encourage monitoring, evaluation and research

Encourage participation of the civil society organisations (CSO) in planning and implementation of government economic policies. This can be achieved through holding consultative forums, exchange of ideas at seminars etc. It is rather unfortunate that, unlike in the UK where the government holds wider consultation with CSOs on a broad range of issues, most governments in Africa look at CSOs as rivals rather than partners in development.



## **SENSITISATION OF COMMUNITY AND LABOUR MARKET AS A VITAL TOOL TO ACHIEVE ECONOMIC EMPOWERMENT OF PWDS**

As a change agent and a key partner in community development, CBR plays a crucial role in sensitising all the stakeholders concerning disability issues, the capabilities and rights of PWDS.

PWDS need to understand the nature of their disability, their limitations, potentials and possibilities. They also need to know about their rights, government policies and programmes that concern them. CBR programmes need to make it clearly known to PWDS, what services are available in the community that would help improve and raise their status and existing opportunities. CBR programmes should also facilitate their accessibility and participation in available services and programmes. They should also be mobilised to form associations or groups, to enable them to advocate for their rights.

On the other hand, CBR programmes should sensitise members of the community on issues of disability, i.e., causes, nature, implications and services available, to help improve the various conditions. Members of the community should also be made to understand about the potential capabilities of PWDS by allowing them equal opportunities to participate in community activities, or through apprenticeship training among other things. This helps the community to understand the nature of PWDS, accept them and allow them equal opportunities to participate in the socio-economic activities of the community.

The labour market needs to be sensitised about the potential, capabilities and possibilities of PWDS in order to reduce doubts about their performance. This can be achieved through presenting personal profiles of intelligent and hardworking PWDS, as well as challenging employers to give qualified PWDS a trial on certain tasks available. The Government's legislation concerning employment, accessibility, rights etc of PWDS need to be discussed with employers for their awareness and appropriate action.

## **METHODS OF SENSITISATION**

There are several ways through which CBR programmes can sensitise PWDS. Some of these ways include:

- Campaigns Workshops  
or meetings
- Role plays
- Stories and songs
- Role models
- Drama
- Puppets
- Radio/TV
- Group Discussions
- Printed leaflets/handbills etc.

## **HOW TO ORGANISE FOR SENSITISATION**

Effective sensitisation requires thorough planning, adequate preparation and good implementation. Involvement of PWDS, DPOs and labour unions, for example, is very strategic and important. Organisers should be mindful of the culture, education etc, of the people they are about to sensitise during the planning stage; this helps in selection of method(s), language etc to be used in implementation. Steps towards organising sensitisation include:

- Choosing an appropriate topic
- Developing an appropriate strategy
- Making adequate preparations
- Implementing a strategy Evaluating the effect of sensitisation

## CONCLUSION

Economic empowerment of PWDs is very crucial in raising their status. However, this cannot be achieved without the involvement and participation of all stakeholders: the government, members of the community, the labour market and PWDs themselves. CBR programmes need to increase sensitisation of the public on disability issues and rights of PWDs. Also, innovation and increased support for economic integration activities is necessary; as well as implementation of realistic and results-oriented plans in order to achieve successful empowerment of PWDs through CBR.

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# Community-based Rehabilitation as Part of Inclusive Education and Development

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## SUMMARY

*This chapter describes the relationship between community-based rehabilitation and inclusive education. It also presents case studies from Uganda and Kenya on special needs education and inclusive education respectively, for other African countries to learn from. Finally, some recommendations have been made highlighting the way forward for African countries, to utilise the community based rehabilitation strategy in the provision of education for all children in the community.*

## INTRODUCTION

Societies respond differently to the provision of services such as education, health, transport, employment, and rehabilitation for persons with disabilities. Accessibility to services by persons with disabilities continues to be a major challenge in all parts of the world, but especially in developing countries. However, many countries have realised the

advantages of including persons with disabilities in all development activities. Policies have been adapted to safeguard and improve their lives, and programmes such as Community Based Rehabilitation (CBR) and Inclusive Education (IE) have been put in place. The overall aim of these programmes, is to develop the potential of persons with disabilities and for them to become productive citizens in the community.

IE and CBR are strategies that address the issues and challenges affecting persons with disabilities and their families. They have been developed to challenge the exclusionary policies and practices, which have predominated in previous decades. They recognise the value of individuals with disabilities and challenge professional and community attitudes. Parents of individuals with disabilities are valued as participatory partners, since they provide first hand information and support to the special needs educators and CBR workers.

CBR aims to focus on rehabilitation, equalisation of opportunities and social inclusion of all persons with disabilities and their families. IE has a similar philosophy and aims to include disabled children in mainstream education, overcoming barriers to learning and participation in community educational settings. Both approaches value diversity and promote inclusion. They both aim to ensure that individuals with disabilities have equal access to the services that are available to other people in the community, such as education and employment.

Education empowers and strengthens all people in the community. It equips people with knowledge and skills that are crucial to the development of individuals and their capacity to access their rights. According to a recent report for the World Bank Disability Group, "*Education is widely seen as a means to develop human capital, to improve economic performance and to enhance individual capabilities and choices in order to enjoy freedoms of citizenship*" (Peters 2003). Therefore, through CBR and IE, persons with disabilities are empowered to change their life chances and obtain the means to participate more fully in their communities. This is why 'Education for All (EFA) by 2015' calls for

capacity building of its educational staff so that they can meet the diverse learning needs of all learners in the education system. Community workers and teachers need appropriate training, so that they know how to support and include disabled people within the services that they offer. Teachers, parents, curriculum planners, training institutions, school authorities and community workers are all key players in the development of a truly inclusive education and community service. This mutual dependency is key to the connection between these paradigms. For example, CBR workers may identify children with disabilities whom they refer to ordinary schools. This is a first and vital step in the beginning of the inclusive education process and needs to be met with acceptance and interest by the teachers. The reverse association may occur when educators refer learners with disabilities to CBR workers for vocational training placements and other related community services. Therefore, CBR and IE are inter-related and co-exist in some communities to complement each other.

### **CBR WITHIN SPECIAL NEEDS EDUCATION IN MALAWI AND UGANDA**

In 1992, the Ministry of Education in Uganda, established a special needs education programme with two clearly different branches. These were Educational Assessment and Resource Services (EARS) which were established in every district of the country to assess and assist children with disabilities at the community level and the Uganda National Institute of Special Education, set up to train teachers in special education practices (Kristensen, 1996). Meanwhile Malawi in 1992, established the Malawi Integrated Education Programme (MIEP). The aim of this programme was to reduce the number of children in special resource rooms (attached to regular schools) and residential schools in the 9 districts where CBR programmes existed. Unfortunately, MIEP was not a multi-disability oriented programme. It only targeted learners with hearing and visual impairments and proved to be of limited success.

Currently, the majority of CBR programmes in Malawi mainly focus on adults with disabilities. Few CBR programmes focus on children with disabilities. The Ministry of Education still continues with what was laid down by the faith-based organisations. A survey has not been conducted to find out the number of children with other disabilities in need of special needs education services. However, charitable organisations like Feed The Children Malawi, formerly Cheshire Homes Malawi and SOS Children's Village have come in to assist children with learning difficulties and those with physical impairments. They have established special needs education units in their institutions. CBR workers assist them in the identification of children with disabilities and referral services.

In 1994, Malawi introduced Free Primary Education. It was politically articulated such that no wider consultations were made though on the other side it is a response to many UN documents including the Salamanca statement (UNESCO 1994) and the Standard rules on the equalisation of opportunities of disabled persons. These documents promote the spirit of inclusive education and an inclusive society.

Unlike Malawi, Uganda started Universal Primary Education in 1997 with clearly stated policies, aims and objectives for the shift from special needs education to inclusion. Kristensen (1997) says "*Uganda may be the first country in the world to give children with disabilities priority to other children in the allocation of school places.*" Links were made to ensure that services reach all children with special educational needs. Teachers in the field were oriented and Uganda National Institute for Special Education (UNISE) introduced part-time special needs education courses, so that teachers could continue teaching in their normal schools. In June 1997, a component of special needs education was introduced in primary teacher training colleges so that all primary school teachers had some basics on aspects of special needs education. The relationship between these initiatives and the international legislation concerning these issues is clearly described by Millward et al (2005) and three key ingredients are identified as determinants of Uganda's success. These are, a powerful organisation of disabled people, the political

will and the relevant international guidelines. Every country has access to the latter commodity, the international guidelines, but how well they use them may differ depending on the other two determinants.

Recently, Malawi has finalised its new teacher-training curriculum that has units on special needs education and some aspects of community-based rehabilitation, as it moves towards inclusive education. Classroom teachers in inclusive settings require different coping strategies so that they can include, support and retain learners with disabilities in their classrooms. In addition, some families of children with disabilities lack problem-solving skills. They depend on professionals. Teachers and CBR workers must provide up-to-date information on disabilities, to families of children with disabilities and equip them with coping skills in caring for their children especially in rural areas (Chavuta, 2002, Hartley et al 2005). Malawi needs to extend CBR programmes to all rural districts so that parents and individuals with disabilities are able to access the CBR services like in Uganda. For instance, in Karamoja in Uganda, the Karimojong people depend on livestock for their survival and are semi-nomadic. Among them only 11.5% are literate. The children's domestic duties are essential to their family's survival. For the children to access basic education, a programme called Alternative Basic Education for Karamoja (ABEK) was introduced. The programme is strongly community-based (Stubbs, 2002) and has promoted inclusion in education as follows:

- o The community initiated ABEK and facilitators are selected from the community
- Learning areas are totally relevant to the community and their survival. They include livestock education, crop production, peace and security and health
- The facilitators have lessons early in the morning before they need to go the fields and again in the evening when work has finished
- Girls are able to bring younger children whom they have to care for
- Boys are able to bring their herds to graze and still take part in learning to read and write

- Participation of children with disabilities
- Parents and elders are welcome to attend and take part
- Instruction is in their own language
- Teaching methods are active and involve music and dance
- The elders themselves are specialist facilitators on subjects such as indigenous history and knowledge of survival
- The District Education Office has a key role to play. It is involved in the administration of ABEK and ensures a strong link with the formal system

Since Uganda is ahead of Malawi, Malawi must learn how CBR strategy has been used in Uganda, to provide special needs education to children in rural areas. Through CBR, Uganda has achieved the following:

- Persons with disabilities have been trained in appreciating and managing disabilities. This has happened by increasing accessibility to educational facilities like the ABEK programme and many stakeholders taking an active role in community development issues
- Local communities have contributed assistive devices and other appropriate resources to assist children with disabilities access educational opportunities in schools. Some of the resources/devices provided include: wheel chairs, brailled textbooks, low vision devices
- Local communities have been assisted to establish resource centres/schools for children with disabilities
- Many families have been facilitated to secure corrective surgery for their children. This has been done in collaboration with CBR supporting NGOs e.g. Sight Savers International, religious organisations and charitable organisations, which paid for medical bills and transport costs
- Through CBR, local communities have been empowered to identify children in need of special needs services

## **INCLUSIVE EDUCATION AS PART OF CBR: ORIANG CHESHIRE INCLUSIVE EDUCATION PROJECT IN KENYA**

Like Uganda, Kenya has also responded to the call for inclusive education using the CBR approach. The Oriang Project has introduced inclusive education in the Kabondo Division of Rachuonyo District in western Kenya. Leonard Cheshire International is providing technical and financial assistance to the project. The project is being implemented in five pilot primary schools, with the vision of influencing inclusive education and community inclusion within Kenya. There is a Management Committee composed of 16 members. The committee has been trained in project management and supervises the work of 5 School Disability Committees (SDCs).

The Oriang project benefits 2568 children of whom 282 are school-going children with mild to severe disabilities while 25 are under home-based care programme. The cases identified so far, are children with visual impairment, physical and hearing impairments. The majority are children with specific learning disabilities thought to be mainly caused by malaria.

The Oriang project and the Uganda activities have been initiated in an environment with the following challenges:

- Inaccessible infrastructure
- Lack of specialised trained personnel e.g. psychologists, physiotherapists, occupational therapists, sign language interpreters, Braille transcribers
- Lack of adapted curriculum
- Lack of teaching, learning and assessment resources
- Large class sizes
- Negative attitudes
- Inadequate instructional materials
- Theoretical and academic teaching

The Oriang project has shown that its strategies have achieved the following:

- Improved accessibility to and in schools. The five schools have each constructed two-door adapted latrines to minimise sanitation problems faced by learners with physical impairments. Through community involvement, two schools have built ramps in their schools leading to classrooms and roads graded. 40% of the windows in schools have been widened and walls of three schools plastered and painted with brighter colours to improve illumination. The windows have been shuttered and doors secured for improved safety of teaching-learning resources. Families/homes with individuals with disabilities have also been encouraged to make their environments accessible to all people
- The Oriang Disability Resource Centre provides access to play materials and equipment as well as teaching-learning resources to teachers and the community
- The Oriang project has led to the introduction of the learning centre concept. This is a planned area in the classroom where learners are provided with the opportunity to be engaged in active learning, interaction, sharing and cooperating with each other
- Teachers have been equipped with different teaching methodologies that are learner centred and involve all the senses
- Classroom teachers have skills in developing individualised education programmes for learners with special educational needs
- Negative attitudes towards children with disabilities and other persons with disabilities have been reduced

## **SUGGESTED RECOMMENDATIONS FOR THE WAY FORWARD**

- African governments need to work together and introduce more CBR and IE programmes, targeting the majority of their populations who live in rural areas.

- For effective communication and coordination of CBR and IE activities, CBR Africa Network (CAN) offices should be opened up in every sub region of Africa: East Africa, Northern Eastern Africa, Northern Africa, Central Africa and Southern Africa
- To build the research capacity of CBR and IE practioneers, training attention needs to be given to developing their analytical and writing skills
- An African bulletin on CBR and IE should be initiated to be used as a communication and information tool for CAN member countries, scholars, researchers and other interested readers
- School Disability Committees/parent support groups must be strengthened for them to provide support to groups of parents/ caregivers of children with disabilities in schools and in the community
- Regular exchange visits between countries in the region must be made to share CBR and IE experiences

## CONCLUSION

CBR and IE are strategies for opening up opportunities for person with disabilities and including them in mainstream activities together with able bodied people. They both seek to develop the potential of persons with disabilities for them to be productive citizens in the community. Exclusionary policies and practices are challenged by active participation of all stakeholders in the community. Teachers, parents, CBR workers, curriculum planners, social workers, medical and education personnel, training institutions and school authorities are key players in the process of inclusion. They all need to promote multi-sectoral collaboration so that they can manage CBR and IE. CBR and IE programmes are the best ways of reaching children, youths and adults with disabilities in Africa so that they can participate and contribute to the development of their countries.

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## CHAPTER 6

# CBR as Part of Community Health Development

*Alice Baingana Nganwa, Chapal Khasnabis*

## SUMMARY

*This paper discusses how Community Based Rehabilitation (CBR) and community health are mutually sustaining and important to community development. Although CBR started as a strategy under primary health care (PHC), it was soon realised that many of the concerns of disabled people and their families did not fall under the mandate of the health sector; hence CBR shifted its approach to a multi-sectoral one. Despite this shift, CBR and other community health services have many similarities in approach, which could be advantageous to both. CBR has made a contribution to general health care development by bringing to the surface hidden conditions that have bypassed the attention of the PHC worker because this worker was only aiming at stemming death. On the other hand, CBR has not benefited as much from general health care as it has given. People with disabilities do not access most of the health services other people do. Even within existing disability services, the control of professionals renders them irrelevant to disabled people. It is recommended that CBR, community health services and disabled people collaborate in service development with one aim, "Equal rights to health care". Disabled people in collaboration with health and rehabilitation personnel should guide rehabilitation*

*services. Data collection systems of general health care and CBR should be linked and research originating from either should include the other. "Poverty and health " are interlinked - it is through sharing approaches and resources that poverty and lack of access to health care among disabled people can be addressed. CBR is about meeting basic needs - accessing health, education, livelihood and equal membership of the community.*

## INTRODUCTION

### **I11 health and disability- a hindrance to community development**

The link between poverty, illiteracy, poor health and disability is well established. The World Health Organisation (WHO) believes that provision of better health provides an exit from the poverty cycle and that investment in health is an asset to economic development. Community health<sup>1</sup> is, therefore, a result of and a prerequisite for community development<sup>2</sup>. One of the reasons why development processes do not perform as expected, is the assumption that providing loans, farm tools and improved seeds can kick-start or catalyse development. A major hindrance to community development is ill health at the three dimensions of body, soul and spirit. For example, in Uganda, malaria, the most burdensome disease, costs the

<sup>1</sup> A Community is a group of people sharing the same geographical locality and resources. World Health Organisation (WHO) further describes a community as the lowest administrative area. With cosmopolitan urbanisation, a community may share similar culture though the individual members making the community may not be in the same locality.

Health: WHO defines health as well being in body, mind and spirit not merely the absence of disease and infirmity

<sup>2</sup> Community Development is similar to community health development except that in community development the concern is not only the three dimensions of human beings but includes the well being of the environment as well. This environment includes economic, political, social and physical environment. If the above definitions are correct, then community health development is a part of community development and the vice versa can also be true that community development is community health development.



nation about 120 million days of work every year, thus hindering development. Another and more often-ignored hindrance is the neglected potential from marginalised groups that not only retards development, but also impedes the participation of family members of these groups. As long as the marginalised and often poorest of the poor are left behind, the development process will remain static or move forward very slowly. One of the most ignored groups in any country, are people with disabilities (PWD), who do not even enter into bottom-up development processes, since they are often below the bottom line. Ill health and disability are important factors to address in the community, if development is to take place. Ill health does not only refer to disease but the absence of well-being. A better term would be "a state of non-health."

**HOW ARE ILL HEALTH AND DISABILITY BEING ADDRESSED?**

In 1978 at Alma Ata, nations agreed that the strategy to improve people's health, was through the Primary Health Care (PHC) (WHO/UNICEF 1978). Eight to eleven elements were identified as the main focus of PHC depending on the country priority. According to the 1978 Joint report by WHO and UNICEF, PHC was to "address the main health problems in the community, providing *promo live, preventive, curative and rehabilitative health services.* " CBR, therefore has its roots in PHC and is supposed to be delivered along-side promotive, preventive and curative care. Very few Governments, NGOs and UN agencies have implemented this holistic approach to health care. Sixteen years after Alma Ata, WHO, reviewed progress made by PHC but did not mention rehabilitation at all in the review document (Tarimo and Webster,1994). Today, 25 years after Alma Ata, advances have been made in preventive, promotive and curative aspects, but there is still little to show for the rehabilitative arm of PHC.

The programmes that did implement CBR as part of PHC, often applied a two-track approach; one for PHC and another for CBR. Many more implemented CBR as a separate entity that overlapped with community health for medical referral purposes.

It is important to remember that 20% of the world's poorest of the poor, are people with disabilities and only 5-10% of the disabled people have access to health care and rehabilitation services, the latter often fail to reach beyond major towns and cities. Persons with severe and multiple disabilities and women with disabilities, continue to have extremely low access to services and where services do exist, professionals set the agenda whether it is relevant to people with disabilities or not.

An example of the contradiction between disabled people and service providers is illustrated from data collected in two focus group discussions conducted by the second author. It can be seen that the priorities of the professionals are different to those of the persons with disabilities. This is illustrated in the Table 1.

**Table I. Priorities of parents and disabled people, and those of rehabilitation personnel.**

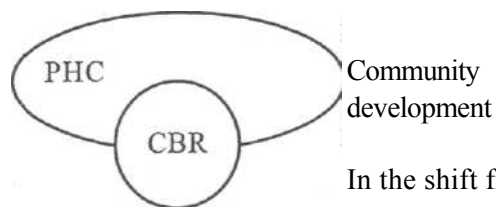
Priorities of Rehab personnel	High priority	Priorities of Persons with disabilities and parents of children with disabilities	
Physiotherapy		Income	
Corrective surgery		Food	
Calipers and assistive devices		Clothing	
Gait training		Better shelter and at least a toilet	
Education and schooling		Water	
Accessible classrooms and toilets		School	
Vocational training		Treatment or cure	
Income to family		<b>Low priority</b>	Exercises and calipers

Experience indicates that a professionally directed programme often fails to meet the priorities of disabled people and their families. Community-based rehabilitation (CBR) needs to be a community action to ensure that people with disabilities have the same rights and opportunities as all other community members. This includes, for example, equal access to health care, education, skills training, employment, family life, social mobility and political empowerment. The professional's role is to support these actions, but not to prescribe.

The focus in the formative years of PHC and CBR was on reducing ill health and not the totality of well-being or development. Although health workers left the hospital compounds and entered the community, it was done in the compartment of the health sector. CBR started by using a medical approach. This aimed at correcting to correct impairments using services in and close to the community. It was spearheaded and owned by health workers. The priorities were set by the professionals as shown in Figure 1.

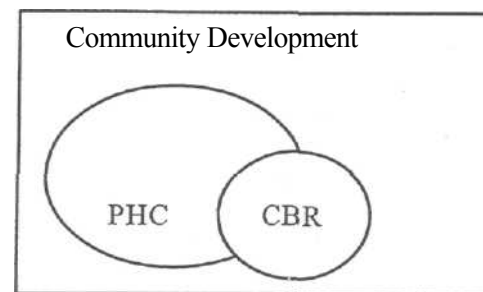
Figure 1 illustrates the situation in the early eighties, when CBR was a part of PHC and community (social) development structures were external to the arrangement. In the figure it can be seen that CBR is bursting out of the seams of PHC. This is because the health workers found many issues they could not address, the major one being poverty.

**Figure 1. CBR as part of PHC and Community Development external to both**



In the shift from the medical to the social approach the relationship between PHC and CBR changed. The effect is shown in Figure 2.

**Figure 2. PHC and CBR as Part of Community Development with overlap between CBR and PHC**



PHC focused on improving community health (removing ill health) and CBR focused on the integration of PWDs into the community. PHC was embraced by community development as sectorial walls began to break. For example in Uganda, one of the reasons for the success of immunisation revitalisation was the use of community development workers and local leaders to mobilise families for the various immunisation campaigns, instead of depending on health workers alone.

The overlap or intersection between CBR and PHC is in some aspects of medical rehabilitation like therapy, simple assistive devices etc. CBR's main link with community health services was early identification, simple interventions, transfer of knowledge and skills and referral of disabled persons for "medical correction of impairments and prevention of secondary complications". But PHC and CBR programmes still have separate compartments even within the same community. It is only recently, that concerns such as the reproductive health of people with disabilities, their access to sanitation and immunisation, entered the agenda of CBR programmes. This did not advocate providing these services to PWDs separately, but promoting access to the community health services available to other members of the community. For example in the 2001 Africa regional Conference on CBR (Hartley 2002), sexuality, reproductive health and HIV/AIDS were important discussion issues. One of the conference resolutions was that CBR should be a link between people with disabilities and HIV/AIDS programmes.

The community health programmes too, need to realise that PWDs require all the services that are offered to other community members. Environmental barriers and the attitudes of professionals often create limitations for people with disabilities, in accessing these services. On the other hand, CBR need not limit itself to providing support to people with disabilities, but may also benefit the whole community by promoting and facilitating access to other health services, by identifying previously "hidden" health problems and by influencing the development and implementation of other medical services. Examples to support these observations will be given in the following sections.

There is need to avoid "compartmentalising" disabled people in special programmes ordained by the CBR programmes, and work towards mainstreaming them into the development programmes that others are enjoying. In support of this, WHO believes that an ideal national rehabilitation programme is a nationwide network, linking specialist rehabilitation and other secondary and tertiary health units, outreach services, primary health care centres and CBR programmes/initiatives.

**SIMILARITIES AND DIFFERENCES IN APPROACH BETWEEN CBR AND COMMUNITY HEALTH SERVICES**

Both CBR and community health services had similar origins and so not surprisingly, the similarities out number the differences. The major similarities and differences are summarised in the table below.

	<b>Similarities</b>	<b>Differences</b>
Area of operation	Both leave institutions and work in and with the community.	CBR moved into the community before it had developed adequate referral institutions. Most of the health units for community health referral are available but most do not include medical rehabilitation services.

Frontline worker	Both use community based volunteers and a variety of other workers at the community level.	Some community health programmes have paid community nurses as the front-most health personnel.
Community participation	This is a pillar in both programmes.	CBR has succeeded in bringing traditional non-participants (marginalised) on board.
Multi-sectoral approach	Both strategies use this.	More tangibly seen in CBR programmes that use the social model.
Support structures	Both need support structures for sustainability.	Community health care services have better developed support services.
Equal opportunities	CBR aims at equal opportunities for PWDs in all aspects of life. Community health advocates for equal access to basic health services for all.	CBR is for PWDs and their families. PHC is for all, but often excludes people with disabilities.

**CBR FOR ALL, CBR PART OF ALL**

To be part of something is to *receive* and *give*, to *belong* and to *have a stake*.

For CBR to receive wide acceptance in community development, it must be seen as 'a programme for all'. PHC before the turn of the century was perceived to be a programme for all and not just for the sick or the

rich. We all recall the slogan, *"health for all by the year two thousand."* A government official heading one of the districts in Uganda explained it very well when he said, *"As long as your programme (CBR) is seen to benefit one group of people, it will receive very little support. Present it like it benefits all of us."* The rest of this paper discusses how CBR has been a part of community health development and ways of strengthening this.

### **CBR'S CONTRIBUTION TO COMMUNITY HEALTH DEVELOPMENT**

CBR's contribution to community health development is often underplayed in the literature. Emphasis in evaluation is correctly placed on how the CBR programme has improved the quality of life of disabled persons and their families, but in doing so, CBR's contribution to general community health development is overlooked.

#### **Reaching the Unreachable**

CBR has been the main vehicle through which marginalised people with complex health problems have reached referral services. The needs of these people would not have been met because community health departments often conduct outreach programmes, that focus on simple health problems, or for health education purposes or immunisation. They do not reach those who are hidden or cannot come forward easily like others. Through CBR, persons with disabilities can access the same health care services as others and persons requiring surgery and complex medical care have been reached, assessed and persuaded to go to centres where they can be assisted. People with disabilities who are too feeble or too heavy to move, have received assistance at home through CBR workers. Together with CBR, HIV/AIDS programmes have reached poor people with complex health problems in their homes. For example, a child with active tuberculosis of the spine was identified by a CBR worker in Tororo district, Uganda, where she had already developed difficulty moving and dropped out of school. She was referred to the

district hospital where a diagnosis was made, anti-TB drugs started and the moving difficulty was reversed. This child should have been identified earlier by the community health programme, but it was the CBR programme that brought a turn around in her life.

Community health services are supposed to reach all and CBR has facilitated this process in situations where health programmes lacked the ability either to intervene, or to reach the people. In Eritrea, it is through the CBR programme that the only psychiatrist in the country is able to provide mental health services. In one of the district CBR programmes in Uganda, 40% of all those referred for surgery successfully received it (Nganwa et al 2004). Most of the surgery was either orthopaedic or neurological and without CBR the surgeons would never have seen these clients. More importantly, people in dire need but with very little capacity, accessed corrective surgery that they would never have received without CBR. In the referral process, both disabled people and the non-disabled people have benefited. An outcome of CBR in this particular district was the triggering of self-referrals especially for surgery.

CBR programmes in Uganda have helped chronically ill patients with goitres, backaches and impotence, children with otitis media reach the primary and secondary health facilities. A common condition that is generally not included in disabilities, although it carries high stigma is vesicular - vaginal fistula (VVF). Women with this condition leak urine continually as a result of difficult labour during child delivery. Through the CBR programme in Northern Uganda, many of these women were brought to health facilities. The burden of WF was so high that the hospital could not continue to fly in a gynecologist to repair the fistulae. As a result, the government posted a gynecologist in the area, trained other doctors in WF repair in Ethiopia and an NGO has taken this as an issue and brought in an expatriate surgeon in the neighbouring region.

In Tororo District, Eastern Uganda, an NGO providing tertiary referral eye care services (mainly surgery, in addition to primary and secondary eye care), was not achieving its target of cataract and other surgeries.

To improve this, the NGO decided to refund transport for a round trip to the Centre. This improved access to eye surgery. However, the biggest contribution to the NGO's eye care and general rehabilitation services was when a CBR programme was introduced on a large scale in the district. The number of cataract surgeries has increased by nearly 30% over one year.

### **Better Health Services**

In an evaluation of Dehub CBR Programme in Ethiopia (Ethiopian Ministry of Labour and Human Welfare 1998), the second most common effect of CBR on PWDs was recorded as improved health status. In Uganda, health services have been improved at three levels, this improvement is more marked in the district where CBR is in place. Uganda Society for Disabled Children (USDC) is implementing CBR in 8 districts of Uganda. Wherever this NGO has worked, it has successfully advocated for districts to employ rehabilitation staff especially physiotherapists, occupational therapists and in some instances, orthopaedic technological assistants. Once the rehabilitation staff are in place, the NGO then provides support to the therapists to reach the disabled children. The rehabilitation staff, however, are also available to treat adults with disability, patients with diseases such as pneumonia, fractures, burns and others. The support from USDC is at district level, an important first referral point for community health services and this support is beneficial to all and not only to the disabled community.

In Lesotho, the CBR programme is advocating for the revival of physiotherapy assistants, a cadre that was active and dwindled due to lack of support. The physiotherapy assistant will not only serve disabled people but all those in the community who require the physiotherapy. At the National level, citing Uganda again, the National CBR programme through concerted advocacy, succeeded in getting the Ministry of Health to start a desk for Rehabilitation. Recent down-sizing of the public sector worked to the advantage of CBR, by having the section become a fully-fledged one in the community health department. The section has not

only benefited disabled people, but patients with temporal functional limitations and illnesses. Three examples of these are prevention of blindness, prevention of deafness and injury prevention and control programmes.

### **Revealing Hidden Conditions**

Common things occur commonly, or so we are taught at medical school. This is not always so in community health. There are common illnesses that do not appear in health management information systems and therefore are not planned for, such as epilepsy and otitis media. Each country may have their own hidden diseases until the CBR programme brings them to light. Uganda has very high prevalence of epilepsy although exact figures are not known. In all districts implementing CBR, epilepsy is the most common disability recorded (Nganwa et al 2004). The alarming levels prompted a stakeholders meeting to be held about this condition. Despite the high level of epilepsy in CBR programme records, the health information system records show less than 1 % of the numbers recorded by CBR. Another example is the formally hidden burden of middle ear disease, until a CBR programme reaches a district. This phenomenon is seen in all parts of the country. Wherever CBR has been started, patients with middle ear disease have come forward for help. The reason why family members with otitis media are brought to CBR and not to community based health care programmes or health facilities, is still to be explored. Perhaps this is because of the broad call made by the CBR programme that not only attracts severely disabled people, but the sick and more minor disabilities as well.

### **Prevention of Disabilities**

Although many CBR programmes are not directly involved in primary and secondary prevention of disabilities, they often manage to prevent avoidable disabilities and prevent secondary complications through community education activities. CBR workers will pass on information based on actual examples seen within the community and thus prevent

avoidable disability. Disabled members of communities, who are the genuine owners of CBR, have often argued that disability resources should not be spent on prevention of disability, because preventing disability is accepting that it is not a normal difference in society. Secondly, there are already a lot of resources at all levels already committed to the prevention of disability, but very little resources are available for disability rehabilitation. WHO sees this very sensitive issue with a different perspective and believes that CBR should address prevention of all avoidable impairments and also contribute to the elimination of barriers, which create disability.

### **WHAT CBR RECEIVES FROM COMMUNITY HEALTH SERVICES**

All services provided by community health departments should be available to PWDs. Both the CBR and community health personnel need to make sure PWDs are able to access the general health services available to others. For example HIV/AIDS prevention programmes, curative services and the rest of the essential/ basic health package including reproductive health, environmental health and sanitation, nutrition, oral health and epidemics and disaster management should be available to all, including PWDs. Community health staff need to have information and services available, while the CBR programme advises the community health workers on how to make the services accessible to PWDs. CBR will then refer PWDs to a service that is friendly and relevant to them. The gaps that limit access of PWDs to other community health services need to be explored jointly by providers of general community health care, CBR workers and PWDs. Current exploration of these issues is driven by specialist disability professionals, while the provider of general health services and the disabled people are the objects of the research. This may result in providers of general health services misinterpreting research results as criticism. This is why it is important to involve all three players - CBR workers, health providers and PWDs as researchers and implementers in health care access research.

In order to try and bring the special contribution of CBR and community health together, a model CBR programme in Uganda is utilising three professionals as CBR supervisors at sub-district level. The three are; a social worker who heads the trio, a special needs education supervisor and a health assistant. These three workers complement each other and a near holistic service is provided at family level. The output of using the trio is yet to be evaluated.

### **POVERTY, CBR AND COMMUNITY HEALTH DEVELOPMENT**

The importance of a multi-pronged programme to address economic development was discussed earlier. This agrees with the disabled people's driven programme that has economic and basic needs prioritised above health care and rehabilitation. CBR is a strategy that harnesses the elements of a multi-pronged programme, in a way that is relevant to persons with disabilities, thus lifting them and their families out of poverty. The Millennium Development Goals (MDG) are closely linked with health care and their attainment in any community will correspond to improved access to health care. CBR is therefore an important strategy not only for community health development but for attaining all of the MDGs. The joint position paper (ILO, UNESCO and WHO 2004) describes CBR as a "*strategy for rehabilitation, equal opportunities, poverty reduction and social inclusion of persons with disabilities*".

The disability issue and the role of CBR in attaining the MDGs needs to be highlighted in poverty reduction strategy papers. This can only be done by development workers who have been exposed to the wider realities of CBR and although they are few, their input can make a change in policy and programme documents at theoretical level of work.

***It is through a community health development approach that disability and poverty issues can reach the priority list of poverty reduction strategy papers, thus contributing to holistic community development.***

## CONCLUSION

CBR can and does play an important role in community health development. However, CBR will fail to bring about development of PWDs unless the community health programmes are provided. The relationship between CBR and community health programmes are reciprocal and the synergy brought about by their interaction will bring about community health development. There are, however, very few situations where both these approaches coexist and mutually feed into each other. Often, CBR will exist within weak community based health services or the latter may be in place and the former is not available. Communities need health care that provides all four areas of PHC. This care should blend with community (social) development so that a continuum of care is provided. Only then, will community health development contribute towards socio economic and political development.

## RECOMMENDATIONS

- For community development to occur, both CBR and Community health care need to be in place since they are interdependent. There is therefore, need to advance the two community interventions simultaneously and where one has developed without the other, bring the missing programme on board
- Both CBR and community health care approaches need to be promoted simultaneously. It would be a mistake to perceive CBR as part of PHC only
- There is a need for the two programmes to remain distinct, because CBR goes beyond the borders of PHC. This will also maintain the identity of each area of care and the PWDs who are already marginalised will not be denied services due to competing priorities that could arise, if there is a merger between CBR and general community health services

- Stronger inter-sectoral collaboration and coordination at national, sub national levels between community health programmes, CBR, education and community (social) development is required to ensure continuum of care ranging from preventive, promotive, curative and rehabilitative, through to education and economic development thus achieving true health and development
- Community general health services and CBR should not be driven by professionals alone, other stakeholders should include knowledgeable women, community representatives, persons with disabilities and their families
- CBR needs to provide services for all, including the families and communities supporting disabled people and persons with non-permanent health conditions that require CBR workers. This will benefit the health and well being of the whole community; facilitate access to health, education and livelihood. CBR will then be appreciated as a programme for all and not only for disabled people
- CBR along with Disabled Peoples Organisations (DPOs) and community general health services need to ensure PWDs are able to access the whole basic package of services that is available in the community. CBR and DPOs have to take the lead in creating this access, since the general health worker is not informed about the unique needs of PWDs
- The basic training of all health workers should include a component on disability and the trainers for such a programme should include people with disabilities and/or their family members
- An area of special collaboration is the sharing of data to influence service delivery of both CBR and general community health services
- Research and evaluation of CBR should include CBR's contribution to the non-disabled population and the contribution of community health programmes to disabled people. Community benefits accruing from CBR, need to be documented and appreciated by both the disabled and non-disabled communities

- Research on factors affecting the access of PWDs to general community health care services needs to be undertaken by all parties (general Community health, CBR and PWDs) participating

In all these recommendations, CBR needs to provide the leadership and initiate the required change. One indicator that will show basic health services are reaching all, is when preventive, promotive, curative and rehabilitative health services have reached all PWDs.

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## CHAPTER 7

# HIV and AIDS, and Disability

*Lisa Davidson*

## SUMMARY

*This chapter describes a Voluntary Services Overseas (VSO) initiative in Namibia, which aimed to identify the needs of disabled people in relation to HIV and AIDS and to develop mechanisms for including them in mainstream activities. A needs assessment showed that PWD were often not seen to be at risk of HIV or AIDS and therefore their specific needs regarding prevention, education, access to testing, care and treatment were being over-looked or ignored. There are assumptions that PWD are not sexually active, or at risk of sexual violence or are intravenous drug users. Our studies showed that this was not the case and that most PWD were at equal or increased risk to infection. A national conference was used to identify strategies for meeting these identified needs. The programme concludes that until PWD are recognised as people with sexual rights, until they are seen as a vulnerable group, until they are included in planning, designing, implementation and dissemination of information about HIV and AIDS they will remain marginalised and vulnerable.*

## INTRODUCTION

Part of the overall Voluntary Service Overseas (VSO) programme in Southern Africa started in response to the growing need regarding HIV and AIDS. This initiative is called the Regional AIDS initiative of Southern Africa (RAISA). It has programmes in Zambia, Mozambique, Zimbabwe,



Malawi, Namibia and South Africa. The aim of RAISA is to join forces with governments and civil society organisations, to provide effective prevention, treatment, care and advocacy for people affected by HIV and AIDS, and to mitigate the personal, social and economic impact of the pandemic. RAISA does this through the provision of:

- Skilled volunteer development workers
- Training and capacity building programmes
- Financial assistance through a small grant fund
- Networking opportunities through regional exchanges and conferences
- Mainstreaming services

### **RAISA AND THE DISABILITY SECTOR IN NAMIBIA**

In 2002 VSO Namibia had one volunteer working for the National Federation of People with Disabilities in Namibia (NFPDN) and two working for ministry of Lands, Rehabilitation and Resettlement (MLRR). These volunteers requested funding from RAISA Small Grant Fund to do a needs assessment about HIV knowledge of PWD. The first workshop took place in 2003 in Okakarara, with 25 participants, half were physically disabled and half mentally disabled. Within the group the knowledge of HIV and AIDS was found to be very limited even though they had all heard of it, they did not apply the information to themselves. This was partly due to the low level of education (only 2 people were literate) and partly due to the attitude that sex and prevention against AIDS had nothing to do with disabled people. However, all the mentally disabled people were accompanied by their children, most of them clearly also mentally disabled, providing absolute evidence that they were involved in sexual activities. One quote that indicated the vulnerability of disabled people and the cultural attitudes towards them was *"and then the woman was put in the room with a man, because a blind woman will need a child to take care of her"*. The results of this assessment indicated very poor knowledge about HIV and AIDS amongst the disabled population and the programme was built on this information.

This chapter aims to share some of the experiences and lessons learnt from this programme, whilst at the same time recognising the importance of including people with disabilities into mainstream HIV and AIDS programmes.

The main reason why people with disabilities have been excluded from most HIV and AIDS programmes in the past, is because they have often been seen as human beings without a sexual life and therefore not potentially affected by HIV and AIDS. For example a 32 year old visually impaired man reported that he had been repeatedly refused condoms at a clinic, as the nurses said a blind man did not need condoms. This lack of understanding by service providers seems to be one of the main reasons why mainstream service providers did not direct information towards disabled people, or even thought of including them in their programme. A counsellor said that they are unable to test people who are blind or deaf, as they cannot sign the consent forms or communicate with the counsellors - no attempt was being made to adapt the services to meet the needs of the PWD, so that they could have access. Because of this belief people with disabilities have had limited access to training about AIDS and HIV, AIDS service organisations, prevention programmes, testing counselling and other treatment. In a survey of 246 PWD only 32 had received some training and none had received specific training taking into account their special needs. Contrary to this belief, PWD are often at greater risk to HIV. For example they are less able to negotiate safe sex, they are often the victims of rape, sexual abuse and incest and they are sometimes encouraged to produce children to care for them. They generally have less access to information and the information that is available is often not designed for their needs, for example, not in Braille or sign language.

There are no national figures available concerning the incidence and prevalence of HIV amongst the disabled populations in Namibia, but in 2002 the national census estimated that 85,000 Namibians live with a disability and 23.5% of the population is HIV positive. Assuming that the HIV rate is the same in the disabled and the able population this

would mean that approximately 10,000 disabled people are HIV positive. If, as one might suspect it is in fact higher as the qualitative evidence suggests, then this number would be greater.

It is therefore important for organisations working with PWD, to ensure that they have access to mainstream HIV and AIDS services. Our experience in Namibia has shown us that community programmes need to recognise the vulnerability of PWD and implement ways to overcome this through inclusion of PWD into programme planning, designing, implementing, developing materials and training programmes designed specifically to meet the needs of PWD, and also by introducing user friendly buildings and staff into HIV programmes.

In Namibia, VSO, RAISA and the NFPDN have worked together to ensure this happens through encouraging the membership of disabled people on the Multimedia Task Force, including organisations representing PWD in the Global Fund Proposal, involving Aid Service organisations in planning and training activities at the NFPDN and training of PWD in counseling, care and prevention. Most importantly by ensuring that HIV and AIDS is "mainstreamed" into the disability sector and disability is "mainstreamed" into the HIV and AIDS sector.

Firstly, this has been done in Namibia through a comprehensive survey of PWD throughout Namibia to access their:

- Level of knowledge about HIV and AIDS
- Perceived risk to HIV and AIDS
- What they felt they needed in regard to training, prevention, care and access to treatment

This survey was carried out with 264 PWD, between the ages of 16-40 years. 64% of them were women and 38% of them men. In terms of impairment groups, 53 had visual impairments, 78 hearing impairments, 5 intellectual impairments, 14 physical impairments. Four were Albinos and 10 were parents of disabled children. Concerning their education and employment, 42% of the sample had never been to school at all, 21 % had attended primary school only and 5% (mainly people who had

acquired their impairment later in life) had been to tertiary education. 93% had never been in paid employment and 3% were currently employed.

In this sample 56% were sexually active, 78% had had sex, 19% had never had sex. Less than 2% of those sexually active said they had used a condom. The study concluded that PWD in Namibia were sexually active, but there was a need for education and a preventative programme and a need to raise levels of awareness for both PWD and service providers.

Secondly, through a National conference called 'HIV and Disability', which brought together participants with disabilities, organisations representing them and Aid Service organisations. The purpose was to get a better understanding of what was currently happening in the country, identify the gaps and work to develop ways in which these can be addressed. The tangible outcomes from the conference were:

- HIV and AIDS programme officer employed by the NFPDN to coordinate programme
- PWD included as members on the National Task Force for HIV and AIDS
- Material are now being designed specifically for the needs of PWD
- PWD included in the 2003 World AIDS Day (WAD) campaign
- Training programme implemented for Health care providers and PWD
- Recognition by Aid Service organisations that PWD are a client group

Finally until PWD are recognised as people with sexual rights, until they are seen as a vulnerable group, until they are included in planning, designing, implementation and dissemination of information about HIV and AIDS they will remain marginalised and vulnerable.

# International Classification of Functioning, Disability and Health (ICF), and CBR

*Margie Schneider, Sally Hartley*

## SUMMARY

*This chapter describes how the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) can provide a general framework for understanding and 'unpacking' the different aspects that make up the phenomenon of disability. In this respect it can be a useful tool in implementing Community Based Rehabilitation (CBR) programmes. The framework is guided by the definition of disability as being the outcome of an interaction between a person's health condition and the context in which the person lives. This outcome can be described at three levels - body, person and societal. The ICF can be used in assessing individuals, their communities and environment to determine the factors that are creating the disability and provide structure for appropriate interventions.*

*The initial section provides a brief review of the main CBR concepts relevant for the discussion on using the ICF. This is followed by a more detailed description of the ICF and the main features that should be clearly understood in applying the framework to CBR implementation. The final section provides a series of examples of how to use the ICF concepts and framework in CBR implementation and concluding remarks.*

## WHAT IS CBR AND WHAT ASPECTS ARE IMPORTANT FOR USING THE ICF?

The International Labour Organisation (ILO), United Nations Education, Scientific and Cultural Organisation (UNESCO) and the World Health Organisation (WHO) produced their second Joint Position Paper in 2004 entitled "CBR A Strategy for Rehabilitation, Equalisation of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities". In this document Community Based Rehabilitation (CBR) is defined as:

*"a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. CBR is implemented 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" (ILO, UNESCO, WHO, 2004, p 2).*

The International Disability and Development Consortium (IDDC) also set out what they consider to be the core components of CBR (IDDC website accessed October 2005). These include being community based, using rehabilitation techniques that would aim to improve an individual's ability to do various activities (e.g. increasing muscle strength, treating psychiatric conditions, etc.), considering cultural compatibility and utilising local resources. Millward et al (2005) cite the 1995 revision of the Uganda constitution and say that in order for them to realise their full mental and

physical potential, disabled people must have access to both individually as well as environmentally focused intervention strategies.

These reviews highlight the need to consider the whole person, their family and friends, as well as the immediate and broad physical, social and policy/legislative environment. An important aim of (and measure of outcome for) CBR programmes is the social inclusion and integration of disabled people in all spheres of life. In order to plan and implement CBR programmes as well as monitor and evaluate their effectiveness, we need a way to assess or measure the relevant factors and determine the extent and direction of change of these overtime.

Thus, CBR programmes must include both individual, as well as environmental and social aspects in planning and implementation. The disabled person requires medical care and rehabilitation to ensure that they are able to undertake activities as independently as possible. At the same time social and environmental interventions are needed to ensure that a maximum level of independence<sup>1</sup> can be achieved and maintained.

This description of CBR fits in well with current definitions of disability and reflects the complex and multidimensional nature of this phenomenon. It is now widely accepted that disability is not merely the problem of an individual nor a static phenomenon. The experience of disability and the associated disadvantage is an outcome of an interaction between a person's health condition and the context in which that person lives. If the individual condition or the context change, the outcome will also change. So, in order to understand an individual's experience of disability and ensure that interventions are targeted appropriately, we need to

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Independence in the context of disability is not limited to the notion of being able to do an activity oneself, but also includes the notion of having a choice in deciding when one does something. For example, a person with quadraplegia might never be able to do activities of self care and mobility without assistance, but they can be independent in deciding when they want to do these activities. This implies that the disabled individual has access to personal assistance when they want it and not as decided by the assistant.

understand and describe both the health condition and the context, as well as the outcomes. In line with the above, the ICF defines disability as being the outcome of the interaction between a person's health condition and the context in which the person lives.

#### **Important factors to consider include:**

- The assessment of the individuals' health conditions and impairments to understand their health care and specific impairment needs (e.g. need for glasses, a wheelchair, personal assistance) as well as the prognosis for the health condition
- The impact of impairment on the individuals' ability to carry out daily activities
- The impact of different forms of personal or technological assistance on performance levels
- The availability of these different forms of assistance
- The impact of broader environmental factors on the individual and the family. For example, attitudes of others, accessibility of the environment, availability and accessibility of services, regional and national policies
- The individual and their family's general well-being and quality of life

Effective CBR programmes need to be able to assess these factors if accurate interventions and programme evaluations are to be undertaken. The ICF provides a framework for structuring and undertaking the assessment of the context and outcomes of the interaction.

#### **WHAT IS ICF?**

The ICF does not necessarily present anything new in our understanding of disability, but rather it provides a framework to organise the information in a way that allows us to analyse and understand disability more effectively.

## PRINCIPLES OF THE ICF

The ICF has three important principles:

- **universal application**, which highlights that all people experience disability at some point, not only a minority group of people traditionally referred to as disabled
- **an integrative approach**, that acknowledges the impact of both individual features, as well as social factors as important to consider in the understanding of disability; this is called the bio-psychosocial approach to describing functioning and disability
- **an interactive approach**, that recognises the complex and multi dimensional phenomenon that is disability. There is no single, or simple way of describing disability. The complexity must be understood and described, and the ICF is a tool that provides a descriptive framework to do this

The principle of universalism highlights the importance of understanding disability as a continuum. We all fall at some point on this continuum, which has full functioning at one end and full disability at the other.

ICF works with a concept of disability that arises from a health condition.<sup>2</sup> A health condition can be acute, chronic, progressive or intermittent, and may need ongoing medical intervention (e.g. being HIV positive), or may not need medical intervention (being blind from birth). This health condition interacts with the person's context. As elements of this interaction change, so the outcome will change. This means that disability is not a static feature of an individual but rather a complex, multidimensional and changing experience for the individual. It is determined only in part by the inherent features of that individual (i.e. health condition and personal factors).

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<sup>2</sup> It does not look at disadvantage arising, for example, from poverty.

## SOME ILLUSTRATIVE EXAMPLES

A child with cerebral palsy from a poor family may not be able to access the necessary rehabilitation and educational services that he or she needs. This results in the child having an educational and developmental disadvantage. A child with a similar health condition living in a well resourced community, would have a very different experience as he or she would be able to access the necessary rehabilitation and educational services and experience less disadvantage than the first child

A wheelchair user faced with an inaccessible physical environment will experience severe disability, whereas the same person in a fully accessible environment will experience little disability

**The ICF** comprises 4 classifications:

1. Body Functions
2. Body Structures
3. Activity and Participation
4. Environmental Factors

Further details on each of these classifications can be found at the ICF website [www.who.int/classification/icf](http://www.who.int/classification/icf). The ICF provides a rating scale for describing the extent of the difficulty a person has in any particular domain. This is a 5 point scale and ranges from "no difficulty", through to "unable to do". For example, a person who has quite a lot of difficulty walking would rate themselves, or be rated by someone else, as having a moderate difficulty with walking. The exact definition of what is a mild vs a moderate or moderate vs severe difficulty, remains somewhat vague and requiring further work. Existing assessments can be used to do assessments and the scores "translated" into ICF domains with different scores, providing the definitions for each of the ratings on the ICF domains.

The last classification, i.e. the classification of environmental factors (but not of the personal ones), describes the different elements of the

external environment that interact with a person's health condition and are of importance to functioning and disability. The other three classifications provide a detailed description of the outcome of the interaction between the health condition and the context of the person. These three classifications in fact, describe all the domains of human functioning. The sister classification, the International Classification of Diseases (ICD) provides the means to describe the health condition that gives rise to disability. The health condition is not classified in the ICF.

### **OUTCOMES AT BODY, PERSON AND SOCIETAL LEVELS**

The outcome of the interaction between the person's health condition and the context in which they live, will be at one of more levels of human functioning. These levels are the body level (e.g. individual body parts, organs or body systems), the whole person (e.g. in doing various activities such as walking, communicating, learning), and/or the person within society level or societal level<sup>3</sup> (e.g. whether person does walk, communicate or learn in their individual and usual environment).

#### **Body level functioning : body functions and structures and related impairments**

Impairments of body function or body structure describe difficulties a person experiences at the body level and are largely features of the individual, and are not generally determined by the external environment. There are exceptions such as night blindness which only manifests in an environment where there is little light. Impairments are very closely linked to the health condition and are the manifestations of the health condition in the form of symptoms. For example, in mental illness, the underlying condition is usually diagnosed on the basis of the symptoms that are

<sup>3</sup> The societal level refers to the fabric that makes up societal structures, but does not mean that it is functioning with other people necessarily. For example, a person participating in activities of self care would not necessarily do them with others.

impairments of mental functions, such as lack of emotional control, psychotic thought patterns, and so on. Impairments of body structures include aspects such as a loss of a limb, or deformity of a body structure. Many people have one or more impairments that are mild or moderate in severity, but that do not necessarily cause the person to have difficulty in overall functioning, such as:

- a person with a mild or moderate vision problem and who does not do much reading or sewing
- a person with mild hypertension or asthma
- a person who is HIV positive but who does to have any symptoms of illness
- a person with a finger missing and who manages to compensate using the remaining fingers

The environmental factors of significance with impairments of body function and structure, are those of access to health care. The importance of describing a person's impairments (and associated health condition) is to ensure adequate provision of relevant health care. At a community level, the most prevalent health conditions and impairment should be documented to allow for accurate planning of health services. While this might not be the primary focus of a CBR programme, the need to collect this information remains important.

Because of the close link between the health condition and impairments of body function or structure, the two terms are often used interchangeably.

#### **Person level functioning: activity and related activity limitations**

The activities a person needs and wants to execute in their daily lives are undertaken in a purposive manner and involve a coming together of a range of body level functions and structures. The level of complexity is higher than for functioning at the body level. However, the person

level functioning is still a feature of the individual. It describes what the person can do given an environment with no personal or technical assistance available. For example:

someone with a moderate hearing loss would not be able to hear soft warning sounds (e.g. footsteps approaching) without a hearing aid

or a person with a lower limb amputation would not be able to walk without assistance from a person or a prosthesis

This information is important as an indication of activities that the person is able to do, or those she or he has difficulty doing (activity limitations). Interventions can then be focused appropriately. If a person has difficulty in doing an activity, the intervention can either teach the person to improve their capacity to do that activity, or find ways of compensating for that difficulty. If the person has no or little difficulty but in fact does not do the activity (assuming they want and/or need to do it), then an individual focus of intervention will not change that person's overall functioning. The intervention must then rather focus on the barriers that are hindering the person from doing the required activity.

An example would be a child with cerebral palsy who can communicate, but with some slurring of the sounds. If this child is discouraged from communicating because people do not have the patience to listen to him carefully, he will not engage in the activity of communication. The child has the capacity to communicate, but is being prevented from communicating because of environmental barriers, i.e. people's impatience. At the person level we are only concerned with what the child's capacity is. Rehabilitation interventions at the person level would aim to improve the child's ability to produce clear and fluent speech.

### **Societal level functioning: participation and participation restrictions**

While the person level of functioning is a feature of the individual, the societal level of functioning is determined by the impact of different

barriers and facilitators in their environment e.g., at work, school, home, local shops, etc. This can happen in a number of different ways.

A person has the capacity to do an activity, but they in fact do not participate in doing that activity because of some barriers in their environment

### **An example**

The negative attitudes of employers when they refuse to employ a person because of their disability, are barriers to a person working.

A person in a wheelchair might have no difficulties in maintaining a job and completing the required tasks. If they are not given the necessary assistive devices and support, they will not work. The focus of intervention in this case is clearly environmental, i.e. to change the attitudes of potential employers.

A person has difficulty in doing an activity (e.g. walking, communicating, following a conversation in a noisy environment, learning) but they do in fact, participate in that activity in their usual environment. This case suggests that the person has a number of facilitators in their environment that assist them in compensating for, or managing the difficulty

### **An example**

Facilitators are typically technological devices such as a walker or walking stick, an augmentative communication device, a hearing aid, or personal assistance and support.

If a person has difficulty in communicating and is provided with a communication board, their ability to be involved in communication will increase because of this facilitator. The focus of intervention in this scenario would be both the individual (e.g. to teach communication strategies), as well as the environment (providing a communication board).

A person has difficulty in doing an activity and does not participate in doing that activity in their usual environment. This suggests that either the person does not have the necessary facilitators in the environment, or, there are no facilitators available

### **An example**

A person has a severe intellectual impairment and lives alone with his mother who cannot go to work, as she must look after her son. The environmental barriers include lack of services to support his mother and provide her with care for her son and the possibility of finding work. A further barrier might be lack of any stimulation for the son to allow him to reach the best level of functioning he can.

The focus of intervention would again be both the individual and the environment.

It is only by understanding both what the person's capacity is for doing the different activities as well as what happens in their usual or current environment, that a holistic picture of a person's functioning can be obtained. The ICF provides a framework for doing this.

The classification of Activities and Participation is a single one with each domain being assessed and described in terms of the person's capacity to do an activity (activity level) and their performance of that activity, in their usual or current environment (participation level).

### **GENERAL POINTS ABOUT THE ICF**

The above description of the ICF provides an introduction to the ICF framework. Once that framework is understood, further details on using the ICF can be obtained relatively easily from the books or the website ([www.who.int/classification/icf](http://www.who.int/classification/icf)). However, there are a number of important points that should be noted about the ICF.

### **Neutral Language**

The ICF uses neutral language in the naming and definition of every domain included in the classification. For example, the term 'walking' is

defined as, "Moving along a surface on foot, step-by-step, so that one foot is always on the ground, such as when strolling, sauntering, walking forwards, backwards, or sideways". This allows the classification to be used to describe both what a person can do, as well as what the person has difficulty doing.

### **A Classification and not an Assessment Tool**

The ICF is not an assessment tool as such, but rather a classification that can be used to develop assessment tools. Some such tools have been developed and include a checklist and the WHO Disability Assessment Schedules which can be found on the ICF website.

## **ICF Codes and Qualifiers**

Every domain and sub-domain in the ICF has a specific code. These codes are a summary way of recording the domains described. So, for example, instead of recording "moderate difficult in walking but severe difficulty walking in usual environment", one can use the code for walking plus the qualifiers for activity and participation giving M450.32'. Detailed explanations of how to use the codes are available on the website.

While the codes are useful in many contexts, they are not essential to an effective use of the ICF. As stated above, they serve as a summary for the written code and as such do not add any meaning to the ICF.

### **USING ICF IN CBR**

The ICF can be used for a range of different purposes within a CBR programme. These are listed below and further described and reviewed within the context of three case examples of disabled individuals.

### **Purposes for using the ICF**

- planning individual intervention programmes
- looking at whole community issues



monitoring and evaluation of CBR generally  
 motivating policies that promote inclusion of disabled people

**Example 1:** Siphon is an intellectually disabled child

Siphon is an intellectually disabled child with a single mother. His health condition is related to brain damage at birth, that has resulted in the intellectual impairment. The cause of this health problem would be useful to determine, as it can have relevance for improving, for example, antenatal and obstetric services. Siphon's overall functioning at the three ICF levels should be assessed together with an assessment of the environmental factors.

Siphon's intellectual impairments can be described using the classification of body functions with mental functions being the main chapter of relevance. An assessment will look at aspects such as paying attention, perceptual functions, memory, language functions, and so on and can be done using existing assessment instruments and/or an ICF based checklist. The results will provide Siphon's profile in relation to the impairments at body level.

The next level of assessment will determine the difficulties Siphon has in relation to, for example, learning, communicating and socialising and will provide a profile of his activity limitations as well as his abilities. This is the person level.

The third level would assess Siphon's participation or involvement in various activities such as learning, communicating and socialising. This is the societal level and would assess what happens when Siphon is in his usual environment at home and other places where he might go.

The last assessment would entail a detailed review of the different environmental factors that have an impact on Siphon's functioning. This assessment would look at his physical environment, the family structure and support provided to Siphon and his mother, the services and financial support available for his mother.

It would also be important to understand the expectations, aspirations and satisfaction of Siphon's mother concerning his life, as well as hers. This is not part of the ICF, but is an important complement to it.

The results of these assessments would provide a clear indication of where the intervention needs to focus. If Siphon's environment is supportive, there are enough financial resources, services are available and the mother feels that she has access to assistance when required, then the main focus of the intervention would be on building Siphon's abilities. However, if the environmental factors are creating barriers for Siphon and his mother, (e.g. lack of services, social exclusion of the mother and child, lack of stimulation for the child, poverty), the focus will be on changing these environmental factors, together with individual work with the child.

**Relating this to the different purposes**

**Individual intervention:** The individual intervention for Siphon would include both a focus on developing his abilities as well as providing an environment that is supportive to him and his mother, providing the necessary services, as well as financial and other support.

**Community level issues:** the cause of the health condition and the different environmental factors within the community, provide an indication of what interventions can be implemented to prevent certain health conditions from occurring, as well as ensuring that, if they do occur, the necessary services and support structures are available for both Siphon and his mother. The environmental assessment of Siphon and his mother's situation will provide a good understanding of what can be changed in the community and would benefit children in the future.

**Monitoring and evaluation of CBR programme:** The full assessment of Siphon's experience of disability, using an ICF framework, will provide clear information on what impact the CBR programme is having. This impact can only be measured or

determined if an initial assessment is undertaken and follow up assessments are done during the course of the intervention programme for the child. The impact would be determined for both the individual child and his mother as well as changes within the overall community. It is important that both the person (activity) and societal levels (participation) are assessed in determining the outcome of the CBR intervention to understand the different impact of individual and environmental interventions.

**Motivating for inclusive policy development:** the information gathered for Siphso can be put together with information from other children, with similar experiences to provide the necessary evidence for the need for services (e.g. respite care for the care givers, access to educational facilities, better antenatal and obstetric services), or changes in eligibility criteria for access to support, such as social welfare services or free health care. This evidence is strengthened when presented in a holistic manner that clearly demonstrates the effects of the health condition and the environmental factors, on the overall functioning of Siphso and his mother.

**Example 2:** Maria is an adult with a spinal cord injury

Maria sustained a spinal cord injury after a taxi accident while travelling from her place of work to her home. She lost her job as a cashier at a local supermarket and lives with her teenage children, in a small house on the outskirts of a town.

The assessment of Maria's functioning and overall experience of disability will provide information on her impairments (most likely involving the neuromusculo skeletal domains of body function), her activity limitations (most likely to be in the domain of mobility), and her participation in her home and other environments (most likely involving mobility again, as well as others, such as work and socialising). Lastly, the assessment would provide a detailed assessment of the barriers and facilitators in her environment. These would include aspects such as her use of assistive devices and personal attendants, access to rehabilitation after the

accident, the physical accessibility of her home, local shops, and other areas that she goes to, the availability of financial support in the form of employment or social security grants, and generally the attitudes of others in her environment.

The results of her assessment will be mapped onto the ICF framework and the intervention priorities determined according to what the profile highlights. If Maria had and continues to have, access to rehabilitation services and assistive devices services, but lacks the necessary financial support, then the focus will be on ensuring that she has access to some form of support to assist her in meeting hers and her children's needs. This might require an intervention that goes beyond Maria, to one of changing attitudes of employers, making skills development and self employment opportunities available for disabled people, or other such interventions.

Once more, the main benefit of the ICF here, is to provide a clear organisation of the relevant information into a framework that helps clarify what the intervention priority is. In addition, the domains of socialising and taking part in recreation activities, for example, might not be domains covered in a standard assessment for a person with a spinal cord injury. However, using the ICF as a checklist would ensure that these would be assessed in relation to what the person can do (person level activity) and what happens in their usual environment (societal level participation). The difference between these two assessments will provide the information on whether the intervention should prioritise the individual or the environment.

### Relating this to the different purposes

**Individual intervention:** the assessment at the different levels provides a clear set of priorities for intervention for Maria. The individual intervention for Maria would focus on ensuring that she has the necessary rehabilitation and assistive devices, but then focus more on the environmental barriers to ensure that these are minimised.

**Community level issues:** the incidence of spinal cord injury in Maria's community will be information useful for developing prevention measures. This information should be presented together with a full picture of the impact of having a spinal cord injury on a person's overall functioning, within that particular environment. The assessment of Maria's community environment will provide information on what needs to be changed, to accommodate not only Maria's needs but also those of other people with difficulties, in moving around.

**Monitoring and evaluation of CBR programme:** The ICF framework will provide clear information on what impact the CBR programme is having. This impact can only be measured if an initial assessment is undertaken and follow up assessments are done during the course of the intervention programme for Maria, as well as within the community.

**Motivating for inclusive policy development:** the information gathered for Maria can be added to information from other similar experiences of disability, to motivate for policies that create inclusive employment practices, ensure the implementation of building regulations for accessibility, develop a transport system that is accessible and cost effective, and so on. The presentation of this information within the ICF framework, makes the picture holistic and provides decision makers with a good understanding of the impact of health conditions and the environment, on people's functioning and experiences of disability. **Example 3:** Ahmed is a young adult with stage 4 AIDS

There is some controversy about whether people who are living with AIDS are in fact disabled or not, with some people including people living with AIDS as being disabled, while others being very against including them as disabled. While the ICF does not concern itself with political issues, it does, however, provide a clear theoretical perspective on the issue. Using the definition of a health condition interacting with the context in which the person lives, we can clearly show that HIV/

AIDS is the health condition and the outcome can then be described using the ICF levels of functioning. In this sense Ahmed is disabled.

The impairments that a person living with AIDS presents, will be varied and differ from person-to-person. Ahmed may well have significant weakness generally in his muscles and this would translate into difficulty with doing a range of activities such as self care, mobility, working and so on. Depending on his access to personal assistance and to medical treatment, his ability to participate in doing many activities will be limited.

The environmental factors of note when considering HIV/AIDS, are access to medical care services (e.g. treatment for opportunistic infections, treatment with antiretroviral medication), and social welfare services (e.g. food parcels, home-based care). Stigma leading to social isolation is also an important barrier.

### Relating this to the different purposes

**Individual intervention:** the assessment at the different levels of functioning for Ahmed, provides a clear set of priorities for intervention. The individual intervention for Ahmed would focus on ensuring that he has the necessary medical care and social welfare support, or support from family and friends, as well as ensuring that stigmatising attitudes do not isolate and exclude him from his family, friend and broader community. The focus, would be both Ahmed individually as well as addressing the external environmental factors.

**Community level issues:** the prevalence of HIV/AIDS in Ahmed's community will determine the nature of the intervention in relation to HIV/AIDS; whether the focus should be on prevention and education, reduction of stigma, increasing access to relevant medical care, or all three. The description of functioning at all levels of people living with AIDS in Ahmed's community, will provide a good picture of the social, economic and other impacts of the illness on the person holistically.

**Monitoring and evaluation of CBR programme:** The full assessment of Ahmed's experience of disability, using an ICF

framework will provide clear information on what impact the CBR programme is having. This impact can only be measured or determined, if an initial assessment is undertaken and follow-up assessments are done during the course of the intervention programme for Ahmed and other people living with AIDS, within the community.

**Motivating for inclusive policy development:** the information gathered for Ahmed can be added to information from other similar experiences of people living with AIDS, to motivate for policies that ensure good access to medical care and home-based care services. The presentation of this information within the ICF framework makes the picture holistic and provides decision makers with a good understanding of the impact of health conditions and the environment on people's functioning and experiences of living with AIDS.

## CONCLUSION

ICF can provide an organised, comprehensive and holistic description of a person's functioning at three levels, as well as describing the environmental factors that play a significant role in determining a person's experience beyond the individual's characteristics.

The ICF does not bring new information to our understanding of disability, but does bring a clear and simple framework for us to gain a clearer understanding of disability. It encourages us to assess the different components, yet retain a holistic picture. This holistic picture is one of the major benefits of using the ICF in CBR.

The 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.

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# CBR Research as Part of Community Development

*Harry Finkenflügel, Servious Dube, Alister Munthali, Mitchell Loeb*

## SUMMARY

*Over the past 25 years, many developing countries have initiated CBR projects. Articles on CBR have been published in international journals indicating that CBR has become an accepted approach in supporting people with disabilities, in their own community. Exploration of these articles indicates that the research base for this assumption remains weak. In this chapter, studies on CBR published between 1978 and 2002, are reviewed to assess the evidence base for CBR. It is shown that although there are an increasing number of publications on CBR, the research they describe concentrates mainly on theory and less on the evaluation of interventions. Organisations involved in setting up CBR programmes are in a unique position to combine the implementation of projects with systematic documentation of efforts and outcomes. This is illustrated by the work of the Leonard Cheshire Foundation in Southern Africa, where they integrate community-intervention-based research within the projects. This approach is perceived to be promising and powerful. Other approaches based on utilising the theory of disablement also have potential for future research in CBR. An example given is related to utilising the ICF classifications*

*for structuring disability surveys. The chapter concludes by suggesting that CBR research is vital for the development and accountability, of "CBR as part of community development".*

## INTRODUCTION

In CBR, people work together in an inter-dependent way and rely on each other to achieve programme and individual objectives. Within this framework, they have distinct roles and so their individual objectives will differ. Objectives might be directly related to the needs of people with disabilities, to other stakeholders, or to more general community development issues. As such, "empowerment" does not only apply to people with disabilities but to all people involved. It is important to recognise people's own interest in CBR to avoid disappointments and to fully appreciate their input. Their particular interest can be used to build the competence of other stakeholders in the CBR process and to enhance the decision-making capacities of these stakeholders. Every stakeholder has a say, "a stake", in the process and should be allowed to exert influence and gain a feeling of ownership. CBR is about people, not just people with disabilities, but people living together in a community with a desire to develop their community. CBR is most of all, a learning experience. People learn by getting involved in a project and by taking note of other people's experiences through, for example, workshops, conferences, project documents or articles. Articles in national and international journals have a specific function for the development of CBR. Not only do these attract attention to the concept of CBR, they create a knowledge and evidence base for CBR and thus contribute to the efficacy, transparency and accountability of the concept.

The academic community, in direct cooperation with disabled people and service providers, have much to contribute to the CBR debate. Accurate descriptions of successful and unsuccessful CBR activities, critical analysis of the contributing factors, discussions about CBR in relation to Primary Health Care, community development, poverty and the millennium development goals can serve to influence policy makers, governments and NGOs. It provides information that helps to decide on

the most effective way of setting up a support system for people with disabilities, within community development.

## STATE OF THE ART OF CBR

Following its debut in 1976 (WHO, 1976), the CBR concept gained momentum with many CBR programmes being implemented in developing countries after 1984. At the same time, an intense discourse developed on the underlying concept of CBR. In this discourse people agreed on the need to develop support services for people with disabilities, but held different views on the involvement of lay people and (semi) professionals, the roles of governments and (inter)national NGOs, the need for institutions and referral centres and the feasibility of an adequate support service at community level. In the 1990s a period of consensus emerged, marked by the production of the "joint position paper" of the UN organisations (ILO, UNESCO, and WHO, 1994). Surprisingly, this consensus did not lead immediately to improved information sharing. In 1991, Thorburn wrote, *"A major problem in the study and evaluation of CBR is that there is no forum for publication of information and experience, so it is very difficult to find relevant reports"*. Documentation on CBR (e.g. project proposals, evaluation reports, annual reports, brochures, books, articles) have gradually become available in the past ten to fifteen years. The database 'Source' - gives over 1000 references when searching for "community-based rehabilitation" (see Chapter 10 for more information). Nevertheless, at the turn of the century, researchers commented negatively on the number and quality of studies on CBR. Lagerkvist (1998) remarked, *"CBR is gaining increasing interest but very few studies have been published"*, and Mitchell (1999b) added, *"Little quality research on CBR has been placed in the mainstream of scientific literature"*. Wirz and 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."*

<sup>1</sup> Healthlink: <http://www.asksource.info/>

In taking these comments seriously, questions arise regarding how many and what type of studies have been actually published, and what is the knowledge and evidence base for CBR after 25 years of experience with the concept?

## WE DO NOT KNOW WHAT IS KNOWN

Scientific journals have published articles on CBR and at the same time multifarious "grey" literature such as programme reports, newsletters, conference proceedings etc. have become available. However, according to Miles (2003) *"no serious, critical appraisal had yet been made of even a quarter of this material"*. It would appear that we do not know what information is available, what the quality and usability of that information is and which aspects have been well covered or which should be a priority for further research.

As a first step in this process, a study looking at stakeholders' influences in CBR, examined articles in international scientific journals in order to assess the knowledge and evidence base for planning, implementation and evaluation of CBR, after 25 years of experience with the concept (Finkenflugel, Wolfers, and Huisman, 2005). For this literature review electronic databases (PubMed<sup>2</sup>, PsycINFO<sup>3</sup>, Source<sup>4</sup>, CIRRIE<sup>5</sup>, Rehabdata<sup>6</sup>) and bibliographies<sup>7</sup> were searched on (combinations of) the key words: "CBR", "disability", "rehabilitation", and "community". The search was limited to the time period 1978 - 2002 and only articles in English were included. Additionally, three more inclusion criteria were applied. First, only articles with "Community based rehabilitation" or "CBR" in the title, key words, abstract, introduction, or discussion were included. Secondly, CBR was described in the context of developing countries. Developing countries are defined here according to criteria

<sup>2</sup> PubMed: <http://www.ncbi.nlm.nih.gov/PubMed/>

<sup>3</sup> PsychInfo: <http://www.apa.org/psycinfo/>

<sup>4</sup> SOURCE: <http://www.asksource.info/databases.html>

<sup>5</sup> CIRRIE: <http://cinie.buffalo.edu/>

<sup>6</sup> REHABDATA: <http://www.naric.com/search/rhab/>

<sup>7</sup> Miles: <http://cirrie.buffalo.edu/bibliography/SAfricatoc.html>

set by the World Bank (undated) and thus, only countries in the so-called lower and middle-income range were included in this review. Thirdly, to ensure a certain scientific standard and quality, only articles in journals that were either indexed by Index Medicus (IM)<sup>8</sup> or the Social Sciences Citation Index (SCI)<sup>9</sup>, or listed in PubMed<sup>10</sup> were included. Editorials, letters to the editors, and descriptions of more private experiences were excluded. This resulted in 128 articles that met all the inclusion criteria.

The number of articles published per year, is still increasing. The average over the last five years, is now eight articles per year. It was possible to specifically connect 100 articles to a little over 35 different developing countries". Sub-Saharan Africa, South Asia, and East Asia and Pacific are best presented in 34,27 and 22 articles, respectively. Figure 1 shows the distribution of articles on CBR in the different regions.

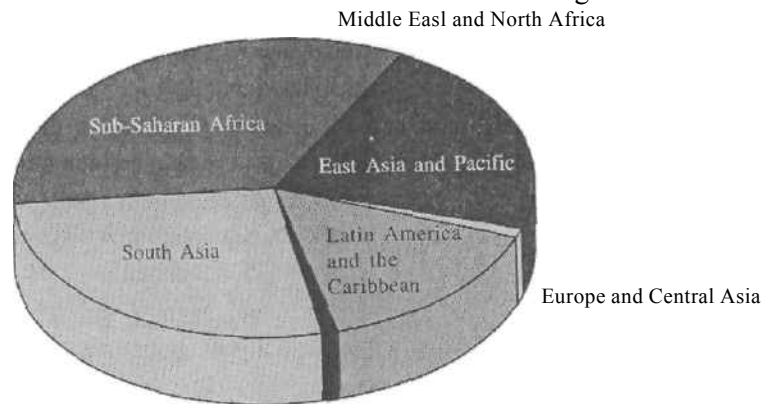


Figure 1. Distribution of articles per region N=102 (100 articles, two articles were counted in two regions)

Index Medicus: <ftp://nlmpubs.nlm.nih.gov/online/journals/ljiweb.pdf>

Social Sciences Citation Index: <http://www.isinet.com/isi/products/citation/ssci/>

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=PubMed>

Palestine is not on the World Bank lists but for this thesis it has been made part of this review.

Looking more specifically at countries, it is noted that Jamaica (12) and India (10) are most frequently listed, followed by three countries in the Sub Saharan African region: South Africa, Botswana, and Zimbabwe (with 9, 9, and 8 articles).

Although 128 articles might seem an adequate number, it is hard to judge if the CBR concept is well covered or underexposed in scientific journals. More important than the actual number, is the extent to which these articles provide us with a consistent knowledge and evidence base for CBR. Therefore, the articles were analysed according to the methodology they used and the key aspects they covered.

### TYPE OF ARTICLES

Scientific journals only publish a selection of the articles that are offered to them. The criteria for acceptance are different for every journal but in general, the work has to be original, of interest to the readers and based on a sound methodology. All articles are peer-reviewed to facilitate the highest possible quality. Generally, five types of articles can be distinguished (Helewa and Walker, 2000):

- **Intervention studies:** Reports on the effect of an intervention for a specific group (e.g. a training programme or therapeutic strategy)
- **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)
- **Case reports:** Articles describing a particular CBR project, an approach to a specific problem, or other aspects of a CBR project
- **Review studies:** Articles based on earlier published work, which give an overview of knowledge in a specific area
- **Theory papers:** Articles that aim to provide a theoretical base for CBR. It includes ethnographic and phenomenological work as well as discussion papers and articles, presenting general information on CBR

The appreciation of evidence is directly related to the methodology used in the study. Studies using control groups or measuring at different points of time, provide the best evidence for the effectiveness of the intervention. Descriptive studies, theory papers (i.e. ethnographic studies) and case reports, also contribute to the evidence base of CBR, but their impact is rated lower.

Figure 2 presents the distribution of the type of the articles. It can be seen that the most common type of articles on CBR are "theory papers" (55 articles). This is followed by "descriptive studies" (40 articles), with only (10) "intervention studies." Over the years, "descriptive studies" increased considerably. However, no "intervention studies" have been published recently.

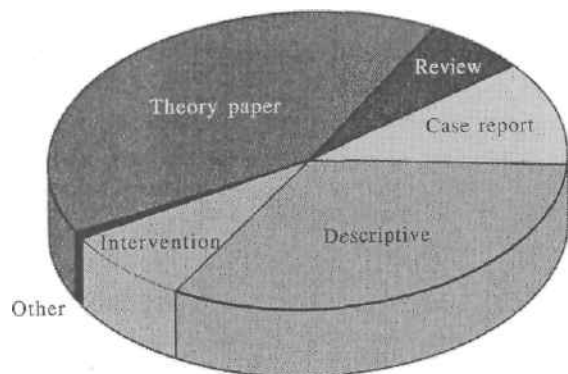


Figure 2. Types of articles published (n=128)

Intervention studies provide the best level of evidence but it is shown here, that this type of study is relatively rare within CBR. And even some of those that have been included here have problems applying rigorous scientific criteria when collecting data. For example, studies using a "before-after design" often define the "before" situation retrospectively and sometimes have serious problems reaching the original group of respondents. Another problem is that the instruments used, such as questionnaires and interviews, are seldom tested for reliability

and validity. An example of a solid intervention study is the one carried out by O'Toole (1988). He used N=1 designs for the 53 children included in the study. Also studies using control groups or alternative interventions (such as Finkenflugel et al., 1996; Mitchell, Zhou, Lu and Watts, 1993; Powell, Mercer and Harte, 2002) are considered to be of good quality.

Descriptive studies can be divided into prevalence studies and studies describing a situation, or change of a situation. A fifth of the descriptive studies under review were prevalence studies investigating the number of people with disabilities and their needs within the project area. Unfortunately, the instruments used and the classification of people identified differed widely, making comparisons problematic. Most studies used self-developed questionnaires and classification was done by medical condition as well as by types of impairment and disability according to the ICIDH (WHO, 1980). Only some sought to establish reliability and internal validity of the instruments used (Beach, Boyce, Peat and Malakar, 1995; Pal and Chaudhury, 1998; Thorburn, Desai and Davidson, 1992; Thorburn, Desai, Paul et al., 1992). A common way to test the external validity of a house-to-house survey, is a two-staged design where the outcomes of the initial survey are checked by professionals like medical doctors, psychologists, therapists (Finkenflugel, 1991; Mitchell, Zhuo and Watts, 1989; Rao, Venkatesan and Vepuri, 1993; Zaman et al., 1990). However, these studies are generally incomplete, as only people identified as "disabled" in the first stage are involved in the second stage, which denies the opportunity to check for "false negatives".

In descriptive studies researchers conscientiously describe characteristics of the research population, the programme and the context. Often, these observations are guided by hypotheses, in which one variable is assumed to correlate with another variable. In this way, they aim to get insight into, for example, different types of rehabilitation (Evans, Zinkin, Harpham and Chaudury, 2001), utilisation of services (Lopez, Lewis and Boldy, 1991), urban and rural populations (Hosain and Chatterjee, 1998; Khan, Ferdous, Munir, Huq and McConachie, 1998), the parents' view on CBR (Thorburn, 1992), the follow-up of clients in CBR (Rottier, Broer, Vermeer



and Finkenfliigel, 1993), neighbourhood support (Bischoff, Thorburn and Reitmaier, 1996), and the repayment of loans (Gershon and Srinivasan, 1992).

Case reports first give an overall picture of the country with a brief analysis of the perceived needs of people with disabilities and secondly, provide a description and discussion of the implementation process. Of the five articles describing the implementation of CBR projects, four relate to Asia and one to Jamaica. Another six articles focus on the role of different stakeholders in CBR. Case reports can be very helpful for learning about a project, but the information is very project-specific and cannot be generalised to other projects, or be used to establish the evidence base of CBR. More rigorous use of case reports can be made through the use of common indicators making comparisons possible between projects and contributing to establishing, "best practices" without making the mistake of presenting a blueprint and ignoring the specific situation in which the project developed.

In review papers, authors give an overview on a specific topic. The most generalised review available, only covers the first decade of CBR (Chermak, 1990). In this review, CBR is described as one of the initiatives to address social integration of people with disabilities in developing and developed countries. Other review papers dealt with more specific issues. Hartley (1998) and Wirz and Lichtig (1998) reviewed literature on services for people with "communication disorders", Mitchell (1999b) discussed the "research base" of CBR (see also next paragraph), Wirz and Thomas (2002) reviewed evaluation studies on CBR with the aim to determine indicators to measure the effectiveness of CBR, and Turmusani et al. (2002) looked for support of their argument, that disability should be included in the development discourse.

CBR has attracted a lot of discussion and this is reflected in the number of "theory papers" available. Most of these articles are related to specific aspects of a CBR project such as methods to set up screening programmes, the development of services, the implementation of projects and the stakeholders involved. Some articles discuss the fundamental

concept of CBR, including the implications of having a disability, the attitudes towards people with disabilities, and indigenous ways of handling and training people with disabilities. Unfortunately, only a few authors have combined ethnographic studies with a vision of how CBR can build on existing perceptions and knowledge. Studies on the implications of having a disability remain popular, although the attention has shifted from more ethnological studies, to consumer and human rights approaches.

### KEY ISSUES COVERED

A further analysis of the articles relates to the key aspects covered. The 8 key aspects selected were based on the "research priorities" defined by the WHO (1988) and the review carried out by Mitchell (1999b). They were:

- **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, curriculum development
- **Evaluation:** Follow up studies, project evaluation, comparing different types of rehabilitation

This classification revealed (Figure 3) that most articles were about stakeholders (33) and implementation (32), knowledge (19), evaluation (17), and screening (16) are also fairly covered. However, the 'key

aspects' participation (5) and local resources (2) have hardly attracted the attention of researchers. This is remarkable as both issues are part of the definition of CBR.

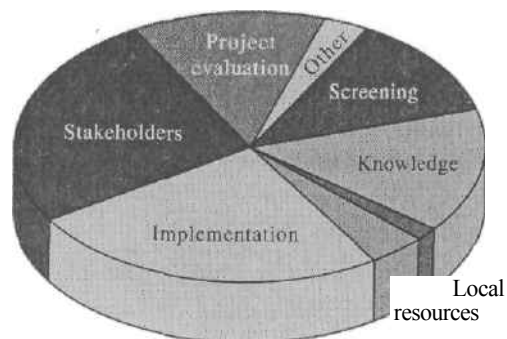


Figure 3. Key aspects of CBR covered in the articles (n=128)

Hereafter, the key issues will be discussed briefly. As project leaders and policy makers have a definite interest in establishing the need for support services, it is not surprising that we found ten prevalence studies in our data set. However, there were also six articles concerned with the methods like house-to-house screening versus Key Informants and instruments like Ten Questions Questionnaire (Thorburn, 1991, 1993; Thorburn, Desai and Davidson, 1992; Thorburn, Desai, Paul et al., 1992; Thorburn, Paul and Malcolm, 1993; Zaman et al, 1990).

Understanding existing knowledge and ideas about the disabling condition and possible functional improvements, should be seen a precondition for setting up appropriate and acceptable services. Local beliefs and customs regarding people with disabilities are studied in four articles (Ingstad, 1990, 1999; Kassah, 1998; Whyte and Ingstad, 1998) whereas Miles, with eight articles, focused on local knowledge of handling disability and disseminating appropriate information (1987, 1989, 1990b, 1990c, 1993; 1996, 1997, 1998). The five descriptive studies covered a wide variety of interests, ranging from parental adjustment (Pal and Chaudhury, 1998), attitudes of Community Rehabilitation Workers towards people with disabilities (Paterson, Boyce and Jamieson, 1999), traditional ways of

handling children (Werrij, Voeten, Adriaanse and Thorburn, 2000), the needs of families with children with mental retardation (Brodin and Molosiwa, 2000), and the training needs of relatives and Community Workers (McConkey and Mphole, 2000). Only one study actually reported on changes in the attitudes towards people with disabilities, after introducing a CBR project (Mitchell et al., 1993).

The use of "local resources" is generally seen as an important element for the sustainability of projects. To quote Pal et al. (1998) *"a successful control policy has to be affordable, sustainable, acceptable and effective"*. They compared the costs of identifying children with epilepsy using a house-to-house screening and using Key Informants and concluded that using Key Informants is, *"ultimately twice as cost effective"*. Jagannathan et al. (1993), assessed the costs of vocational training of leprosy patients by local craftsmen in the community. However, these are the only two articles explicitly dealing with the use of 'local resources'.

Only a few articles were available on 'participation'. This is indeed surprising since 'participation' is at the heart of the definition of CBR (ILO et al., 1994). In a descriptive study, Pal et al. (2002) reported on the social activities of children with epilepsy. The other four studies are 'theory papers' discussing issues such as educational services for children with disabilities (Cavanagh, 1994), a community development approach (Ferrinho, Robb, Cornielje and Rex, 1993), attitudinal obstacles in accessibility (Peat, 1997a), and constructing ideas of community (Lysack, 1997).

'Implementation' has been relatively well covered, but the studies and recommendations formulated for implementation of CBR projects were very diverse. More than half of the studies were theory papers discussing the supposed benefits and potential of CBR (Cardenal, 1981; Gregory, 1996; Hai, 1993; Johnston and Tjandrakusuma, 1982; Kibria, 1989; Marincek, 1988; Mitchell, 1999a; Peat, 1991; Thomas, 1992), different models that complemented and integrated the CBR approach (Serpell 1986; Miles 1990; Jelsma, Cortes- Meldrum et al. 1995; Miles 2002;

Miles 2002) or fundamental changes to the CBR concept, including changing the name CBR (S. Miles 1996; Momm and Konig, 1989). The five descriptive studies are more specific. Coetzee and Kemp (1982) studied the needs and rehabilitation potential of discharged schizophrenic patients. Utilisation of services was researched by Hosain and Chatterjee (1998) and McConachie et al. (2001) and they concluded that economic problems affected attendance. Boyce and Johnston (1998) discussed the collaboration between community-based rehabilitation agencies. Finally, on the basis of their study on the mortality of young children with cerebral palsy, Khan et al. (1998) suggested that PHC and feeding programmes be included in intervention programmes. "Case reports" appear to be a suitable method to describe the implementation processes of CBR. In general, the eight case reports included in this review, are positive about the implementation of CBR. However, Stuelz (1999) argued that it is easier to integrate people with disabilities through educational programmes than within a PHC system.

The discussion on key stakeholders in CBR focuses on: (1) people with disabilities, (2) families and family trainers, (3) the volunteers or Local Supervisors, (4) the Intermediate Local Supervisors or Rehabilitation Assistants, (5) the trainers, and (6) the specialists and project implementers (Finkenflugel, 1998, 2004; Peat, 1997b). To accommodate all of the studies, an extra category called "other stakeholders in the community" was added. This, for example, included the study about the neighbours of families with a child with a disability (Bischoff et al., 1996).

Although the people with disabilities are described as the primary beneficiaries of CBR, only three articles have been devoted to this stakeholder. Also, studies on the family and their perceived role in CBR were surprisingly limited. Different authors were shown to be concerned about the role of parents but only Thorburn (1992; 1999) discussed this topic explicitly. With ten and thirteen papers respectively, the main interest in discussing stakeholders was regarding the Local Supervisors and the Intermediate Local Supervisor.

Project evaluation was the main area of interest in seventeen articles. Five of these were intervention studies, describing the whole project

(Manga and McConkey, 1987; O'Toole, 1987), or specific issues within a project (Finkenflugel et al., 1996; Lagerkvist, 1992; Lundgren-Lindquist and Nordholm, 1996). Also some attention has been paid to the development of instruments to compare different types of services (Beach et al., 1995; Evans et al., 2001). Lopez et al. (1991) compared the actual services with the planned services and concluded that CBR, indeed represented a low cost intervention system. Similar conclusions were drawn by three other studies: Menon (1984) stated that CBR through PHC is feasible and acceptable, Sharma and Deepak (2001) concluded that the CBR project evaluated, had been successful on three of the five key components of CBR, and Gershon and Srinivasan (1992) illustrated that leprosy patients involved in CBR were better in repaying loans. A dissonant finding was presented by Rottier et al. (1993). In their study about client follow-up, they found that, after initial identification, rehabilitation workers did not see half of the clients again. Consequently, for these clients the training had not even begun. The only review paper on "project evaluation" was from Wirz and Thomas (2002). Their concern was that too few studies on the evaluation of CBR have been published and those that exist, describe practices rather than their effectiveness.

### **THE EVIDENCE-BASE FOR CBR**

In conclusion, the concerns expressed by Lagerkvist (1998), Mitchell (1999), Wirz and Thomas (2002), and Miles (2003), and discussed in the introduction of this chapter, seem, at a general level, to be addressed by researchers and practitioners interested in CBR. A steady increase in articles about CBR has been seen and these articles cover a wide range of aspects in many developing countries. However, the quality and output from these articles often required attention and these showed little coherency: key aspects were insufficiently covered, for example participation and use of local resources. Theory papers and descriptive studies predominated and were not followed by intervention studies researching assumed relations and mechanisms. The evidence base for CBR, despite 25 years of experience with the concept, is still weak and fragmented. The nature and effectiveness of CBR cannot be sufficiently

established from examining this data set. There is a need for more high quality published research, before a meta-analysis can be conducted to draw together the evidence, into a coherent interpretation of the present situation concerning the development of CBR programmes.

The first challenge, is to continue to review already published articles and documents and make these available to researchers, project implementers, policy makers etc. Two types of reviews are potentially interesting. The first, is reviewing a specific aspect relevant to CBR. For example, in studying the involvement of volunteers, not only articles on CBR should be included but also articles on different development programmes (e.g. HIV/AIDS programmes, education for all). The second type of review includes chapters in books and 'grey literature' (newsletters, project reports, conference proceedings, annual reports, etc.). This "grey literature" has a limited circulation and is seldom critically assessed. When its merits are judged consciously, this type of literature can be used in creating a more comprehensive view on specific aspects of CBR, or in describing CBR in a specific country.

The second challenge, is to introduce research methodologies into CBR projects. Every CBR project collects data on the stakeholders involved, resources used, progress made etc. Many projects have developed a "Monitoring and Evaluation" system and collect information in a systematic way. However, up to now, very few projects have been able to make this information understandable and accessible to people outside the project. In the second part of this chapter, an example is given on how systematic data collection can be part of the project and can be used to judge the effectiveness of the interventions, and possibly make a contribution to the evidence base of CBR.

The third challenge, is to take the theoretical concepts reported in the CBR related literature and evaluate them in empirical research structures. An example of this is described later in this chapter, where the concepts in the ICF (WHO 2001), are utilised for the identification of disabled people. The ICF structures relate much more closely to the holistic nature of CBR, than to the impairment categories of the medical model which

have previously been the used as a basis for collecting and reporting survey data on disability.

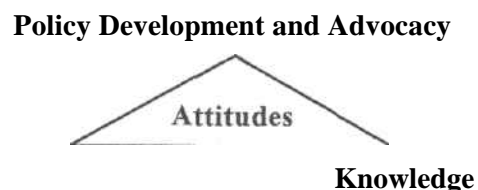
### **RESEARCH AS PART OF CBR PROJECTS**

A digital search using Google and the search terms "community-based disability and rehabilitation research in Africa", revealed over 36,000 references. This illustrates that much more information is available, than the 34 peer reviewed articles on CBR reported in the first part of this chapter.. The scientific work on CBR is therefore, only the tip of the iceberg, the majority of information being generated by service providers. This information is rich, but often not systematically reported, so difficult to replicate and limited generalisation capacity. Of course, the information is vital for the development of individual projects but is too seldom used to develop and substantiate knowledge base of CBR itself. To establish what kind of interventions are effective in CBR, we need to collect systematically, the information used to set up, monitor and evaluate CBR projects.

### **CBR RESEARCH AS PART OF COMMUNITY DEVELOPMENT**

To illustrate how research in CBR can enhance the capacity, build a knowledge base, inform practice and influence the development of policy and advocacy, an example from Leonard Cheshire International (LCI) in the Southern African region is explored. The first LCI services in the Southern Africa region were established in South Africa, in 1965. There are now 46 Leonard Cheshire (LC) services in the Southern African region. LCI have established a highly skilled and experienced regional support team. The team is there to support Leonard Cheshire services and other partners to develop strategies, build their capacity and influence national government to formulate policies directed to meet the needs of people with disabilities.

The LCI Training and Development Programme developed a conceptual framework, the "Three Pillars Approach" (figure 4), as a tool for programming.

**Figure 4: The Practice Pillars Approach (TPA)**

The three distinguishable elements are:

**Practice:**

- Skills training programmes for disabled youths in the region
- Providing start-up kits for skills trained graduates and job placements
- Local communities sensitised on disability issues

**Knowledge:**

- A model for economic empowerment to be replicated
- Training materials developed and shared
- Interest and opportunities for further research

**Policy and advocacy:**

- Successful implementation turned into influence
- Linkages with Ministry of Education (Vocational Training Unit), community development, public and private financial institutions and money market
- Model guidelines for donors to use in funding similar projects

This concept integrates programme experience with the accumulated knowledge from reviews and community-based research, to enrich practice. This approach was conceived as a tool, which takes one through the process of designing and implementing programmes. The pillars are the building blocks of the programmes, that transform into research designs, implementation, dissemination and feedback (learning process). For example, action research uses programme activity interventions as opportunities and sources for collecting data, which is then analysed to produce evidence-based practice guidelines.

In LCI programmes, quality of care and rehabilitation interventions are usually implemented in residential or community settings. The service providers use a planning and assessment technique termed, "individual service planning" (ISP) approach, which involves parents or carers and multi-disciplinary service providers. The team includes social workers, physiotherapists, occupational therapists, doctors, nurses, carers, teachers, psychologists. They work together to draw short and long-term plans for disabled children and youths. The ISP assessment tool is incorporated into the design and provides the structure for the prospective data collection process, where a project information data bank is maintained. It keeps raw data that can be analysed retrospectively for various purposes such as, in developing guidelines of good practice, training materials, evaluation processes, theories and hypothesis, evidence for practice. In this manner, knowledge is used in informing and/or sharpening practice and for advocacy and policy development. The ultimate goal of this conceptual framework is to facilitate changes towards mainstreaming disability into all development work. The TPA is viewed and adopted as a guiding principle for planning, implementation, monitoring and evaluation processes of the programme activities. This framework is still into its infancy stage, the programme staff and stakeholders are keen to see this framework evaluated to determine its practical usage in the region.

**SUGGESTED RESEARCH THEMES**

Looking at the key elements of CBR and the work of LCI in the region the following research themes can be suggested:

**Quality of care and rehabilitation:**

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*Evidence and research is required to look into long-term benefits of the programmes that aim to improve the quality of care and life of disabled children.*

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**Inclusive education:**

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*A good intervention research project should be able to document the factors militating for inclusion and give easy and low cost solutions to make inclusion effective for all children.*

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**Economic empowerment:**

*LCI Training and Development programme in the Southern Africa region has made economic empowerment a priority area for the current implementation period, but has no easy solution to implementing micro-financing models appropriate for disabled people.*

Valid research into CBR is more likely to be achieved if the academic institutions and service providers work together during project design, implementation, monitoring and evaluation stages. Such an approach has the following strengths and benefits:

- a. Validity in terms of asking the relevant research questions
- b. Validity in terms of having the research skills and available time to carry out the research programme with rigour
- c. Long-term partnerships between independent partners through regional and national programmes
- d. Facilitation of access to resources for the target groups
- e. Supporting each other with technical assistance, training and specialised expertise
- f. Sharing of information and communications
- g. Global network of services and organisations (disability, development, mainstream)

Service provider organisations have an important role to play in the process of collecting evidence, to support the service strategies that they are promoting. Rigorous practices of monitoring and evaluation, together with documentation and dissemination of that information to interested parties, can go a long way towards closing the research gap in CBR. This process can also contribute towards clarification of the CBR concept and the nature of its various manifestations throughout Africa.

**RESEARCH BASED ON THEORY GENERATED BY THE LITERATURE**

The theoretical concepts which underpin The International Classification of Functioning, Disability and Health (ICF) (WHO 2001) have been well

reported in the literature. The ICF is a tool which conceptualises disability in a new way, one which encapsulates the dynamic nature of the phenomenon of disablement, but at the same time, identifies its different dimensions: physical impairments, activities limitations and participation restrictions, within a specific socio-environmental context. In this respect, the ICF has chosen to approach disability by focussing on how people live with their health condition, rather than merely classifying or grouping individuals according to their physical, mental or psychological impairment. Many of the articles mentioned in the review earlier in this chapter, have contributed to the formulation of these new classifications. As such, the classifications can be seen as a product of theorisation. These classifications have been used in the research process, to generate a new way of looking at disability, a new way of seeking information in a survey and a new way of introducing an intervention.

The ICF theory of what constitutes disablement, has been used in a project in Southern Africa to develop new ways of classifying the functional status of individuals and place disability as a part of a wider concept of health. The project has undertaken to examine Living Conditions among People with Disabilities in Namibia, Zimbabwe, Malawi and Zambia. It has used the ICF in national household surveys and focused on how people function and what they need, to live to their full potential. In this way the ICF has helped to change the way people think about "disability".

**The project is in several phases:**

- Phase 1 (1999-2000): design development and pilot studies in Namibia and Zimbabwe
- Phase 2 (2001-2003): national surveys conducted in Namibia and Zimbabwe and included capacity building activities of DPOs and relevant professionals and ministries
- Phase 3 (2003-2004): national living conditions survey conducted in Malawi, addressing how disabled people can improve their degree of activity and levels of participation and including capacity building activities (At this stage the survey intersects with the CBR approach)
- Phase 4 (2005-current) national living conditions survey in Zambia

Each national survey has been accompanied by a series of capacity building workshops targeting DPOs, relevant professionals and representatives from the ministries. The aim of these workshops has been to increase the participants' understanding of disability, how this affects living conditions and what can be done to maximise existing opportunities.

The approach used to screen for disability was agreed upon at a workshop in Kampala in 2001, organised by the UN Statistical Division which focussed on issues of measuring disability prevalence and relied on an understanding of disability, as encountering difficulties in doing day-to-day activities and/or restrictions in social participation. The screening questions used reflect an understanding of disability in accordance with the ICF.

**Screening question 1:** *Does anyone in this household ever have any difficulty in doing day to day activities because of a physical, mental or emotional (or other health) condition which has lasted, or is expected to last for six months or more?* (Response categories: yes, no).

**Screening question 2:** *Does anyone in this household need assistance in participating in any of the following activities? (walking, seeing, speaking, hearing, breathing, mental coping, learning/comprehending)* (Response categories: yes, no).

In order to operationalise the ICF in a large survey, we developed a matrix of 44 specific activities of daily living in 9 categories covering sensory experiences, basic learning and applying knowledge, communication, mobility, self care, domestic life, interpersonal behaviours, major life areas and community, and social and civic life. This matrix was intended to capture as many of the constructs as possible, in a simple and non-time consuming manner. The matrix attempts to capture activity limitations and participation restrictions through two questions:

1. How difficult is it for you to perform this activity without any kind of assistance at all? (That is, without the use of any assistive devices - either technical or personal).
2. Do you experience any problem(s) in performing this activity in your current environment? (*Current environment* refers to the surroundings in which one lives, works, plays etc. for the majority of their time).

For each of the 44 activities under these 9 domains, the degree to which an individual is capable of carrying out that activity without assistance (activity limitations) is recorded on a scale from (0) no difficulty, to (4) unable to carry out the activity. In the same manner the person's performance in their current environment (participation restrictions) is also recorded on a scale from (0) no problem, to (4) unable to perform the activity. By adding up an individual's responses to each of the 44 items, a single activity limitation score and a single participation restriction score is developed.

In addition to mapping an individual's degree of activity limitations and participation restrictions and determinants of a person's environment are sought through the categorising of facilitators and/or barriers that they may come up against, with respect to those activity limitations/participation restrictions they experience.

#### **A few simple examples to clarify:**

1. A young boy lost the use of his legs in an automobile accident 25 years ago. He has used a wheelchair since being discharged from the hospital. Today, he is an active member of society, working and supporting a family. Since his independence is facilitated by the wheelchair, his scores on certain elements in the matrix will be high: he cannot move about easily without assistance. At the same time, this person has become accustomed to life in a wheelchair, and in his current environment, he is able to get around with little hindrance - he will score lower on the scale of participation restrictions.

2. Consider two individuals, 20 years old, both of whom are blind. One was born without the benefit of sight and the other became blind 6 months ago, as a result of a work-related accident. Both have identical impairments and their activity limitations will, for the most part, be the same - but the person who was born blind has had the benefit of 20 years to become accustomed to living with that condition - and in fact, has never experienced living with sight. That person may be able to carry out all or most of his/her activities of daily living with little or no problem. The person who has been experiencing blindness for only six months may be quite helpless in his/her current environment.

We find that if disability is measured according to some pre-defined societal norm (based on impairments), then we neglect to take into account the individual's own experiences (interacting with their social and physical environment) with respect to their particular disability. Measurements should, rather be based on an individual's experience and capability in their environment.

This paradigm shift has been supported through the research results from the study conducted by SINTEF (Loeb and Eide, 2004, 2006). From the data analysis perspective, the research challenge, we believe, lies in a shift in the dependent variable from a dichotomous outcome measure (disabled, not disabled) to a continuous measure of activity limitation/participation restriction - mirroring the range of disability we see in society. The figures that follow present such scenarios.

A relatively small sub-sample of those in our sample were identified as NOT having a disability (405 individuals). They were asked to complete the activities and participation matrix. Their responses are illustrated in the two following figures.

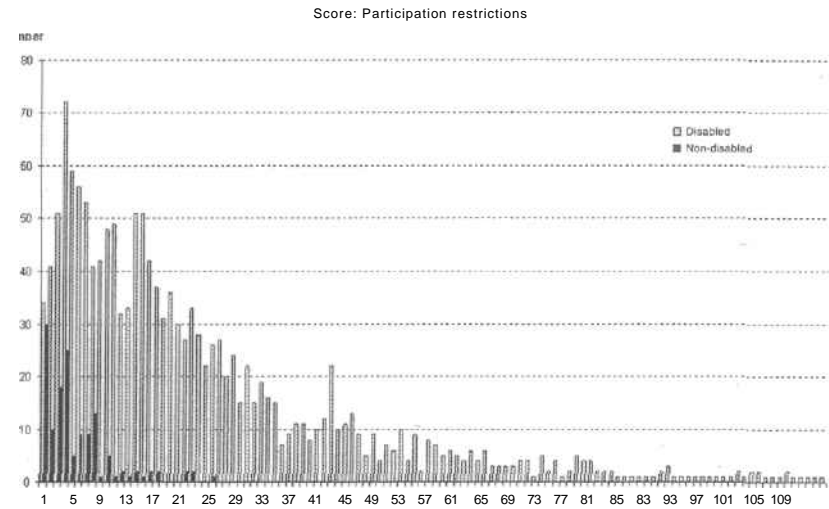


Figure 5. Participation restrictions among people with and without disabilities

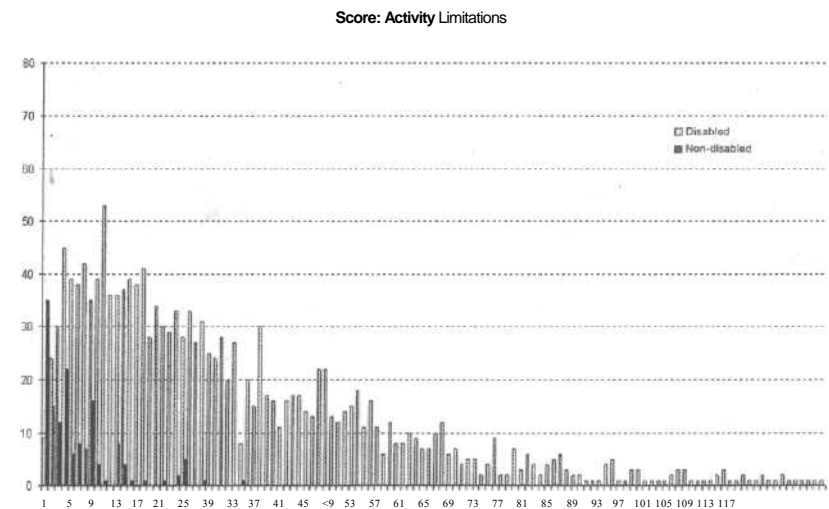


Figure 6. Activity limitations among people with and without disabilities



These figures clearly indicate that there is an overlap; that is, even people **without** disabilities live with certain limitations in their daily life activities and restrictions in their ability to participate in all levels of social interaction, and some people with disabilities are able to function in society with little or no problem. While only 10 (0.6%) of those with disabilities scored 0 on the activity limitation score as compared to 63% of those without disabilities, it is important to stress that some of those people identified with disabilities, are functioning well in society. Using the same reasoning, we found that 37% of those individuals who were identified as not having a disability, experienced at least a little problem in their capability to perform certain daily life activities.

Also, the range of scores on both activity limitations and participation restrictions, reflects the diversity of disability in society - and clearly indicates that being disabled is not a singular, two-dimensional phenomenon, but rather, a complex process that deserves to be understood as part of the human condition and not as something that represents a deviation from the norm.

Finally, these measures of activity limitations and participation restrictions must be interpreted as relevant to the environment, society and culture from which they are derived. This will require an expanded view of disability data and effect substantially greater measurement challenges. We have in this research, attempted to meet these challenges through the development of a matrix, based on the concepts inherent in the ICF and have thus taken a step in the direction of a new paradigm, defining a new concept. Disability research can no longer afford to be restricted to counting impairments, handicaps or even people with disabilities - but, using a better definition to identify a population based on activity limitations and participation restrictions and ensure that they are enfranchised.

## OVERALL CONCLUSION

Good research practice in any domain requires the active participation of all the key players and nowhere could this be more important than in establishing the nature of disability, the effectiveness of CBR and how it

relates to community development. More research needs to be conducted and the evidence made available in the public domain, so that good practice can prevail. Without such work, CBR development will be slow and many programmes will continue to function in ways that others have already discarded.

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## CHAPTER 10

# Information Sharing and Community-based Rehabilitation

*Stefan Lorenzkowski*

### SUMMARY

*Information technologies offer opportunities for improving community-based projects and programmes. Through the use of computers and access to the internet, information and experience can be located and exchanged more easily. However, the amount of information available on the internet grows every day and it becomes more and more difficult to identify what is relevant. Resource centres can help organisations or individuals in this process. This chapter explores how these new information technologies have developed and how they can help CBR workers become more informed. A list of useful web sites is presented at the end of the chapter.*

### INRODUCTION

Since the 1980s, community-based rehabilitation has been implemented in many countries in Africa, Asia and Latin-America. Despite the common name it developed in various forms appropriate for the local and regional conditions, probably due in part, to difficulties in communication between the communities concerned. Until some years ago the exchange of information and experiences between organisations in different continents was mainly limited to meetings, articles in journals and slow letters. Publications took a long time to reach people who were interested in them.

During the last two decades new ways of publicising, presenting and communicating, have developed through Information and Communication Technologies (ICT) such as the Internet, affordable computers and CD-ROMs.

ICT have changed the ways of exchanging and obtaining information over the last decade. Personal computers have become more powerful and affordable to individuals and organisations. Floppy disks and CD-ROMs have enabled larger amounts of information to be circulated and shared with people all over the world, making it possible to print documents or watch films.

In particular, the increasing popularity of the Internet in the mid-1990s, improved accessibility of information and ease of communication - including the flow and exchange of experiences, knowledge and publications - between organisations and individuals in different countries. Even in countries with limited and very slow internet connections, it is now possible to go online in an internet cafe, library or resource centre.

These possibilities have enabled organisations to exchange information resources and experiences more easily. Publications in electronic form are easier to distribute and share. Forms and formats of communication have also changed over the last few years. It is now possible to join a mailing list, an online forum or just to browse through recent websites to get access to important and up-to-date information. Online discussion forums such as the DGroups ([www.dgroups.org](http://www.dgroups.org)) and online encyclopaedias such as Wikipedia ([www.wikipedia.org](http://www.wikipedia.org)) now attract users worldwide.

The national and international disability movements have made use of these new opportunities. Many DPOs and disability NGOs have started to publish materials and to spread news about their activities on the Internet (e.g. [www.disabilityworld.org](http://www.disabilityworld.org)). The Internet has become a platform for lively discussion and information exchange.

However, despite the many possibilities that the Internet offers, many people are still excluded or have limited access. This may be for logistical

reasons, economic or social factors, discrimination or just the unfamiliarity with the use of computers. Even with full access to the Internet, it can be difficult to find particular information. Lack of accessibility is largely a problem for organisations in developing countries. As the UNDP Sustainable Development Programme states on its website:

*"[...] recent statistics indicate that, contrary to many expectations, the information gap between industrialised countries and developing countries is growing. Moreover, within many developing countries, the gap between 'haves' and 'have nots' is increasing at an even faster pace. Recent estimates indicate that the global number of Internet users is about 180 million, of which only 14% are in developing countries. In the African continent alone, there are around 1.3 million users; of these almost a million are in South Africa. In other words, the average number of users is 6,000 people per country - once we exclude South Africa. Some analysts have described this process of uneven development of the Internet as the emergence of the Fourth World in the global economy. "*  
(Source: [www.sdnf.undp.org/about/](http://www.sdnf.undp.org/about/))

The sharing of information, knowledge and experience is necessary for sustainable empowerment and support of people and organisations in middle and low income countries, so their community work in the areas of civil society, rehabilitation and disability can further be improved. A good example has been the mailing list of the Disability Knowledge and Research round tables which were accompanied by a lively mailing list and online resource platform ([http://www.dgroups.org/groups/disability KaR/index.cfm?op=dsp\\_info](http://www.dgroups.org/groups/disability%20KaR/index.cfm?op=dsp_info)).

Information resource centres can play an important role in identifying and adapting information to the local context in which it is required. Resource centres often function as information access points, providing internet access and training facilities, as well as important resources, in different languages. International cooperation between different centres would enable an improved sharing of knowledge and experience in the field of community-based rehabilitation.

One online resource centre is Source ([www.asksource.info](http://www.asksource.info)) that identifies information resources in the field of disability. Beside a key topic area about disability in development, Source offers a number of commented bibliographies, so called *Key Lists*. Especially for developing countries with little access to ICT, access to the internet is a problem that only partly can be addressed through the continuation of paper based information or collections of information resources on CD-ROM.

One example of a resource centre in a developing country is the *Disability Information Resource Centre* in Uzbekistan ([www.dirn.uz](http://www.dirn.uz)). It is part of a network of information points in libraries and rehabilitation centres, which provide disability information resources. The network covers the eastern region of Uzbekistan. Besides the physical collection, the resource centre maintains a website that provides important documents in Russian and Uzbek.

Bearing in mind some of the difficulties of accessing information on the internet, one of the problems to a new user is knowing the address of useful sites. The following list is an attempt to address this problem and aims to provide the reader with a selection of addresses that have useful information about disability and community based initiatives, that provide useful and stimulating information and ideas to readers.



### **Community Based Rehabilitation (CBR) Resources**

Many resources related to CBR are presented on this site. The site is structured in sections: CBR websites, CBR related websites, CBR books, CBR academic programs, CBR NGOs (non-governmental organisations). The site is maintained by a PWD, who has graduate and post-graduate qualifications in rehabilitation and has worked in the disabilities field in the USA. <http://www.cbrresources.org>

### **Community Based Rehabilitation (CBR)**

STUBBS, Sue  
London: IDDC, [2002], 10 p.

This document contains personal reflections from the IDDC co-ordinator, Sue Stubbs on CBR. They are drawn from 10 years of experience working in the field of international disability and development.

[http://www.iddc.org.uk/dis\\_dev/strategies/cbr.pdf](http://www.iddc.org.uk/dis_dev/strategies/cbr.pdf)

### **Empowered to Differ: Stakeholders' Influences in Community-based Rehabilitation**

FINKENFLUGEL, Harry

Rotterdam: Vrije Universiteit, 2004, 202 p.

'Empowered to differ' equally addresses researchers and CBR professionals. The book gives an overview about the developments in the field of community-based rehabilitation since 1978, using the examples of CBR projects in Southern Africa. Finkenflugel asks for the knowledge and the evidence for CBR and to what extent the roles, interests and powers of stakeholders can contribute to this knowledge and evidence.

ISBN:9077595112

<http://cbrresources.org/Empowered%20to%20Differ.pdf>

### **CBR : a Strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities - Joint Position Paper 2004**

WORLD HEALTH ORGANIZATION (WHO); International Labour Office (ILO); United Nations Educational, Scientific and Cultural Organization (UNESCO) et al Geneva: World Health Organisation (WHO), 2004, 31 p.

In 1994, the ILO, WHO and UNESCO published the first version of this joint position paper. Since then progress has been made in several fields. Nevertheless many disabled people are still not reached or included in the fields of rehabilitation, employment or education. Especially disabled women, people with mental health problems or HIV/AIDS and poor disabled people are not reached. This paper underlines that community-based rehabilitation is a strategy promoting multi-sectoral collaboration to reach different community groups. CBR has to be based on the

principles of equal opportunities, participation and human rights.

ISBN: 92 4 159238 9

<http://unesdoc.unesco.org/images/0013/001377/137716e.pdf> World Health Organization (WHO) Marketing and Dissemination, CH-1211 Geneva 27, Switzerland

### **Disability Coming on the Front-line in Development**

KONKKOLA, Kalle

Essen: Behinderung und Entwicklungszusammenarbeit e.V, 2003, 10 p. This article summarises the changes in development work over the last ten years. It describes the work of UN agencies, the different banks and Nordic NGOs as well as overall aspects of disability in development.

Netzwerk Menschen mit Behinderung in der Einen Welt

<http://www.bezev.de/literatur/docs/>

[DISABILITY%20COMING%20ON%20THE%20FRONT-LINE%20IN%20DEVELOPMENT.PDF](http://www.bezev.de/literatur/docs/DISABILITY%20COMING%20ON%20THE%20FRONT-LINE%20IN%20DEVELOPMENT.PDF)

### **A Manual for CBR Planners**

THOMAS, Maya; THOMAS, M J Eds

Manual for CBR Planners Bangalore: Asia Pacific Disability Rehabilitation Journal Group, 2003, 88 p.

This manual has 13 sections. A very useful overview of the history of CBR is given, with valuable introductory reading for newcomers to the field. The following 5 sections cover needs assessment and suggestions of how to understand local communities and encourage community participation in CBR programmes. The final 6 sections are concerned with programme management issues, for example organising self-help groups, training personnel for CBR, and the sustainability of projects including evaluation and management of change <http://www.aifo.it/languages/english/apdrj/Manual%20for%20cbr%20planners.pdf>

## **POVERTY AND DISABILITY**

### **Poverty and Disability**

DURHAM, Michael

London: Healthlink Worldwide, 2003, 4 p.

This is a summary of the report "Perspectives on Disability, Poverty and Technology"<sup>1</sup> written by Albert, B; McBride, R and Seddon, D. This summary defines disability and impairment, and emphasises the social model of disability. It demonstrates the links between poverty, disability and impairment, and advocates for the mainstreaming of disability into all development projects.

<http://www.disabilitykar.net/pdfs/odg-summarv.pdf>

### **Chronic Poverty Report 2004-05**

CHRONIC POVERTY RESEARCH CENTRE (CPRC)

Manchester: CPRC, 2004, 140 p.

This major report presents an overview of the chronic poverty facing some 400 million people, and the policy implications. The report examines what chronic poverty is and why it matters, who the chronically poor are, where they live, what causes poverty to be persistent and what should be done about it. A section of regional perspectives looks at the experience of chronic poverty in sub-Saharan Africa, South Asia, Latin America and the Caribbean, transitional countries and China. A statistical appendix brings together data on global trends on chronic poverty [http://www.chronicpovertv.org/chronic\\_povertv\\_report\\_2004.htm](http://www.chronicpovertv.org/chronic_povertv_report_2004.htm)

### **Disability, Poverty and Development**

DEPARTMENT FOR INTERNATIONAL DEVELOPMENT (DFID)

Issues London: DFID, 2000, 17 p.

This is a major policy document of DFID, the British Government's overseas aid department. It assesses the significance of disability as a key development issue, and its importance in relation to poverty, human rights and the achievement of internationally agreed development targets. It also sets out ways in which development cooperation, including DFID's own work, can help incorporate the rights and needs of disabled people into the mainstream of poverty reduction work and the achievement of



human rights. It is useful for disability policy-makers, NGOs and disabled people working in advocacy and development

ISBN: 1 86192 252 3 <http://www.dfid.gov-uk/pubs/files/disability.pdf>

### **Measuring Welfare for Small but Vulnerable Groups : Poverty and Disability in Uganda**

HOOGEVEEN, Johannes G

Washington: World Bank, 2004, 30 p.

When vulnerable groups such as disabled people are surveyed, representative welfare estimates from non-purposive sample surveys becomes an issue. This paper takes the example of Uganda and describes the connections between disability, poverty, well-being and social welfare. This is possibly the first time that, for a developing country, statistically representative information on income poverty amongst disabled people has been generated.

[http://www-wds.worldbank.org/servlet/WDSContentServer/WDSP/IB/2004/10/14/000090341\\_20041014091219/Rendered/PDF/301680SP004190.pdf](http://www-wds.worldbank.org/servlet/WDSContentServer/WDSP/IB/2004/10/14/000090341_20041014091219/Rendered/PDF/301680SP004190.pdf)

### **Poverty and Disability : a Survey of the Literature**

ELWAN, Ann

Geneva: World Bank, 1999, 51 p.

This review summarises the literature on disability and its relationship to poverty, including education, employment, income, and access to basic social services. Despite the dearth of formal analysis, it is clear that in developing countries, as in more developed areas, disabled people (and their families) are more likely than the rest of the population, to live in poverty. It is a two-way relationship — disability adds to the risk of poverty, and conditions of poverty increase the risk of disability. Disability in developing countries stems largely from preventable impairments associated with communicable, maternal and perinatal disease and injuries, and prevention has to remain a primary focus. An increasing

emphasis on community-based participatory rehabilitation, reflects growing recognition of the inadequacy of past official programmes, particularly involving specialised and exclusionary institutions.

[http://www-wds.worldbank.org/servlet/WDS\\_IBank\\_Servlet?pcont=details&eid=000094946\\_0011210532099](http://www-wds.worldbank.org/servlet/WDS_IBank_Servlet?pcont=details&eid=000094946_0011210532099)

## **RESEARCH**

### **Label us Able: Proactive Evaluation of Finnish Development Co-operation in Disability Issues**

NATIONAL RESEARCH AND DEVELOPMENT CENTRE FOR WELFARE AND HEALTH (STAKES)

Evaluation report 2003:3 Helsinki: Ministry for Foreign Affairs of Finland, 2003, 100 p.

The Finnish Ministry for Foreign Affairs evaluates with this report its development policies for disabled people. This report looks at the last ten years of Finnish development co-operation and how a maximum impact on human rights and social development can be achieved. The four parts of the report investigate the main Finnish policies, the major findings and how disability can be mainstreamed into development issues. This evaluation report is valuable for international NGOs, disabled people's organisations and policy advisors who are looking for ways to mainstream disability. <http://global.finland.fi/evaluations/labelable/>

### **Data and Statistics on Disability in Developing Countries**

Arne H. Eide, Mitch E. Loeb Norwich:

Disability KAR, 2005, 28p.

Current disability statistics is far from robust or comparable globally and is particularly weak in low-income countries. There is a strong need for design development and standardisation of measures to be applied in both censuses and representative surveys. Important work in this regard is underway through the work by the Washington City Group and the DPO initiated research in Southern Africa. It is argued that it is important

to go beyond the issue of prevalence, and to produce statistics that can compare and analyse differences in standards of living between disabled and non-disabled persons. The disability - living conditions - poverty link should be the number one priority for broadening disability statistics (in low-income countries) from the current focus largely on prevalence. This publication explores the needs for data that can give a thorough picture of the situation for disabled people, possibilities for comparing between groups (including disabled and non-disabled people), documenting and analysing mechanisms explaining the close link between disability and poverty.  
[http://www.disabilitykar.net/docs/thematic\\_stats.doc](http://www.disabilitykar.net/docs/thematic_stats.doc)

## INFORMATION SHARING

### **ICT and Development: Enabling the Information Society**

GUISLAIN, Pierre Ed

Washington DC: World Bank, 2003, 84 p.

Prepared for WSIS, this compilation addresses how ICT contributes to economic and social development and how public policy plays a critical role in reducing the digital divide. It emphasises policies related to information and communication infrastructure, including telecommunications and the Internet. It suggests, that bridging the digital divide requires first and foremost, the adoption and implementation by national governments and regulators of pro-competitive policies and regulations that remove existing bottlenecks to sector growth and access.  
<http://wbln0018.worldbank.org/ict/projects.nsf/WebPages/3F67A7E75AF851D585256DEF007706DD'OpenDocument#ictDev>  
[http://info.worldbank.org/ict/WSIS/docs/comp\\_Complete.pdf](http://info.worldbank.org/ict/WSIS/docs/comp_Complete.pdf)

### **Disabled People and the Internet: Experiences, Barriers and Opportunities**

PILLING, Doria; BARRET, Paul; FLOYD, Mike London: Joseph Rowntree Foundation, 2004, 96 p.

This report explores how provision of goods and services over the Internet

affects people's lives. While the Internet might have some capability to provide goods, services and communication at a distance, improving access in doing so, some research findings in the early days of e-commerce suggested diminished access for some groups. This research focuses on the impact of the Internet on people with disabilities. There is the possibility that provision of information and services through the Internet might actually narrow rather than widen choices, because it might lead to the phasing out of traditional ways of providing services preferred by some disabled people. ISBN: 1 85935 185 9 web  
<http://www.jrf.org.uk/bookshop/eBooks/1859351867.pdf>

## EDUCATION

### **Enabling Education Network (EENET)**

Excellent site focusing on inclusive education. This site is regularly updated with publications from the South. Includes a bibliography of resources, a newsletter and information on child-to-child, parents, policy, teacher education, early childhood and communication disability. It also has some publications in documents in Arabic and other languages.  
<http://www.eenet.org.uk>

### **A Blind Child in my Classroom : a Handbook for Primary Teachers Summary**

GALE, Gillian; Cronin, Peter

RVIB Burwood Educational Series Burwood: Royal Victorian Institute for the Blind, 2004, 8 p.

This book gives ideas what can be done in a simple and effective way to include a child with vision disabilities in a class

<http://www.rvib.org.au/publications/pubs/A%20blind%20child%20in%20m y%20classroom%20Summary%2011-04.pdf>

## HEALTH

### **Double Burden : a Situation Analysis of HIV/AIDS and Young People with Disabilities in Rwanda and Uganda**

YOUSAFZI, Aisha and EDWARDS, Karen

London : Save the Children UK, 2004, 76 p.

**Abstract:** This situation analysis gives an in-depth picture of how young people with disabilities in Rwanda and Uganda are affected by HIV/AIDS. Results from focus group and individual interviews conducted in each country, reveal that young people with disabilities are highly vulnerable to being infected by HIV/AIDS. The study also shows how they are less likely to be able to learn how to protect themselves because of communication difficulties, discrimination by health service workers and educators, and difficulties accessing health centres. The situations of Uganda and Rwanda are analysed separately and compared - giving a thorough insight into the extent of the problem. Recommendations on policy, programming and research are given.

[http://www.savethechildren.org.uk/temp/scuk/cache/cmsattach/1600\\_DoubleBurden.pdf](http://www.savethechildren.org.uk/temp/scuk/cache/cmsattach/1600_DoubleBurden.pdf)

### **Rethinking Care from the Perspective of Disabled People : Conference Report and Recommendations**

(Rethinking care from the perspective of disabled people, Oslo, Norway, 22 - 25 April 2001.) BARNES, Colin Geneva: World Health Organization (WHO), Aug 2001, 30 p.

**Abstract:** This conference report includes recommendations for government action, using a rights-based approach. It covers a range of care issues including a holistic approach to access; legislation and funding; medical rehabilitation; support service; and awareness raising, <http://www.who.int/ncd/disability/report.pdf>

### **Revising the United Nations Census : Recommendations on Disability**

MBOGONI, Margaret, ME, Angela (**First Meeting of the Washington Group on Disability Statistics, Washington, 18-20 February 2002)**

Washington: Centre for Disease Control and Prevention, 2002, 27 p.

This paper describes the issues concerned with the revision of the disability section of the United Nations Principles and Recommendations for Population and Housing Censuses. The discussion includes how the newly published International Classification of Functioning, Disability and Health (ICF) can be incorporated in the recommendations. Issues for consideration are: (i) new approaches in defining disability; (ii) a new list of types of disabilities based on the ICF; (iii) improvement of the wording and structure of questions to identify persons with disabilities; (iv) improvement of the dialogue between users and producers; and (v) the need to perform cognitive and quantitative testing of questions on disability. The paper also gives an overview of how countries have used the census to collect data on disability and it underlines advantages and disadvantages of its use highlighting its importance in the collection of information on persons with disabilities, particularly in developing countries. [http://www.cdc.gov/nchs/about/otheract/citygroup/products/me\\_mbogoni.htm](http://www.cdc.gov/nchs/about/otheract/citygroup/products/me_mbogoni.htm)

### **Towards a Common Language for Functioning, Disability and Health : ICF The International Classification of Functioning, Disability and Health**

WORLD HEALTH ORGANIZATION (WHO) Geneva: WHO, 2002, 22 p. This is the introduction to WHO's International Classification of Functioning, Disability and Health, also known as the Beginner's Guide. It provides an introduction to the ICF and its use. It sets out what the ICF offers to health workers, planners and policy-makers. It also includes a list of organisations, agencies and NGOs who are part of the ICF collaborating network. <http://www3.who.int/icf7beginners/bg.pdf>

## CHAPTER 11

# The Malawi Directory of Disability Organisations

Marko Kerac

## SUMMARY

*There are many exciting and dynamic disability-focused groups and organisations active in Malawi, but sometimes, there are insufficient means and opportunities for groups to interact and collaborate. Whilst the impact of individual projects alone may be significant, the potential of utilising a collaborative approach is even greater. A well structured, cohesive and coordinated network is needed in each country to yield results far greater than the sum of individual parts. These networks can then collaborate throughout Africa to further strengthen service delivery, improve strategic planning and resource utilisation.*

*The "Directory of Disability Services in Malawi", aims to provide the information that might make this possible. It brings together in one document all the organizations, groups and services specifically working on disability issues in Malawi. Such a collation provides a tool for strengthening the network. The goal is to benefit persons with disabilities, their families, their communities and ultimately, the whole of society. This project reflects the aims of the CBR Africa Network and provides an example of what each country could do to facilitate information sharing and collaborative working.*

## INTRODUCTION

*"Mutu umodzisusenza denga"*  
*Chinyanja Proverb, Malawi*

The literal meaning of the proverb is, *"One Head does not carry the roof* meaning, *"Come on! All hands on deck!"* Co-operation, unity, and dependency are necessary and good. They lead to mutual benefit and synergy.

The Malawi directory initially grew out of frustrations arising from working in hospital wards and sending children with disabilities home, to face an uncertain future, knowing there were, or probably were, organisations 'out there', who could provide long term specialist help and support - yet not knowing how to access that support. Exploring the directory idea with key disability activists in Malawi, it soon also became apparent that the project was a direct and practical response to one of the four key challenges set at the Uganda 2001, CBR conference: *"The need for CBR training and practice to be documented and synchronised both nationally and inter-continently"*.

## AIMS AND OBJECTIVES - WHY A DIRECTORY?

A directory can serve several purposes. The needs of three principal audiences were considered.

### 1. Persons with disabilities (PWDs) and their families

For people to benefit from the excellent work being done on so many areas and aspects of disability, they must be able to access the organisations and their programmes.

The directory's aim is to help inform service users:

**WHICH** organisation/programme; does **WHAT**; for **WHOM**

This makes it possible to identify and make informed choices about which organisation may be best able to help and support with a particular issue.

It is then important to know:

**WHERE** an organisation is located; **HOW** to access the services offered.

The purpose of a directory is to provide all this information both clearly and accessibly.

## 2. Those who work with PWDs

The first point of contact with support service providers for many PWDs is often a hospital, school, church, social welfare office, or other such general community institutions. It is essential that professionals and others working within such institutions are aware of the specialist services that are available to PWDs. The directory can then provide a reference that can be used, together with PWDs, to identify and access a suitable organisation to support with particular needs or issues.

## 3. Organisations (including international organisations)

Organisations listed within a directory reflect a large and rich range of specialist expertise, but:

- **No one organisation can fulfill all possible needs:**

Many individuals have multiple needs. It is essential for organisations to network, to coordinate services, to pool scarce resources, to work in a spirit of synergy and togetherness, rather than in atmosphere of competitiveness and unnecessary duplication of services. A directory is the first and crucial step towards such a network. It enables contacts to be made and information to be exchanged.

- **All organisations are evolving and continually improving:**

Through comparing and contrasting programmes and activities, organisations can learn from one another's successes and failures.

## METHODS USED TO COMPILE THE DIRECTORY

### Local ownership

For continuity, sustainability and long-term impact, local ownership of the directory project and tailoring objectives to local needs, is crucial.

The work was thus conducted in close collaboration with the Ministry of Social Development and Persons with Disabilities as the key local partner and eventual Malawian owner of the project. Other key organisations in Malawi's disability arena were also centrally involved: in particular, FEDOMA (Federation of Disability Organisations in Malawi) and MACOHA (Malawi Council for the Handicapped).

## Identification of Disability Related Organisations

A 'snowballing' method was used to identify organisations. Starting with a small number of key informants and an existing (but limited in scope and detail), 4 year old directory, organisations were identified and contacted. Each in turn helped with information and contacts to identify yet more organisations.

## Visits and Organisational Profiles

To ensure a level of detail and engagement not possible via a remote/postal survey, personal visits were made to each organisation. Details about the directory project were, where possible, sent beforehand to enable preparation of any relevant information.

Each organisation was profiled through discussion with key project staff and beneficiaries. Core information was collected for publication:

- Name of organisation
- Contact details
- Organisation overview: Aims, Objectives and Mission Statement
- Background information
- Key activities
- Geographical area of work
- Notable successes and achievements
- Target beneficiary group (e.g., adult or child; type of disability)

During the visit, a qualitative survey was also carried out. Organisations' strengths; weaknesses; future plans and needs were discussed. Opinions on networking were also sought.

## OUTCOMES

### Printed directory

A paper version of the directory is currently being finalised. Initial dissemination will be to organisations themselves, to aid with their networking, planning, and developmental needs. Eventually, the hope is to also distribute to health centres, clinics, hospitals, schools and other important social "hubs".

### Internet directory

Aimed principally at the international/policy level audience, an internet-based version of the directory is also planned. Web linkages can grow exponentially, facilitating further sharing of knowledge and other resources. A copy of the directory is now available on the can web site: [www.afri-can.org](http://www.afri-can.org)

With even local organisations increasingly able to access computers, this will ease communications and enable both Malawi-specific and international "discussion forums". News, developments and notification of relevant events also could take place over web media.

### Long term updates and revision

To remain current and useful, the directory will need to be periodically updated. This is most easily done once there is a well accepted "starting format". Feedback and comments on the first edition must be actively sought and refinements made. With the initial work done through visits, updates will easily be possible via post and email, facilitating ease and speed of revisions.

## CONCLUSION

A directory of disability organisations and services is an important step in facilitating a national network of disability services in Malawi.

Programme impact and ultimate benefits to persons with disabilities can be maximised through organisations working together within a well co-ordinated network:

- Both individuals and professionals know which services are available and how to best access them
- Network coordinators can communicate with organisations and identify issues that need addressing - thereby best meeting the rights and needs of persons with disabilities
- Capacity building, mutual support and efficient use of resources is made possible

This project model is relevant and applicable to many other African countries.

## REFERENCES

CHAKANZA J. *Wisdom of the People: 2000 Chinyanja Proverbs*: CLAIM (Christian Literature Association of Malawi); 2000.

# Acknowledgements

All the contents of this book were the results of discussions that took place during the Regional Africa CBR Conference, "CBR as part of Community Development" from 31st August to the 3rd of September 2004, at Kalikuti Hotel in Lilongwe, Malawi. A special thanks goes to the Ministry of Social Development and Persons with Disabilities, who were the hosts of the conference and truly demonstrated that Malawi is the 'warm heart of Africa.'<sup>1</sup>

Acknowledgments go to all the sponsors of the conference and of this publication, without whose assistance the conference would not have been possible: The Norwegian Association of the Disabled (NAD), The Berkley Trust UK, The International Labour Organisation (ILO), UNICEF Malawi, Norwegian Church Aid, CP Charitable Trust, UK, Malawi Broadcasting Cooperation (MBC), Auction holdings and Malawi Council of the Handicapped (MACOHA). The contributions are sincerely recognised and appreciated. A special thanks goes to Chris Serwaniko for designing the cover of the book.

Many thanks go to the members of the organising committee; the Ministry of Social Development and Persons with Disabilities, other key Ministries, organisations of the disability sector in Malawi, Centre for International Child Health and CBR Africa Network (CAN), who worked tirelessly for the whole year prior to the conference, to ensure that everything ran smoothly and to guarantee that all the participants should gain the maximum from the conference and their stay in Malawi.

The conference was officially opened by the Honourable Vice President of Malawi, Dr Cassim Chilumpha, and was accompanied by the Minister of Home Affairs, Honourable Uladi Mussa, the Minister of Social Development and Persons with Disabilities, Honourable Clement Chiwaya and the Mayor of Lilongwe. There were 180 participants from 20 different countries across Africa and Europe. Thanks should be expressed to the guest speakers and the participants, for their support of

CBR in Africa and their willingness to share ideas and experiences, poster presentations and their participation in the discussion groups.

Recognition is given to some members of the disability sector who contributed their skills and services to add to the Malawian flavour of the conference, such as MACOHA'S Bangwe weaving factory that made the beautiful conference bags, Kamuzu vocational training centre for producing the conference badges, SO S Children's Village school band and MACOHA'S Salima CBR Project who hosted the field trip. As most of the organising committee was based in Blantyre, a big "Thank You" must also go to Mrs Naomi Kamanga from MACOHA'S Lilongwe Vocational Training Centre, who was a vital link for the team in Lilongwe, and Mr Eric Mcheke for the photography.

Gratitude is expressed to The Kalikuti Hotel for their collaboration and efforts to make the hotel accessible for people with disabilities and in general for being very accommodating throughout the conference.

## **MEMBERS OF THE ORGANISING COMMITTEE**

Chairman: Mr Wellos Kachingwe

Director of programmes at the Ministry of Social Development and Persons with Disabilities

Mrs Mercy Mwale

Ministry of Social Development and Persons with Disabilities

Miss Rachel Plackett

Ministry of Social Development and Persons with Disabilities

Mrs Torild Almnes

Norwegian Association of the Disabled and Advisor with the Ministry of Social Development and Persons with Disabilities

Mr Peter Ngomwa

Malawi Council of the Handicapped (MACOHA)

Mrs Juliana Mabangwe

The Federation of Disability Organisations in Malawi (FEDOMA)

Mrs Eunice Maonga  
 Ministry of Gender and Community Services

Mr Billy Dingaliro  
 Feed the Children Malawi

Mr Alex Dzinkambani  
 Malawi Against Physical Disabilities

Mr Alick Chavuta  
 Montfort College of Special Education

Mr Costings Kadzongwe  
 Ministry of Labour and Vocational Training

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 Ministry of Labour and Vocational Training  
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 Malawi National Association of the Deaf  
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 Disabled Women in Development  
 Parents' Association of Disabled Children  
 The Association of the Physically Disabled

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 Sue Ryder Foundation  
 Feed The Children Malawi  
 Malawi Against Physical Disabilities  
 Voluntary Services Overseas  
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 World Vision  
 SOS Children's Village  
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 Norwegian Church Aid



## APPENDIX 1

# Group Discussion Questions

During the conference, time was set aside for group discussions based on the on-going presentations. These discussions were guided by different sets of questions. The views and ideas expressed in these sessions have been incorporated into the main text of the relevant chapters presented in this book.

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

## **CBR AS PART OF SOCIAL, CULTURAL AND POLITICAL DEVELOPMENT**

1. What is your understanding about these terms; social, cultural and political development?
2. What is your understanding about CBR as part of social, cultural and political development?

3. In your group please list down the relationships between the social, cultural and political development as part of CBR.
4. How can you implement CBR to promote social, cultural and political development? What would be the advantages or disadvantages?

## **CBR AS PART OF PRIMARY HEALTH CARE**

1. What are the existing health systems within your community?
2. How can CBR use existing health systems to promote community health?
3. How can we promote early identification of health related issues to prevent disability?

## **CBR AS PART OF ECONOMIC DEVELOPMENT**

1. To what extent have people with disabilities been empowered economically through CBR?
2. Which methods or models of economic empowerment have proved to be successful or unsuccessful for empowering persons with disabilities in CBR?
3. What could be our main activities, to improve the effectiveness of CBR programmes for the economic empowerment of persons with disabilities?

## **CBR AS PART OF EDUCATION AND TRAINING DEVELOPMENT**

1. What are the opportunities for education and training in Africa for CBR?
2. How can countries in Africa collaborate in providing training and education in CBR?
3. Which areas should be focused on, during education and training in CBR in Africa?

**RESEARCH ON CBR AS PART OF  
COMMUNITY DEVELOPMENT**

1. What does the existing research about CBR in Africa tell us? Where can it be found? What do we already know about it?
2. How can we make research an important tool within CBR, for community development?
3. What should be the focus for research in CBR in Africa?
4. How can research improve knowledge, practice, policy development and advocacy on CBR?
5. How can research on CBR assist in the development of the community?

**APPENDIX 2**

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APPENDIX 3

# 12 Key Messages

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The seven conference rapporteurs met and generated key messages from the conference proceedings. Feedback was collected and the messages were modified and ratified by the General Assembly at the end of the conference. The key messages were:

1. CBR must address poverty, because it is the major need of people with disabilities.
2. Millennium goals cannot be achieved if they do not include disabled people.
3. CBR is for us all. Every stakeholder has a role to play.
4. CBR should promote rights but also responsibilities.
5. CBR should be more pro-active, promote its activities aggressively and get other services in place.



6. Sharing information is crucial to the development of CBR.
7. Aspects of culture that are negative to CBR cannot be changed overnight.
8. CBR should make sure that deaf people are not being missed out.
9. CBR should promote education at ALL levels if people with disabilities are to have economic empowerment.
10. CBR needs to communicate its concepts in language, which can be understood.
11. The priority of CBR research needs to address local resources and participation. CBR programmes are in the best position to do this.
12. CBR must address HIV/AIDS issues.